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Training Family Carers In-Person and via Telehealth to Implement Function-Based Assessments and Interventions for Challenging Behaviour with Their Child with an Intellectual or Developmental Disability: An Exploration of Feasibility Within a UK Context

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Abstract

Background

Challenging behaviours (CBs) such as aggression, self-injury, or property destruction are commonly displayed by children with intellectual / developmental disabilities (IDDs). Such behaviours often develop early and persist without intervention, making effective early assessment and intervention important. The most widely used assessment and intervention approaches for CB for individuals with IDD are based upon Applied Behaviour Analysis (ABA) and rely on an understanding of the function of the individual's behaviour. However, there is little UK research examining such assessment and intervention approaches for young children with IDD who display CB, or the involvement of their families in this process. As a result, this thesis aimed to explore the evidence base for the use of function-based interventions (FBIs, i.e., behavioural interventions based on prior functional assessment [FA] identifying the contingencies which maintain CB) with young children with IDD and consider how such approaches can be utilised within a UK context via extensive collaboration (within clinical work) with family carers.

Methodology

Previous literature relating to FBIs for children with IDD was examined in a systematic review and meta-analysis combining both single case and group design research (Chapter Two). In addition, literature relating to the use of telehealth (i.e., support provided across distance via technology which may provide a useful method of adapting approaches for a UK context where behavioural expertise is scarce) to train stakeholders such as family carers and teachers in ABA interventions was examined in a second systematic review (Chapter Three). Following this, two empirical studies utilising single case design methodology were conducted examining the feasibility of training family carers (in-person for four family carers in Chapter Four and via telehealth for two family carers in Chapter Five) to complete FAs and FBIs with their children with IDD. A final empirical study examined

the social validity of the use of telehealth for behavioural approaches in the UK via a four round Delphi consultation with 11 professionals and six family carers.

Results

Fifty-two single case and 8 group design articles were reviewed in Chapter Two and all of the FBIs in these articles achieved at least a medium effect size in relation to reductions in child CB (overall Tau U = 0.785, 95% CI: 0.729-0.840 for single case design interventions, and overall glass Δ = 0.62, 95% CI: 0.94-0.29 for group design interventions). However, significant methodological quality issues were noted across the evidence base limiting the strength of conclusions. Chapter Three identified an emergent evidence base for the use of telehealth for training stakeholders (e.g., family carers, teachers, ABA tutors) in ABA approaches (such as FAs, FBIs, teaching techniques) across 20 studies. Training most often involved initial training sessions delivered via videoconferencing with supplemental in-vivo coaching during implementation of procedures. Training resulted in high but variable levels of trainee fidelity and positive outcomes for the focal persons supported by trainees (e.g., meaningful assessment outcomes, reduction in CB or increases in skills). However, methodological quality issues across the evidence base again limited the strength of conclusions for Chapter Three.

Chapters Four and Five together demonstrated emergent feasibility of training family carers in FAs and FBIs in the UK where training was provided in-person (Chapter Four) and via telehealth (Chapter Five). Significant difficulties were encountered with recruitment and retention across both studies, limiting the generalisability and strength of the findings. Various challenges were encountered with the implementation of intervention procedures in Chapter Four, therefore Chapter Five focused on FA procedures only. However, family carers were able to implement FA procedures in both studies with greater than 80% fidelity overall. Social validity was found to be high across both studies, though not meeting feasibility criterion in Chapter Five.

Finally, Chapter Six found that the use of telehealth for behavioural support was generally viewed favourably by the professionals and family carers who took part in the Delphi consultation. Consensus was reached on 36 items for professionals and 22 items for family carers relating to factors that would be influential to their likelihood of using telehealth for behavioural support. Both advantages (e.g., in relation to logistics, greater ease of involving multiple stakeholders) and barriers (e.g., relating to perceived quality of support, ethical concerns with data protection and confidentiality) were highlighted, with solutions to barriers suggested which involve both individual practitioner approaches (e.g., accessing training) and system level approaches (e.g., national guidance for the use of telehealth).

Conclusion

Throughout this thesis, extensive collaboration with family carers was utilised at all stages, and approaches were adapted for the UK context in a number of ways including the use of telehealth. The evidence base for FBIs was noted to be extensive but with significant methodological limitations, and an emerging evidence base was identified for the use of telehealth to train stakeholders in ABA approaches, though again with significant methodological limitations. Emergent feasibility was demonstrated for training family carers both in-person and via telehealth in FA and FBI methodology, though small sample sizes and high participant drop out limits the generalisability of these findings. A number of challenges were encountered relating both to the practical implementation of approaches and the research evaluation, with tensions between clinical practice and research noted which had not previously been documented in the ABA literature. The social validity of the use of telehealth for behavioural support was confirmed via a Delphi consultation with professionals and family carers in which a number of useful recommendations were made for minimising barriers relating to the use of telehealth and maximising advantages for both practitioners and families. Suggestions are made for further research arising from the findings of this thesis, including the extension and refinement of procedures used for training family carers in order to further confirm feasibility and extend evaluation to the effectiveness of these approaches.

Additional work could also further describe any research-practice tensions within ABA and consider ways to minimise these barriers in order to ensure that research is sensitive to clinical practice issues and therefore useful for the field.

Abbreviations

Abbreviation	Meaning
ABA	Applied Behaviour Analysis
ABC	Aberrant Behaviour Checklist
ADHD	Attention Deficit Hyperactivity Disorder
ASC	Autism Spectrum Condition
BSP	Behaviour Support Plan
BST	Behavioural Skills Training
CB	Challenging Behaviour
CBC	Challenging Behaviour Checklist
CBCL	Child Behavior Checklist
CBMS	Child Behavior Management Survey
CDC	NHS Child Development Centre
CI	Confidence Interval
DRO	Differential Reinforcement of Other Behaviour
EE / NCR	Environmental Adaptations / Noncontingent Reinforcement
EFA	Experimental Functional Analysis
FA	Functional Assessment
FAI	Functional Assessment Interview
FAOF	Functional Assessment Observation Form
FBI	Function-Based Intervention

FBPI	Function-Based Positive Intervention
FCT	Functional Communication Training
FMSS	Five-Minute Speech Sample
FQOLS	Beech Centre Family Quality of Life Scale
GBG	The Good Behaviour Game
ICN	Iowa Communications Network
ID	Intellectual Disability
IDD	Intellectual / Developmental Disabilities
IISCA	Interview Informed Synthesised Contingency Analysis
IOA	Interobserver Agreement
IRT	Inter-Response Time
MO	Motivating Operation
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PBIS	Positive Behaviour Interventions and Supports
PBS	Positive Behaviour Support
PDD	Pervasive Developmental Disorder
PECS	Picture Exchange Communication System
PFI	Positive Family Intervention
PTC	Parenting Task Checklist
RCT	Randomised Control Trial

REC	Research Ethics Committee
SIB-R	Scales of Independent Behavior-Revised
SSIS	Social Skills Improvement System
ST / DRA	Skills Teaching / Differential Reinforcement of Alternative Behaviour
TARF-R	Treatment Acceptability Rating Form-Revised

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Chapter One

Early Assessment and Intervention for Challenging Behaviour in Young Children with Intellectual and Developmental Disabilities in the UK, and the Importance of Family Carer Involvement

Chapter Overview

Challenging behaviour (CB) such as aggression, self-injury or property destruction is highly prevalent in individuals with intellectual / developmental disabilities (IDDs: Cooper, S. et al., 2009b; Crocker et al., 2006; Emerson et al., 2001; Lowe et al., 2007; Poppes et al., 2010) and is known to have significant detrimental consequences for the individuals themselves and those who support them. Evidence suggests that such behaviours may develop at an early age (Emerson et al., 2014), and are likely to persist in the absence of intervention (Murphy et al., 2005), highlighting the importance of early assessment and intervention. There is a significant evidence base for behavioural approaches to understanding, assessing, and intervening successfully to reduce CB for young children with IDD (see, for example, Emerson & Einfeld, 2011; Goh & Bambura, 2012; Horner et al., 2002; Mancil, 2006; Wood et al., 2009). However, for young children in particular it is important that such assessment and intervention involves family carers given that they are often the main influences on a child's development and environment in this period (Bronfenbrenner, 1974; Guralnick, 2001; Guralnick, 2005b). Family carers may also be integral to understanding and influencing the child's CB, both in relation to their knowledge of their child and the family ecology, and in relation to the possibility of mutual reinforcement contingencies meaning that the child's behaviour is influenced by the family carer's behaviour and vice versa (e.g., Oliver, 1995; Patterson, 1982; Stocco & Thompson, 2015). Furthermore, the involvement of stakeholders in interventions more generally may be associated with a range of positive outcomes including improved generalisation and maintenance of approaches (Stokes & Baer, 1977), and development of stakeholder skills and knowledge (e.g., Marcus, Swanson et al., 2001; McNeill et al., 2002; Wainer & Ingersoll, 2015), as well as being consistent with key components of dominant models of intervention such as Positive Behaviour Support (PBS: Carr et al., 1999; Gore et al., 2013; Horner et al., 1990). Despite this, the meaningful and extensive involvement of family carers in their child's assessment and support for CB is only recently emerging in the literature with a focus on family centred support (e.g., Keen & Knox, 2004; Lucyshyn et al., 2002), and has not been evidenced in the literature as routine practice in behavioural support.

The current chapter outlines the evidence base relating to CB for young children with IDD as well as providing an overview of early assessment and intervention approaches. A case is made for the involvement of family carers in implementing assessment and intervention approaches for this group of children, with consideration of the challenges to this and the state of the current evidence base. It is argued that assessment and intervention efforts are likely to be more successful where family carers are meaningfully and extensively involved in their child's support.

An Overview of Challenging Behaviour in People with IDD

Definitions

CB commonly refers to behaviours such as self-injury, property destruction or aggression towards others, though the term has also been used to refer to a range of other types of behaviour including noncompliance, stereotypy and socially inappropriate behaviours (Emerson & Einfeld, 2011). Evidence suggests that individuals often display more than one form of behaviour within each class of behaviours (e.g., multiple forms of self-injurious behaviour) and that they may also display behaviours from multiple classes, with varying levels of severity (Lowe et al., 2007). These behaviours can be particularly difficult to define given their varying topographies, characteristics (e.g., duration, intensity, frequency) and impacts for the individual and others around them. In clinical practice, precise operationalised definitions are created for each individual which enable repeated observational measurement of the target behaviours during assessment and intervention efforts (Cooper, J. O. et al., 2020); this approach is used for relevant empirical studies within this thesis (Chapters Four and Five). However, for broader research purposes where the aim is often to describe global characteristics relating to these behaviours (e.g., prevalence, risk factors), two approaches have typically been adopted. The first involves devising definitions relating to individual classes of behaviour such as aggression (e.g., Arron et al., 2011; Cooper, S. et al., 2009b; Crocker et al., 2006) or self-injury (e.g., Arron et al., 2011; Cooper, S. et al., 2009a), and the second involves a broader definition attempting to encompass all possible variations of CB topography. This type of general definition is useful when multiple classes of CB are to be considered as it is not topographically based and is therefore most appropriate for the current thesis. The most widely used of these general definitions states that CB is:

> culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities (Emerson, 1995; Emerson, 2001; Emerson & Einfeld, 2011, p. 4).

This definition avoids a focus on any one topography, and instead defines CBs according to their impact for the individual and those around them. This ensures that it encompasses a wide range of behaviours and is therefore not limited to a specific topography. As this definition is widely used and shares many features with the other dominant general definition in the UK (i.e., Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007) it will therefore be used throughout this thesis where CB is referred to more generally (i.e., rather than within empirical studies in which definitions are individualised for each participant as described above).

Understanding, assessing, and intervening with CB requires an approach based on behavioural theory and Applied Behaviour Analysis (ABA; see below for further discussion). This approach is utilised throughout the thesis and as such a range of behavioural concepts (such as reinforcement, motivating operations, behavioural contingencies etc.) are referred to throughout. The precise definition of these concepts is beyond the scope of this thesis and appears elsewhere, therefore the reader is directed to sources such as Cooper, Heron and Heward (2020) or Mayer, Sulzer-Azaroff and Wallace (2018).

Risk Factors, Development and Maintenance of Challenging Behaviour

Evidence suggests that several factors are likely to influence an individual's risk of developing CB, both generally and for specific types of behaviour. These factors can be grouped into those that relate to individual characteristics, and those that relate to the individual's social or physical environment. These are discussed in detail elsewhere (e.g., Bowring, et al., 2017; Emerson & Einfeld, 2011; McClintock et al., 2003) and will only be briefly outlined here. Integrative models of CB will then be reviewed to highlight how risk factors are likely to interact in the development and maintenance of CB.

Individual Characteristics

Several individual factors are associated with increased rates of CB and have therefore been identified as possible risk factors for the development of CB (see, for discussion, Emerson & Einfeld, 2011). These include gender with males more likely to display CB (Bowring et al., 2017; Emerson et al., 2001; McClintock et al., 2003), age with CB more likely to be displayed by children / adolescents and young adults than older adults (Emerson et al., 2001; Holden & Gitlesen, 2006; Lowe et al., 2007), increased severity of intellectual disability (ID: Bowring et al., 2017; Holden & Gitlesen, 2006; McClintock et al., 2003), presence of autism or specific syndromes associated with a behavioural phenotype that includes CB (Arron et al., 2011; Bowring et al., 2017; Emerson et al., 2001; Holden & Gitlesen, 2006; McClintock et al., 2003), communication deficits (Bowring et al., 2017; Emerson et al., 2001; Holden & Gitlesen, 2006; Lowe et al., 2007; McClintock et al., 2003), sensory or mobility impairments (Bowring et al., 2017; Cooper, S. et al., 2009a; De Winter et al., 2011; Emerson et al., 2001; Kiernan & Kiernan, 1994), social skills deficits (Lowe et al., 2007), sleep difficulties (Brylewski & Wiggs, 1999; De Winter et al., 2011; Rzepecka et al., 2011; Wiggs & Stores, 1996), mental health conditions (Holden & Gitlesen, 2003; Moss et al., 2000), and experience of physical conditions associated with pain (De Winter et al., 2011). However, it is important to note that evidence for many of these individual risk factors is mixed and some of these factors are likely to be correlated (e.g., severity of ID and communication deficits) making it difficult to isolate their unique impact on

CB. Nevertheless, it appears that the development of CB is more likely for specific individuals based on their individual needs and characteristics. This is particularly the case for those with specific genetic syndromes associated with a behavioural phenotype that includes CB, given the high prevalence of CB generally and specific topographies of CB noted for these individuals. For example, individuals with Smith-Magenis syndrome or Angelman syndrome are known to be at an increased risk of developing aggression (Arron et al., 2011), whilst individuals with Lesch-Nyhan syndrome are at increased risk of developing a specific topography of self-injury, namely biting their lips or fingers (Hall, S. et al., 2001). The reasons for the increased prevalence of CB for these populations are complex, likely reflecting gene-environment interactions (e.g., Langthorne & McGill, 2008; Tunnicliffe & Oliver, 2011). However, this illustrates the increased risk of CB for particular populations based on these and other factors (as listed above). Whilst many of the other factors highlighted above are general and likely to be risk factors for the development of CB in several populations, they are often more prevalent for those with IDD (e.g., communication difficulties) and therefore represent unique risk factors for this population.

Environmental Characteristics

In addition to individual factors, characteristics of an individual's social and physical environment have been identified as potential risk factors for the development of CB. However, analysis of environmental risk factors is challenged by the extensive number of environmental variables likely to contribute to the development of CB, and the likelihood that such variables interact with individual characteristics in complex ways. Despite this, some clear risk factors have emerged in the literature. Firstly, CBs are known to serve specific functions for an individual (discussed further below, Emerson & Bromley, 1995; Iwata et al., 1982) which suggests that key characteristics of any environment linked to these potential functions may contribute to the development and maintenance of CB, such as lack of access to preferred items or aversive contingencies motivating the individual to escape. Secondly, research evidence has suggested that CB is likely to be more prevalent as the restrictiveness of the setting increases (Cooper, S. et al., 2009a; Cooper, S. et al., 2009b) which supports evidence relating to behavioural function as restrictive environments are likely to present contexts in which access to preferred items, social interaction or sensory stimulation is limited, and in which aversive contingencies are prevalent. CB may therefore emerge in such environments to meet important behavioural functions for the individual as noted above. Finally, in addition to these general environmental characteristics it has also been suggested that adverse life experiences such as abuse, lack of meaningful activity, and poor social interaction are risk factors for the development of CB, and these factors are likely to feed into other environmental or individual risk factors exacerbating the likelihood of CB developing (e.g., Bowring et al., 2019; Hastings et al., 2013).

As a result of the large number of risk factors identified in the literature and the interactions between these factors, it is difficult to predict whether a given individual will develop CB as no single risk factor in itself is likely to lead to the development of CB. Furthermore, there is no known research specifically examining the cumulative impact of these risk factors, though it seems likely that risk factors may have an additive effect resulting in greater risk of developing CB correlated with a higher number of risk factors (e.g., Bowring et al., 2017). It is therefore generally accepted that the aetiology of CB is complex and unlikely to be explained by one source of risk alone (Emerson & Einfeld, 2011). Integrative frameworks relating to the development and maintenance of CB (e.g., Bowring et al., 2019; Hastings et al., 2013; Langthorne et al., 2007) often incorporate multiple risk factors, supporting the assumption that they may have an additive effect. These models are discussed further below.

Integrative Models of Challenging Behaviour

Integrative models of CB aim to combine evidence relating to the risk and maintaining factors for CB to explain how CB develops and persists over time. The most recent of these models (i.e., Bowring et al., 2019; Hastings et al., 2013) argues that a number of vulnerabilities exist for the development of CB (e.g., those outlined above) which are also likely to feed into processes maintaining the behaviours, such as other people’s reactions and treatment of the person with IDD.

This results in a cyclical relationship in which identified risk factors feed into processes maintaining the behaviour and vice versa, making it more likely that CB will continue to be displayed over time. Furthermore, the authors also highlight that the consequences of CB for individuals may exacerbate some of the individual or psychosocial risk factors, further contributing to the maintenance of behaviours over time. For example, individuals may be more likely to experience harsh or restrictive treatments if they display CB (Allen, D. et al., 2007; Emerson et al., 2000; Matson, J. L. & Boisjoli, 2009), which increases the restrictiveness of their environment and contributes to the development of aversive contingencies which are themselves risk factors for the development of CB. Other integrative frameworks of CB are consistent with this view. For example, Langthorne et al. (2007) identify two main risk categories for the development of CB including “challenging needs” focusing on individual characteristics linked to the development of CB, and “challenging environments” focused on environmental characteristics, which together feed into “aberrant contingencies” contributing to the development and maintenance of CB (p. 481).

Once established, CB is known to be maintained by its consequences (i.e., it becomes, at least in part, an operant behaviour) either due to interactions with other people or via a process of automatic reinforcement in which the behaviour produces internal consequences (i.e., sensory stimulation) which reinforce its occurrence (Emerson & Bromley, 1995; Iwata et al., 1982). CB can therefore be understood as functional for the individual displaying it as noted above. Four common behavioural functions have emerged in the literature, including access to attention, access to preferred tangible items or activities, escape from aversive contingencies such as too many demands, and the modification of sensory stimulation (Emerson & Bromley, 1995; Iwata et al., 1982; Lloyd, B. P. & Kennedy, 2014). However, it has also been shown that the relationship between behavioural topography and function is non-linear in that an individual behaviour may serve different functions dependant on the environmental context, or the same function may be met by a variety of different behaviours (Emerson & Bromley, 1995; Lloyd, B. P. & Kennedy, 2014) making the reliable identification of function complex. Nevertheless, the recognition that CBs persist due to the functions they serve for individuals has led to a wealth of effective interventions tailored to the specific function of an individual's behaviour (e.g., Carr et al., 1999; Carr & Durand, 1985; Dunlap & Fox, 2011; Ingram et al., 2005; Lloyd, B. P. & Kennedy, 2014; Matson, J. L. & Minshawi, 2007; Wood et al., 2009).

Taken together, evidence relating to the risk factors and maintenance of CB suggests that its development and persistence is complex and influenced by a range of factors. As noted above, it is therefore impossible to predict whether a given individual will display CB though it is possible to hypothesise who might be more at risk based on their individual characteristics, experiences, and environments. As a result, it is also important to examine the prevalence of CB amongst the population of individuals with IDD in order to identify trends and support targeted interventions in the absence of a reliable identification system for those most at risk.

Prevalence

Whilst quantifying prevalence is an important aim, it is difficult to draw definitive conclusions about the prevalence of CB for people with IDD due to differences between studies in the definition of CB used, and in the measurement of such behaviours (Emerson & Einfeld, 2011; Simó-Pinatella et al., 2019). Prevalence estimates should therefore be interpreted with caution. However, where available, estimates generally suggest that 10-15% of individuals of any age with IDD display such behaviours (Emerson et al., 2001; Lowe et al., 2007) with rates varying dependent on a number of factors such as those outlined above, including type or level of IDD (Arron et al., 2011; Poppes et al., 2010; Sloneem et al., 2011), or specific behavioural topography (Cooper, S. et al., 2009a; Cooper, S. et al., 2009b; Crocker et al., 2006; Lowe et al., 2007). Prevalence rates are also known to vary based on age and a pattern has been observed suggesting that such behaviours often emerge in childhood, persist and peak around late adolescence / early adulthood and then gradually decline throughout later adulthood (see, for discussion, Emerson & Einfeld, 2011). Despite this, few studies have examined prevalence of CB in children specifically, with fewer still examining prevalence in young children (e.g., aged under seven years). This is an important omission given the documented emergence of CB in early childhood and persistence of such behaviours. Where prevalence estimates for children exist, they suggest somewhat higher but widely varying rates of CBs when compared to adults, of between 22.2% and 65.3% (Hartley et al., 2008; Kiernan & Kiernan, 1994; Totsika et al., 2011), with some studies citing rates as high as 94% or 100% depending upon the population under study (see for review, Simó-Pinatella et al., 2019). Analysis of data specifically for England (Emerson et al., 2014) suggests that 11.7% of children aged 0-18 with IDs display CB, though the authors note that this is likely to be an underestimation due to limitations in the measure used to identify CBs. Despite this limitation, these data are the only data to allow for detailed examination of prevalence by age in years and suggests that nearly half (46.7%) of children with ID who display CB are aged under seven years, underscoring the importance of early intervention for this group given the known persistence of CB throughout childhood and early adulthood (Murphy et al., 2005).

Impact

The importance of early intervention is also clear when the impact of CB across the lifespan is considered. In the most extreme examples, CB has been implicated as a risk factor exposing adults to increased likelihood of placement in out-of-area, restrictive and / or inappropriate settings (Allen, D. et al., 2007; Hassiotis et al., 2008), and these settings more generally are associated with a risk of poor care (Beadle-Brown et al., 2006), with several high profile cases in the UK (e.g., Winterbourne View Hospital in 2012, Whorlton Hall Hospital in 2019) highlighting the risk of abuse for individuals placed in such settings.

For children, CB is often cited as a key reason that families seek out-of-home placements for their child such as residential educational settings (McGill, Tennyson et al., 2006) which themselves may be linked to placement out-of-area as an adult and may not be associated with good outcomes (Gore et al., 2015). Children may also experience inappropriate or ineffective treatments in order to manage their behaviour, with high use of medications (McGill, Papachristoforou et al., 2006; McGillivray & McCabe, 2006; McQuire et al., 2015; Unwin & Deb, 2011; Wodehouse & McGill, 2009), physical interventions including chemical, manual, and personal restraint (Adams & Allen, 2001; Allen, D. et al., 2006; Menon et al., 2012), and exclusion from recreational and educational settings (McGill, Papachristoforou et al., 2006; McGill, Tennyson et al., 2006; Wodehouse & McGill, 2009). They may also experience significant injuries as a result of their behaviour along with injuries sustained to parents / carers (Adams & Allen, 2001; Allen, D. et al., 2006).

For parents / carers themselves, supporting a child with IDD who displays CB is associated with significant levels of stress and psychological distress (Baker et al., 2003; Bromley et al., 2004; Hassall et al., 2005; Hastings, 2002; Lecavalier et al., 2006; Plant & Sanders, 2007), and CB is often identified as the strongest predictor of family carer stress rather than other child characteristics (e.g., Baker et al., 2003; Hassall et al., 2005). Parents / carers also report high levels of dissatisfaction with service support for their child’s behaviour due to professional lack of understanding about their child’s needs and behaviour, and inadequate access to services (McGill, Papachristoforou et al., 2006; McGill, Tennyson et al., 2006; Wodehouse & McGill, 2009). CB may also be associated with lower levels of support from other sources such as family, which further exacerbates parental / carer stress (Bromley et al., 2004). Staff supporting children who display CB similarly report high levels of stress and burnout (Hastings & Brown, 2002; Kelly et al., 2007; Lecavalier et al., 2006; Male, 2003) and head teachers of schools express concerns about the impact of CB on the school more generally and on the education of other children within the school (Kelly et al., 2007).

Early Assessment and Intervention for Challenging Behaviour

Given the impact of CB for individuals with IDD and those who support them, early assessment and intervention is imperative to prevent and reduce the persistence of CB and improve outcomes across the lifespan. Prevention and early intervention often involve a series of inter-related approaches that can be separated into three main levels (World Health Organization, 2012) as outlined below. However, it is important to note that these levels do not necessarily follow a chronological timeline (i.e., with earlier levels always targeted at younger individuals) since they focus on the development and trajectory of a particular issue. As a result, each level may be applicable to individuals of any age, though when considering CB it is likely that the majority of prevention and early intervention efforts will focus on children and adolescents given the identified age trajectory for the development of CB as previously described. A full discussion of interventions for CB at each level of prevention is beyond the scope of this chapter and can be found elsewhere (e.g., Allen, D. et al., 2013) therefore a brief overview of assessment and intervention efforts linked to each level of prevention will be provided here.

Assessment of Challenging Behaviour

Common across interventions at all levels of prevention is the completion of a detailed assessment of the individual's needs prior to the design and implementation of interventions. Where the aim is to prevent the development of CB (primary prevention; see below), such assessments might focus on individual or family goals for intervention and individual or family needs since it is assumed that CB is not currently being displayed by the individual. However, where CB is emergent or established (secondary and tertiary prevention; see below), a thorough understanding of the nature of the behaviours is needed to devise sensitive and appropriate interventions. There is considerable evidence for the use of functional assessment (FA) procedures derived from behaviour analysis in assessing CB (e.g., Iwata et al., 1982; O'Neill et al., 2014). These procedures usually involve several approaches (see Emerson & Einfeld, 2011; Lloyd, B. P. & Kennedy, 2014; O'Neill et al., 2014) including informant interviews, direct observation, completion of rating scales, and experimental manipulations of environmental contingencies (i.e., experimental functional analyses [EFA]). Data are triangulated across a range of sources in order to provide reliable information about the characteristics and operant function of an individual's behaviour which can then inform interventions (O'Neill et al., 2014), and interventions based on a clear identified function are known to be more effective than those not based on function (Ingram et al., 2005). As noted above, the evidence base for the use of FAs for both children and adults with IDD who display CB is well established, and as a result a thorough FA has become the gold standard in intervention design for individuals with IDD who are already displaying CB. Comprehensive assessments are also recommended in the National Institute for Health and Care Excellence (NICE) guidelines (NICE, 2015) and form a key component of dominant approaches such as PBS (Carr et al., 1999; Gore et al., 2013; Horner et al., 1990). Assessment findings are then used to devise interventions which may target one or more areas of prevention (World Health Organization, 2012).

Primary Prevention

Primary prevention approaches aim to prevent the development of a disease or other issue (e.g., CB) through public health interventions targeting all members of a population (World Health Organization, 2012). Common general interventions at this level involve routine vaccination programs and population wide campaigns such as the NHS stop smoking campaign or Change4Life. Interventions at this level for CB in people with IDD are relatively underdeveloped since the development of CB is complex and difficult to predict as noted above. However, interventions at this level are likely to rely on general approaches aiming to improve quality of life and support for people with IDD (Allen, D. et al., 2013) to reduce known risk factors. For example, Jones et al. (2013) argue that implementation of Active Support can act as primary prevention for CB by increasing activity levels and thereby reducing the likelihood of CB developing due to a lack of engagement in meaningful activity. For children with IDD, recent primary prevention approaches focus on promoting skills development to reduce the likelihood of CB developing by targeting common functions of behaviour (e.g., Ala'i-Rosales et al., 2019), focusing on the development of key skills such as tolerance to delays in reinforcement (e.g., Luczynski & Hanley, 2013), and general parent / carer training programs targeting outcomes linked to the development of CB (e.g., Sanders, M. R. et al., 2004; Webster-Stratton, 2005).

Secondary Prevention

Interventions at the secondary level of prevention focus on screening all members of a population, such as national cancer screening programmes, to detect the early development of a disease or issue and provide early intervention to halt its development (World Health Organization, 2012). Much of the work in early intervention for both mainstream populations and those with IDD focuses on this level of prevention by targeting approaches at those who are identified as in need of early intervention following routine or targeted screening (e.g., Guralnick, 2001; Guralnick, 2005a; Guralnick, 2005b; Guralnick, 2017; Ramey & Ramey, 1998). In relation to CB, work at this level could usefully focus on the development of screening tools, and the provision of early supports for individuals who are displaying emergent behavioural difficulties to reduce the likelihood of CB escalating and persisting throughout the lifespan. Many existing tools might be used for this purpose and research highlighting cumulative risk factors may also be useful in the development of screening tools (e.g., Bowring et al., 2017), though a comprehensive tool identifying all relevant risk factors for the development of CB is yet to be developed (Allen, D. et al., 2013). In addition, as noted above there does not appear to be a linear relationship between risk factors and future development of CB, making screening efforts complex, and a further key challenge remains the resource implications of screening all members of a population, particularly where screening might be expected to benefit only 10-15% of a population based on prevalence estimates as outlined above. Instead, as Guralnick (2001) notes, the dominant identification system for children who may require early intervention is currently family self-referral (e.g., to a General Practitioner or other support service), and this may not be effective in identifying all individuals at risk as many families may not be in contact with primary care services or aware of supports available to them. Nevertheless, there is emerging work relating to the development of screening tools to identify future behavioural difficulties (e.g., Schroeder et al., 2014) and some existing examples of evidence-based supports delivered early in the emergence of behaviour (Conroy et al., 2002; Harrower et al., 2000; Wood et al., 2009). Further discussion of intervention approaches at this level of prevention for young children with IDD can be found in Chapter Two.

Tertiary Prevention

This final level of prevention focuses on maximising the effectiveness of interventions and supports where a disease / issue has already developed to minimise its impact and shorten its duration (World Health Organization, 2012). Most examples of medical treatment fall into this category and, in relation to CB, the majority of targeted behavioural approaches such as Functional Communication Training (FCT: Carr & Durand, 1985) operate at this level of prevention. Tertiary prevention efforts are most relevant where CB is already established and is having an impact on the individual's quality of life, and therefore are often targeted at older children and adults.

Multicomponent Approaches to Prevention

Whilst many interventions might target just one level of prevention, as noted above prevention and early intervention efforts often involve inter-related approaches and the most effective intervention frameworks for CB encompass each of these levels of prevention. For example, PBS (Carr et al., 1999; Gore et al., 2013; Horner et al., 1990) delivered both to individuals (e.g., LaVigna & Willis, 2012; Moes & Frea, 2002) and within whole settings (e.g., Horner et al., 2005; McGill et al., 2018) involves multi-component interventions which target each level of prevention. PBS incorporates environmental / antecedent strategies and stakeholder education (primary prevention), ongoing monitoring and review (secondary prevention), and direct behavioural strategies to reduce CB (tertiary prevention). When applied to whole settings, PBS based interventions at each level of prevention are even more explicit, with primary prevention strategies targeting all individuals in the setting, and secondary or tertiary intervention strategies focused on those with more established behavioural difficulties for whom primary prevention strategies are insufficient. PBS has an extensive evidence base relating to the reduction of CB for individuals with IDD (e.g., Carr et al., 1999; LaVigna & Willis, 2012) and is recommended in policy and guidance within the UK as the most appropriate approach for individuals with IDD displaying CB (Local Government Association & NHS England, 2014; NICE, 2015). However, evidence for the full PBS framework when used with young children with IDD is still emerging and there is typically more evidence involving individual elements of the framework for this population (see Chapter Two). This thesis focuses specifically on young children with IDD who are displaying emerging or established behavioural difficulties given the recognised age trajectory for CB and the potential to improve long term outcomes for this group. As a result, the approaches used within this thesis are designed to be consistent with PBS but focus primarily on secondary prevention strategies (i.e., FA and function-based intervention [FBI]), given the relative lack of evidence at present for the full PBS framework when used with young children with IDD.

The Use of Functional Assessment and Function Based Interventions for Young Children with IDD in the UK

Whilst the evidence base for the use of FAs and FBIs is well established as outlined above, there is currently little evidence of such approaches being used within the literature in the UK. This is a significant omission, and it cannot be assumed that approaches which have been developed and evaluated in other contexts (e.g., the USA) will translate well into a UK context given key differences between these contexts, for example in culture, the arrangement and structure of support services, the availability of behavioural expertise etcetera. As a result, UK demonstrations of the use of such approaches are needed. In addition, the scarcity of behavioural expertise in the UK requires particular consideration as demand for support far exceeds available resources meaning that alternative approaches to providing support are likely to be important. One alternative approach could involve training for other stakeholders such as family carers (see, for example, Shayne & Miltenberger, 2012). This would not only increase the reach of professional support but is also likely to have beneficial outcomes for family carers themselves (see below). This is also consistent with a model of support which places significant emphasis on collaboration with stakeholders (e.g., PBS, Gore et al., 2013), and is likely to be a key consideration for work with young children with IDD in particular as discussed below. However, a number of practical barriers may exist in training family carers such as the ability to attend appointments for training when supporting a child who displays CB, or the time required to travel to client’s homes where professionals provide support in-situ. Providing training in-person may therefore be particularly difficult in some circumstances.

Telehealth approaches may offer an appropriate alternative in these instances where support in-person is not possible. Telehealth is defined as “the use of telecommunications and information technology to provide access to health [or behavioural health] assessment, diagnosis, intervention, consultation, supervision, education, and information across distance" (Nickelson, 1998, p. 527). It often involves the use of technology such as videoconferencing, telephone or email support either in isolation or in combination with in-person support, and has been demonstrated to be effective for providing support in other fields (e.g., healthcare, Katzman, 2013; Torres-Pereira et al., 2008; Zollo et al., 1999; speech and language therapy, Georgeadis et al., 2004; Grogan-Johnson et al., 2011; mental health support, Klein et al., 2010; Mitchell et al., 2008). Significantly, it has also been effectively utilised for parent training interventions for children without disabilities (e.g., Reese et al., 2015; Xie et al., 2013) achieving positive outcomes for both parents and their children.

An emerging evidence base is examining the use of telehealth for training in ABA procedures. For example, Barretto et al. (2006) utilised videoconferencing to provide in-session coaching to a teacher and a parent to support them to conduct EFAs for a child with IDD. Results suggested that it was possible to implement the EFA conditions and achieve differentiated assessment outcomes for each child. Machalicek et al. (2009a, 2009b) similarly achieved meaningful assessment outcomes for EFAs and preference assessments when providing in-session coaching via videoconferencing and extended these findings by verifying assessment outcomes in subsequent interventions. Other researchers have also focused on providing initial training and in-session coaching to families for EFAs and FBIs with promising outcomes in relation to assessment results, trainee fidelity and reductions in CB (i.e., Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). Taken together, this emerging evidence suggests that the use of telehealth may be an effective methodology for training a range of stakeholders in ABA / PBS procedures, however, there are no examples of such approaches being used in the UK therefore UK demonstrations of the use of telehealth for this purpose are needed. Nevertheless, the extensive involvement of stakeholders (and in particular, family carers) in such approaches is an important consideration, particularly for young children with IDD for whom family carers have a greater influence on outcomes. The remainder of this chapter will focus on assessment and intervention for young children with IDD and the role of family carers (e.g., parents, siblings) in this process.

The Role of Family Carers in Early Assessment and Intervention for Challenging Behaviour in Young Children with IDD

As outlined above, an effective technology for supporting individuals with IDD who display CB (including children) has emerged and continues to develop. This technology involves comprehensive assessment and multicomponent interventions, often utilising a PBS framework. Furthermore, the emerging literature relating to the use of telehealth for behavioural support provides additional flexibility to practitioners in providing behavioural support and may be particularly important in contexts where behavioural expertise is limited as in the UK. However, these approaches require extensive understanding of an individual's social and environmental context (i.e., through thorough FA) to design effective interventions that are sensitive to the individual's needs and their specific behavioural function. For young children with IDD, the social and environmental context is likely to be heavily influenced by their family carers highlighting the importance of understanding both family and child factors relevant to interventions. However, to date family carers have been involved in early assessment and intervention for their child's behaviour in mainly tokenistic ways, with an expert led model dominating the literature (though with notable exceptions, e.g., Keen & Knox, 2004; Lucyshyn & Horner, 2002; Turnbull & Turnbull, 1990). More recently, emphasis has been placed on the importance of involving stakeholders (such as family carers) in all aspects of an individual's support, and this represents a key component of PBS (Carr et al., 1999; Gore et al., 2013; Horner et al., 1990) and relevant policy and guidance (Local Government Association & NHS England, 2014; NICE, 2015). Despite this, it remains a challenge to effectively involve family carers in their child's support and success will often depend on a range of factors relating to the child, family, and environmental context. The following sections outline the case for involving family carers in their child's support, factors that require consideration when supporting family carers in behavioural support, and the existing evidence for the effectiveness of a collaborative model for supporting young children with IDD who display CB.

The Case for Involving Family Carers

The involvement of family carers in assessment and intervention for their child's behaviour can take several forms and is likely to be hierarchical in nature. Specifically, clinicians may consider the family context in assessments and interventions, but not actively involve the family. This is often the case in expert led models in which the practitioner conducts all observations and assessments with little input from the family themselves (e.g., Lalli et al., 1997; Roberts et al., 1995). Alternatively, and most commonly, families may be involved in a consultative role in which they are asked to input into the process through interviews or completing questionnaires, but are not extensively involved in the assessment procedures themselves, synthesis of assessment results, or intervention design and implementation until the procedures are already established. Many of the assessments and interventions found in the literature are suggestive of this model (e.g., Hanley et al., 2014; Steege et al., 1990) though it is often difficult to ascertain the extent of family carer involvement from published reports alone. Finally, the most extensive model involves families being integral at each stage, through conducting assessments themselves, working with clinicians to interpret and synthesise assessment findings, collaborating on the design of interventions, and implementing interventions themselves. This is best reflected in family centred PBS (e.g., Keen & Knox, 2004; Lucyshyn et al., 2002) which places a heavy emphasis on family involvement throughout the process, however it is also possible in approaches that are less extensive or more targeted (e.g., Derby et al., 1997; Schieltz et al., 2011; Wacker et al., 2011; Wacker, Harding et al., 2013). Evidence suggests that there are specific advantages to involving family carers in this way both for the family carer themselves such as increased knowledge or skills in supporting their child (e.g., Marcus, Swanson et al., 2001; McNeill et al., 2002; Wainer & Ingersoll, 2015), and for their child in relation to more effective assessment and interventions leading to reductions in CB and increases in skills (e.g., English & Anderson, 2004; Hanley et al., 2014; Ringdahl & Sellers, 2000; Strohmeier et al., 2017). This therefore highlights the importance of involving family carers as extensively as possible in assessment and intervention for their child’s behaviour.

In addition, there are several reasons that family carers are well placed to be so heavily involved in the process of assessment and intervention for their child’s behaviour. Specifically, in the early years family carers are the main source of influence in a child’s life (Bronfenbrenner, 1974; Guralnick, 2001; Guralnick, 2005b), involved in arranging the child’s environment, providing support for their child’s development, and mediating their social environment. For families of children with IDD, this role is often even more extensive, additionally involving navigating service contexts and negotiating service support, arranging and / or providing therapeutic services for their child, and advocating for the child’s needs. Family carers may also provide the main social environment for their child as children with IDD may struggle to form or maintain social relationships (Guralnick, 2006; Guralnick et al., 2007; Rotheram-Fuller et al., 2010; Webster & Carter, 2007), and this is often further exacerbated by the documented social isolation families of children with IDD experience (Bromley et al., 2004; Hubert, 2011; Johnson et al., 2006). Taken together, these factors mean that families of children with IDD are likely to have a significant influence on their child’s social and physical environment and are therefore key to developing a thorough understanding of environmental variables influencing the child’s behaviour. This is particularly the case for young children who have not yet reached school age and therefore often spend the majority of their time with family carers, underscoring the importance of family carer involvement in work aiming to prevent CB or provide early intervention services for emerging behavioural difficulties.

Due to the extensive role family carers play in a child’s life, they are also often the most knowledgeable individuals about their child’s needs, abilities, and behaviours, meaning that they can offer valuable insight during FAs. Family carers are well placed to identify influences on their child’s behaviour and have often become adept at arranging environments to minimise the occurrence of behaviours which can provide valuable information during an assessment. Family carers may also be able to identify idiosyncratic variables affecting their child’s behaviour which clinicians may be unaware of (Strohmeier et al., 2017), and there is evidence that child behaviour is influenced by family carer behaviour, and vice versa (e.g., Oliver, 1995; Patterson, 1982; Stocco & Thompson, 2015), suggesting that the role of family carer behaviour may also be particularly important to consider when working with children with IDD. This underscores the importance of at least consulting family carers during the process of FA. The role of family carers in consulting with clinicians during an assessment of their child's CB is also imperative in ensuring that such assessments are aligned with the family and child's needs, goals, and beliefs. Given that CB is socially defined (as described above), it is likely that families will have a role in defining what constitutes CB for their child, and therefore where assessment and intervention work should be focused. Without the involvement of family carers here, it is possible that assessment and intervention work may not align closely with the family and child's needs, and therefore potentially be less acceptable and useful.

Whilst this evidences the importance of consulting with family carers during FAs, evidence also suggests that FAs may produce more meaningful outcomes when actually conducted by those who routinely interact with and support the individual such as family carers (English & Anderson, 2004; Ringdahl & Sellers, 2000; Strohmeier et al., 2017) due to the increased likelihood of isolating contingencies that maintain the individual's behaviour in natural settings. This therefore emphasises the value of involving family carers in more than just a consultative role and instead seeking their involvement in conducting the assessments themselves.

Following the assessment, family carers are able to advise on intervention approaches that are likely to fit within the family context and which are socially acceptable to them, increasing contextual fit and the likelihood that the approaches will be utilised and accepted by the family (Kennedy, 2002; Wolf, 1978). They may also be key mediators in implementing interventions, particularly where interventions involve modifying the child's social or physical environment which is often arranged by the family as described above. As a result they are often involved in some way in implementing or maintaining interventions for their child, and such implementation may be enhanced where family carers have been fully involved in the process of designing the intervention itself rather than their involvement being limited to continuing the intervention after it has been established by clinicians.

Whilst the importance of involving family carers so heavily for young children's support is clear, it is also important to consider the role that family carers play in their child's life over the longer term. It is likely that the family carer's role as described above will extend beyond the typical timeframe for families of children with IDD, as the child may require support for longer and they may not reach typical milestones of adulthood (e.g., independent living, financial independence) or may reach these later and / or in different ways than their typically developing peers (Gerber, 2012; Gray et al., 2014; Hall, I. et al., 2005; Pascall & Hendey, 2004). Furthermore, children with IDD may have significant needs meaning that families often retain their role in advocating for and supporting their child even throughout adulthood (e.g., Mansell & Wilson, 2010; Walden et al., 2000) and a large proportion of adults with ID are cared for by their family, often in the family home (Department of Health, 2001). Family carers may therefore remain a significant influence on their child's life for a greater period of time than family carers of children who are typically developing. This is important as supports which heavily involve the family carer will also necessitate knowledge and skill development for family carers which may be useful throughout the child's life and may potentially reduce future behavioural difficulties. Finally, family carers are also inevitably impacted by their child's behaviour and they may experience significant negative outcomes as a result of supporting their child as outlined above. Taken together with the negative outcomes for the child themselves, family carers may be highly motivated to engage with support services relating to their child's behaviour and to implement strategies for reducing their child's CB and improving outcomes for both their child and the wider family.

In addition to this, there is also an emphasis in recent times on co-production and family-centred practices (e.g., Dunst et al., 2007) within research and support services, with a number of organisations advocating for the extensive involvement of family carers (e.g., Contact, Carers UK, Council for Disabled Children) and policy emphasising the importance of coproduction (e.g., Department for Education, 2014). It can therefore be argued that there is an expectation that family carers and children themselves will have a greater role in support, rejecting the historical expert led model. This approach is already evident in behavioural support for other populations (e.g., typically developing children), in which family carer involvement, training and support is often the first line of intervention (e.g., Barlow et al., 2010; De Graaf et al., 2008; Pidano & Allen, 2015), but has been slower to emerge in support for families of children with IDD. As a result, in addition to the conceptual and technical justifications outlined above it would seem that there is a clear precedent for greater family carer involvement in behavioural support for children with IDD who display CB, even though extensive involvement is rarely reported in the literature at present. However, it is important to note that the extent to which individual family carers are able and / or willing to engage in support for their child with IDD is likely to be highly individualised and influenced by a range of factors meaning that some families will be more willing and able to engage in support than others. Clinicians therefore need to consider individual factors for each family and these factors will now be outlined to highlight areas that clinicians may need to take into account when working with families.

Factors Relevant to Supporting Family Carer Involvement

Whilst the value of involving family carers in assessment and intervention for their child's behaviour is clear, as noted above it is likely that family carers will vary in the extent to which they are able and willing to be involved in this work. This may be due to a range of factors relating to their personal circumstances, needs and characteristics, or attitudes and values. Many of these factors will require sensitive support from clinicians and therefore should be considered at the outset of any work, whilst others may be relatively unchangeable and represent barriers to family carer involvement more generally. As a result, it is important to consider the extent to which these factors influence an individual family carer's ability to support behavioural assessment and intervention for their child, and considering these factors early in the process will help to ensure that family carers are supported and empowered to be as involved in the process as possible.

Firstly, family carer personal characteristics are likely to influence their ability to support behavioural work with their child. This might include their confidence in supporting their child which is thought to be influential in determining outcomes from parent training (Solish & Perry, 2008). Whilst being involved in approaches that are effective in reducing CB might in itself increase family carer confidence, clinicians may need to provide additional support to families in order to empower them to take active roles in their child's behavioural support. This is likely to be necessary even where family carers do not take on an extensive role, given that they will often be involved in continuing interventions over the long term as noted above. Evidence suggests that approaches can be adapted to include elements that are likely to improve family carer confidence or self-efficacy (e.g., Durand et al., 2013) and these approaches may need to be considered where these issues are relevant for a family. In addition, family carer knowledge and skills may act as barriers to their involvement in their child's support. Given that behavioural approaches are not currently widespread in the UK, it is unlikely that all family carers will have experienced these approaches previously and they may therefore have only limited knowledge of such approaches. Overcoming this will require training and coaching for family carers to enable skills development relevant to the behavioural approaches used with their child. There are numerous examples in the literature of effective training methods for family carers (e.g., Chadwick et al., 2001; Matson, J. L. et al., 2009; Matson, M. L. et al., 2009) and clinicians will need to select the most appropriate approach based on the work being conducted, and family carer preferences and individual circumstances.

However, even where clinicians are able to support and empower family carers by focusing on outcomes relating to supporting their child (e.g., confidence, knowledge, skills), other barriers relating to family carers' personal characteristics may exist and require careful consideration. For example, family carers of children with IDD who display CB are known to experience significant stress and emotional difficulties (Baker et al., 2003; Bromley et al., 2004; Hastings, 2002; Lecavalier et al., 2006; Plant & Sanders, 2007) which may be exacerbated by other factors such as sleep deprivation (Gallagher et al., 2009; Wiggs & Stores, 1996), resource needs for their child (Guralnick, 2005a; Guralnick, 2017), and tensions or dissatisfaction with service support (McGill, Papachristoforou et al., 2006; McGill, Tennyson et al., 2006; Wodehouse & McGill, 2009). As a result, family carers may require emotional or therapeutic support before they are able to undertake targeted work with their child and it is important for clinicians to recognise that experiencing significant stress or emotional difficulties is likely to limit the ability of family carers to be heavily involved in their child's support. Behavioural work may therefore need to begin by involving families in a consultative role and increasing or supporting their involvement over time, rather than requesting that families take on an active role from the outset. In addition to emotional difficulties, family carer attitudes and understanding about their child's CB may also impact the ability to which they are able or willing to be involved in behavioural support (Mah & Johnston, 2008; Morrissey-Kane & Prinz, 1999). Some families may not wish to be heavily involved and may instead prefer clinicians to work with their child. Family carers are also likely to have diverse attitudes about their child's behaviour, some of which may be more helpful than others to behavioural work. For example, individuals who believe the child's behaviour to be controllable by the child may experience this behaviour more negatively and feel less able to influence the child's behaviour (Woolfson et al., 2011) which may lead them being less likely to engage with behavioural support.

Finally, family carers' own learning histories may represent barriers to implementing effective interventions with their child, and clinicians will often need to consider contingencies affecting family carer behaviour alongside the behaviour of the child (Allen, K. D. & Warzak, 2000; Fryling, 2014; Oliver, 1995; Patterson, 1982; Stocco & Thompson, 2015). For example, Stocco and Thompson (2015) noted that family carers often engage in behaviours that avoid or minimise contact with circumstances which evoke their child's CB and that reduce behavioural incidents when they occur, meaning that the family carer's behaviour may have been strengthened by the avoidance of their child's CB or through negative reinforcement processes due to the cessation of the child's behaviour. These contingencies may have existed for long periods of time and have been strengthened over time (Stocco & Thompson, 2015), and it may therefore be difficult for clinicians to overcome these when supporting family carers to conduct assessments and implement interventions with their child. This highlights the importance of building competing contingencies into work with the family to support family carers to overcome any unhelpful contingencies that have naturally emerged throughout the child's life (Stocco & Thompson, 2015).

In addition to personal characteristics as described above, a family carer's personal circumstances may also influence their ability or willingness to take an active role in assessment and intervention for the child's behaviour (Fryling, 2014). These factors may have practical implications that make it difficult for family carers to take an active role in their child's assessment and support or they may act as stressors which influence the family carer's broader wellbeing. For example, whether the family carer is a single parent or has good social support may influence both the amount of time they can devote to such approaches and their emotional wellbeing. Research suggests that family carers of children with IDD often have limited social support outside of the immediate family (Bromley et al., 2004; Hubert, 2011; Johnson et al., 2006) and this may have a particularly profound impact in single parent households. This is likely to be further exacerbated if the family carer has additional caring responsibilities (e.g., to other children in the family) and evidence suggests that this is the case for many families, as children with disabilities are more likely to live in households in which there are others with disabilities (e.g., siblings, other adults), increasing the caregiving burden for family carers (Blackburn et al., 2010). In these instances, the clinician may need to ensure that higher levels of support are offered to the family carer, particularly at the outset of work when the family carer may be unfamiliar with the procedures.

In addition, the family's resources may act as stressors influencing the extent to which they are able to undertake assessment and intervention work. Families with children with disabilities may be more likely to experience financial difficulties (Blackburn et al., 2010), or may live in inappropriate (e.g., overcrowded, unsafe) accommodation and may therefore find it difficult to prioritise assessment and intervention work for their child due to increased stress or emotional difficulties associated with daily life. Finally, families experiencing extreme adversity (e.g., domestic violence, trauma, extreme poverty) may require support to manage their experience and improve their own wellbeing before being able to implement assessment and support for their child. Many of these factors can be incorporated into initial work with a family in relation to assessments of the family environment and contextual fit for any interventions proposed. These are hallmarks of family focused PBS which often involves extensive work with family carers as well as the focal child (e.g., Keen & Knox, 2004; Lucyshyn et al., 2002). Nevertheless, these circumstances are likely to represent barriers to a family carer's involvement in their child's support and the clinician may have only limited ability to influence these factors, therefore it will be helpful to be aware of these and consider their impact on an individual basis for each family.

Evidence Relating to a Collaborative Model of Assessment and Intervention for Young Children with IDD

Whilst there may be challenges inherent in supporting family carers to be heavily involved in assessment and intervention for their child's behaviour, examples are evident in the literature of instances where this has been successful and led to positive outcomes for both the family and child. For example, Fettig and Barton (2014) review thirteen studies which utilised a collaborative model with family carers when supporting their child who displays CB. The included studies focused on involving family carers in FAs and / or multi-element behaviour support plans (BSPs) to reduce their child's CB during family routines. Some studies incorporated family carer involvement in conducting the FA, whilst all studies trained families to implement the BSP. Although the methodological quality of studies varied, all reported positive outcomes in relation to family carer fidelity (where reported) and reductions in the child's CB. However, the extent of collaboration with families across the thirteen studies was not always quantified with detail about the specific nature of their involvement, and little information was provided in the review about the extent to which family characteristics and circumstances (such as those described above) were considered. Furthermore, few studies collected maintenance or generalisation data, making it difficult to determine whether interventions were successful over time. Nevertheless, this review provides clear evidence of the effectiveness of involving family carers in the implementation of assessments and intervention for their child's CB.

Numerous examples of family carers being involved in individual elements of behaviour support also exist in the literature (e.g., Fettig & Barton, 2014; Fettig et al., 2015; Gerow et al., 2018; Suess et al., 2016; Wacker et al., 2017) though few studies focus exclusively on the element of family carer involvement and instead report this in only limited detail. Some more extensive examples can be found such as Keen and Knox (2004) in which the authors outline the rationale for a clear focus on family centred work and provide a case example in which behavioural support was developed to be sensitive to the family context. As a result, the authors' work with the family incorporated multiple elements including FA and behavioural strategies for the focal child, as well as strategies for broader family support such as referral to counselling services, creation of new family routines which enabled all family members to achieve goals that were important to them, further diagnostic support for the children to clarify their needs etcetera. The authors argue that this broader work was imperative in enabling the family to make positive changes to their quality of life and support the focal child's behaviour. Other examples report similar strategies and positive outcomes (see Lucyshyn et al., 2002).

These case examples demonstrate a more extensive model of family involvement than the studies reviewed by Fettig and Barton (2014) and it is likely that most behavioural support provided by clinicians will fall somewhere between these two approaches. However, taken together these studies demonstrate an emergent literature focusing on family-professional collaboration, which Keen and Knox (2004) argue represents an evolution of behaviour support methodologies. As noted above, the involvement of family carers in support for their child's behaviour is likely to enhance the effectiveness of such approaches and is therefore an important area for further research as the field develops.

Conclusion

This initial chapter aimed to provide an overview of CB for individuals with IDD and outline the theoretical underpinnings of early assessment and intervention for young children with IDD who display CB. The importance of involving family carers in this process was highlighted with reference to their extensive role throughout their child's life, and their unique position in relation to their knowledge and skills in supporting their child. Whilst the involvement of family carers in conducting assessments and implementing interventions for their children is not without challenges, evidence suggests that this may enhance assessment and intervention outcomes, highlighting positive outcomes for both the child and their family carers. As a result, this chapter has argued that the involvement of family carers is vital to the success and longevity of approaches aiming to reduce CB in children with IDD.

Overview of Thesis

Given the evidence and gaps in the literature highlighted in this chapter, the overall aim of this thesis is to explore the evidence base for the use of FBIs with young children with IDD and consider how such approaches can be utilised within a UK context via extensive collaboration (within clinical work) with family carers. Detailed methodology is described in each chapter given the divergent methodologies utilised within the thesis. However, an overview of the approach taken to addressing the thesis aim will be described here. Firstly, in order to provide an overview of the current evidence base relating to the use of FBIs with young children with IDD, and the use of telehealth for training stakeholders in ABA procedures, literature will be synthesised using systematic review methodology (i.e., Chapters Two and Three) to ensure that all relevant literature is captured and objectively described, with the methodological quality of the evidence base systematically examined. Where the aim is to examine the effectiveness of approaches (i.e., Chapter Two), meta-analytic approaches will be employed in order to evaluate effect sizes and the strength of the evidence base overall. Given the extensive use of single case designs and the more limited use of group designs in behavioural research, these approaches will be designed to ensure that both types of design can be incorporated and synthesised (see, for example, Marquis et al., 2000).

In order to demonstrate the feasibility of utilising FA and FBI methodology with young children with IDD in the UK, two empirical studies (i.e., Chapters Four and Five) will be conducted which address this part of the thesis aim. The first will examine the feasibility of training family carers in these approaches in-person, whilst the second will examine the feasibility of delivering this training solely by telehealth in order to provide information about the utility of this delivery format for a UK context. Both studies will focus primarily on the use of behavioural approaches in clinical practice (i.e., by focusing on FA and FBIs for young children with IDD, and behavioural training approaches for training family carers), therefore single case design will be employed in line with conventions in the field. This is most appropriate where the primary outcomes of interest are observational in nature (i.e., CB) based on clinical work, and enables the demonstration of experimental control for individual participants thereby offering more scientific rigour than an uncontrolled case study (see Kazdin, 2019). Where relevant, questionnaire and qualitative measures will also be used to supplement observational data to ensure a holistic approach is taken to data collection providing information across a range of relevant outcomes. For example, Chapters Four and Five both utilise questionnaire measures relating to social validity and family quality of life; these variables are difficult to assess via observational methodology as they are primarily subjective and deal with participant's experiences rather than their observable behaviour.

Finally, in order to examine the social validity of the use of telehealth approaches for behavioural support in the UK, a third empirical study will be conducted which utilises Delphi consultation methodology (Adler & Ziglio, 1996; Linstone & Turoff, 1975). This methodology is appropriate where the aim is to generate consensus amongst experts on a particular topic which was necessary here in order to consider the most influential factors effecting the likelihood of professionals and family carers using telehealth for behavioural support. This method also avoids the need for participants to be in the same location or available at the same time (which may be difficult for both family carers and professionals), and enables participants to comment on a topic anonymously, removing power imbalances which might be present with other primarily qualitative methodologies. This methodology also incorporates a quantitative summary of items reaching consensus and can allow participants to rank these, enabling practice recommendations based on this ranking.

The thesis itself is structured as follows. Chapters Two and Three consider the evidence base relevant to the use of FBIs with young children with IDD (via a systematic review and meta-analysis: Chapter Two) and the evidence for training stakeholders via telehealth (i.e., the use of technology across distance) which, it is argued, may be a useful delivery format for interventions within a UK context (via a systematic review: Chapter Three). Results from empirical studies examining the feasibility and acceptability of these approaches are then presented across three further chapters. Specifically, Chapter Four presents results of a study examining the feasibility of implementing FBIs (specifically, FCT) with young children with IDD in the UK, collaborating with and training family carers throughout the process, whilst Chapter Five then adapts methods utilised in Chapter Four for delivery via telehealth and presents results of a study examining the feasibility of the use of such approaches within the UK. Finally, Chapter Six presents results of a study examining the social validity of the use of telehealth within the UK for both professionals who might utilise such approaches, and family carers who might receive support via telehealth. Chapter Seven then presents a general discussion of the findings of the thesis and how such findings contribute to the evidence base relating to the use of function-based approaches for children with IDD and involvement of family carers in the process within a UK context.

Chapter Two

The Effectiveness of Positive, Function-Based Interventions for Young Children with Intellectual or Developmental Disabilities who Display Challenging Behaviour: A Systematic Review and Meta-Analysis

Chapter Overview

In Chapter One, the evidence base relating to assessment and intervention for challenging behaviour (CB) was reviewed and it was argued that Positive Behaviour Support (PBS: Carr et al., 1999; Gore et al., 2013; Horner et al., 1990) has received the most empirical and professional support in recent years. However, as noted in Chapter One, the evidence base for PBS with young children with intellectual / developmental disabilities (IDD) is still emerging and is not yet well established. This is an important omission given the documented early emergence and persistence of CB (see Chapter One), highlighting the importance of early intervention to reduce CB and improve outcomes across the child's life span. As a result, this chapter presents a meta-analysis of single case and group design studies examining the effectiveness of PBS based interventions for specifically young children with IDD. The results of this analysis will be used to inform empirical studies in this thesis by identifying effective intervention components that can be used to support families of children with IDD in the UK.

Introduction

In recent years, there has been increasing recognition of the effectiveness of using behavioural approaches including PBS to support individuals with IDD who display CB (see Chapter One). Key elements of these interventions (e.g., use of functional assessments [FAs] and function based interventions [FBIs]) are supported by the National Institute for Health and Care Excellence (NICE) in the UK (NICE, 2015) and a number of reviews have demonstrated the effectiveness of these elements in reducing CB for this population. For example, Carr and colleagues (Carr et al., 1999; Marquis et al., 2000) reviewed 109 articles relating to PBS for individuals with developmental disabilities across a range of ages. They concluded that PBS is applicable to a wide range and severity of behavioural difficulties and was more than 90% effective in reducing CB. More recently, Lavigna and Willis (2012) reviewed twelve studies presenting 423 PBS based interventions for adults with severe or high rate CB, finding that PBS was effective in all cases, in a range of environments, was cost effective, and easy to disseminate. Two recent meta-analyses have also provided quantitative evidence for PBS based interventions for individuals across a range of ages (i.e., Harvey et al., 2009; Heyvaert et al., 2012), and a number of other reviews or meta-analyses have demonstrated the effectiveness of specific types of interventions (e.g., functional communication training [FCT]: Kurtz et al., 2011; augmentative and alternative communication, Walker & Snell, 2013), of interventions for individual response classes of behaviour (e.g., elopement, Lang et al., 2009; self-injurious behaviour, Prangnell, 2010), and of interventions for individuals with particular diagnoses (e.g., Autism Spectrum Condition [ASC]: Campbell, 2003; Heyvaert et al., 2014).

Despite this, there have been few reviews of the effectiveness of PBS based interventions for specifically young children with IDD. A number of reviews have demonstrated the effectiveness of interventions based on behavioural methods for young children with ASC (e.g., Horner et al., 2002; Mancil, 2006), and system wide implementations of PBS for young children have also been evaluated in one meta-analysis (Goh & Bambara, 2012) highlighting their effectiveness for children with and without disabilities across a range of ages. Taken together, these reviews suggest that PBS based interventions for young children with IDD are likely to be effective in reducing CB. However, the evidence base for this assertion is weak for several reasons. Firstly, many of the reviews include participant groups with a wide range of ages, those without disabilities, or with a specific diagnosis. As a result, it is unclear whether PBS based interventions are effective for younger children, and for children with IDD more specifically. Secondly, many of the reviews omit group based interventions, such as those aimed at training family carers, resulting in an important aspect of PBS based research being missed given the emphasis on stakeholder participation in PBS (Gore et al., 2013). Group based parenting interventions have been shown to effectively reduce problem behaviour in children without IDD (e.g., De Graaf et al., 2008; Menting et al., 2013) and it is therefore important to identify whether these types of interventions (when based on the principles of PBS) are similarly effective for family carers of children with IDD (Emerson, 2014). Finally, many of the reviews include interventions inconsistent with PBS, such as solely pharmacological or punishment based interventions (e.g., Horner et al., 2002); the inclusion of these may reduce the strength of conclusions made relating to the PBS interventions included in such reviews.

The current review therefore aims to consolidate PBS based intervention research for young children with IDD who display CB. Whilst PBS interventions should contain multiple components (Gore et al., 2013) there are few empirical reports of such multi-component interventions for young children with IDD. As a result, this review focuses on articles presenting interventions based on PBS principles, and are therefore consistent with a PBS framework. These interventions were defined as those that are based on a prior FA, do not utilise punishment procedures, and are not based solely on extinction (as interventions including punishment or based solely on extinction would not be supported in recent conceptualisations of PBS such as Gore et al., [2013]), hereafter termed "function-based positive interventions" (PFBIs). The review seeks to answer the following research questions:

1. To what extent are FBPIs used to support young children with IDD who display CB?
2. How effective are FBPIs in reducing CB for young children with IDD?
3. Which is the most effective type of FBPI in reducing CB for young children with IDD?

General Methodology

Inclusion / Exclusion Criteria

This review aimed to identify articles presenting findings from FBPIs to support young children with IDDs who display CB. Both group and single case designs were included if they met all the following criteria:

1. The study was published between January 1990 and August 2015. Studies published before

1990 were not included as one of the first descriptions of PBS (i.e., Horner et al., 1990) was published in 1990, and interventions published before this were therefore unlikely to be informed by the full PBS framework. Whilst some of the interventions developed before 1990 were of course consistent with the principles later defined as PBS, for example FCT (i.e., Carr & Durand, 1985), there are few examples of this being the case and the inclusion of studies published at any time would have rendered the number of articles identified unmanageable. As a result, a start date of 1990 was selected for this review. The end date of 2015 reflects the latest point at which searches were updated, and given that the meta-analysis aimed to inform subsequent empirical studies it was not felt appropriate to update the searches again after this date since this may have changed conclusions on which procedures used within the empirical studies were based. However, in the General Discussion below an overview of key literature published since this date has been included to provide an updated summary of the evidence base.

2. Participants were aged under seven years (or, for group designs, included participants who were under seven years within the intervention group). Age seven was chosen for two main reasons. Firstly, due to the large number of studies initially meeting inclusion criteria the age criterion was changed from ten years to seven years in order to reduce the number of studies included, whilst still ensuring that the review encompassed a sufficiently large proportion of the empirical literature. In addition, seven years has been used in a previous review focusing on young children who display CB (Wood et al., 2009), and other reviews focus on six (Conroy et al., 2005; Odom et al., 2003) or eight years of age (Barton & Fettig, 2013; Horner et al., 2002; McLaughlin et al., 2012). An age of seven was therefore chosen as it falls between the ages commonly considered to encompass *young* children in the literature whilst ensuring that the number of studies included in the review was not prohibitively large.
3. Participants had an identified IDD (e.g., ASC, Down Syndrome, Fragile X syndrome etc.), or

global developmental delay.

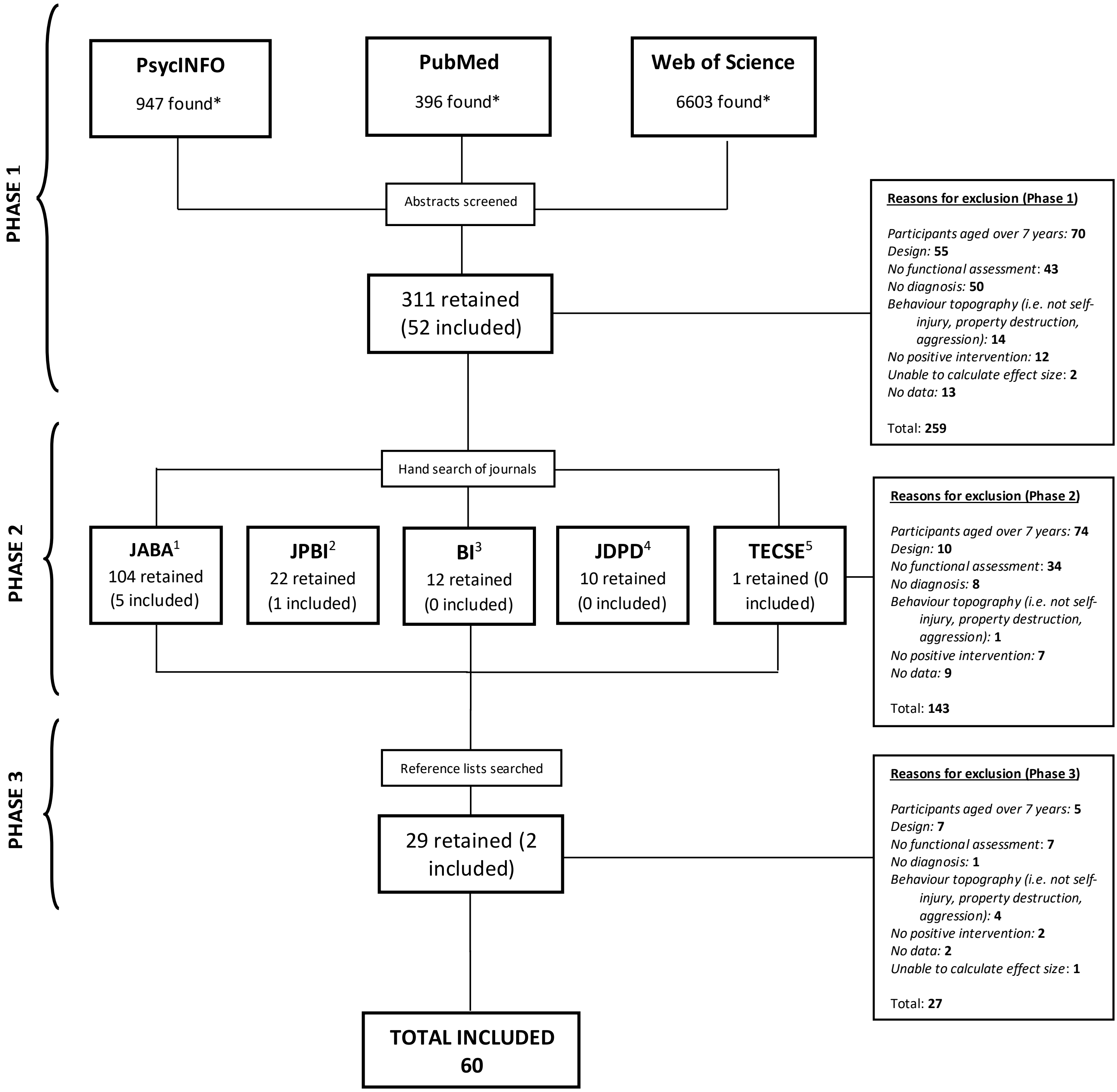
4. Participants displayed at least one form of the following types of CB:
    a. Physical aggression (i.e., any behaviour that can cause injury to another person)
    b. Self-injury (i.e., any behaviour that can cause injury to the child's own body)
    c. Property destruction (i.e., any behaviour that can cause damage to the child's surroundings).
5. A FA was conducted to try and identify the function of each participant's CB. This could be indirect (e.g., observations, interviews with caregivers), direct (e.g., experimental functional analysis [EFA]) or a combination of these approaches. Studies were included as long as a FA was conducted, even if the results were not presented or were undifferentiated as it was assumed that, even if the overall result was undifferentiated, the FA process would provide additional information about the child's behaviour and its possible function that could be used when designing the intervention.
6. A positive (i.e., not solely extinction based and not including punishment procedures) intervention was provided for CB; this could include interventions based on antecedent or consequence manipulations, skills teaching, or differential reinforcement. Articles combining pharmacological and behavioural interventions were included only if it were possible to evaluate the effects of the behavioural intervention in isolation, however no articles were identified that involved the additional (i.e., nonroutine) use of pharmacological interventions. Articles focusing on resurgence of behaviour were included only if it were possible to evaluate the effects of the intervention separate to any phases examining resurgence.
7. The study collected quantitative data related to CB within an experimental design and it was possible to calculate effect sizes from the data presented in the article or obtained by contacting the authors.

Search Strategy

A three-phase search strategy was used to identify studies that met inclusion criteria (see Figure 1 below for an outline of the strategy and number of studies identified and excluded at each stage).

Figure 1

Search Strategy and Reasons for Exclusion at Each Stage



*Includes duplicates across databases. Total found excluding duplicates = 6231. [1] Journal of Applied Behavior Analysis, [2] Journal of Positive Behavior Interventions, [3] Behavioral Interventions, [4] Journal of Developmental and Physical Disabilities, [5] Topics in Early Childhood Special Education.

Firstly, a range of search terms (see Table 1) were entered into three databases that were most likely to identify relevant published articles, specifically, PsycINFO, PubMed, and Web of Science. Each group 1 term was combined with each group 2 term and, where possible, limiters were applied to ensure that only studies published after December 1989 and only studies relating to children were identified. A total of 6231 articles were found (excluding duplicates) and the titles and abstracts of these articles were screened. Three hundred and eleven relevant articles were obtained for further review and, after applying inclusion criteria, 52 articles were included. Next, the five journals (as three of these five published the same number of included articles) which published the highest number of included articles were hand searched to identify additional articles (see). In total, 149 new articles were obtained for review and six articles were included. Finally, the reference lists of all included articles were searched which yielded an additional 29 articles of which two were included. In total, 60 articles were included in the review. Of these, eight utilised group designs and 52 utilised single case designs. (above) displays the reasons for exclusion at each stage.

Table 1

Databases and Search Terms Used to Identify Relevant Studies

Databases	**Search Terms**	
	Group 1	**Group 2**
PsycINFO	Positive behav* support	Challenging behav*
Pubmed	Positive interventions	Problem behav*
Web of Science	Function based	Aberrant behav*
	Functional analysis	Maladaptive behav*

Databases	Search Terms	
	Group 1	**Group 2**
	Functional assessment	Behav* difficulty
	Functional behav* assessment	Aggression
	Functional communication training	Aggressive behav*
	Functional equivalence training	Self injury
		Self injurious behav*

Methodological Quality Appraisal

For both group and single case design studies, the Evaluative Method (Reichow et al., 2008; Reichow, 2011) was used to appraise the methodological quality of studies. This tool was rated highly in a comparison of single case design evaluation tools (Wendt & Miller, 2012) and has versions for both single case design articles and group design articles, with a common final rating scale used across both types of design (Weak, Adequate, or Strong). The tool uses primary indicators (rated as High, Acceptable, and Unacceptable) and secondary indicators (rated as present or absent) to contribute towards the final rating, with criteria to guide users about which rating to allocate.

The tool was adapted in two ways for use in the current review. Firstly, using the original criteria defined by Reichow and colleagues (2008; 2011) the majority of studies included in this review received a weak rating, however it was felt that this did not reflect the range of quality of the studies. In order to remedy this, two additional categories of final rating were added to the scale (Borderline Adequate and Borderline Strong) to allow greater variability in scores and criteria were modified accordingly (see Appendix A for criteria used to assign ratings). Secondly, participant criteria were modified as the tool was originally used specifically for studies relating to ASC only. As a result, modifications were made such that, as long as the participant's diagnosis or level of ID was stated in the article, the study could still score “High” on this indicator.

The reliability of the use of the tool was checked for 10% of the studies by an independent rater. Initial agreement on primary and secondary ratings was 78.38% overall (83.33% on primary indicators, and 76.32% on secondary indicators). However, agreement on final ratings was only 16.67%; this was due to disagreements on primary indicators which have a larger influence on the final rating. As a result, any disagreements were discussed, and agreement was reached on 100% of indicators and final ratings. Where necessary, changes were made to ratings assigned to all articles within the review based on discussions between raters where this influenced the criteria used for assigning ratings. This procedure was adopted in order to ensure that the tool had been applied consistently across the articles and that disagreements between raters were resolved.

Part One – Single Case Design Articles

Methodology

Data Extraction

As is common in single case design studies, data relating to CB were presented graphically in all the articles. Attempts were made to contact the lead author of each article to obtain raw data, however if the raw data were not available the data were instead extracted from the published graphs. In order to ensure that an accurate software package was chosen for extraction, three freely available software packages were tested using ten published graphs for which the raw data were available to the author (see Appendix B for the accuracy results for each software package). Each of the programmes were found to be highly accurate, however GetData Graph Digitizer (Federov, 2013) was found to be the most accurate (98.77% accurate on average) with the lowest variability in error (*SD* = .05 and 2.44 for zero error points and percentage error respectively) and was therefore used in the current review.

If the raw data could not be obtained (either directly from the author or via extraction as described above) for any relevant participants within an article, or the obtained data were not sufficient to calculate the effect size measure (e.g., if there were fewer than three data points per included phase), the article was excluded as described above (this occurred in 26 instances).

Effect Size Calculation and Analysis

Tau U (Parker et al., 2011) was utilised as the effect size measure for the single case design articles included in this review. Tau U is nonparametric nonoverlap method of estimating intervention effectiveness in single case design studies that is able to consider all data from a given intervention, combine multiple phase contracts and control for undesirable baseline trend. It has been shown to be robust to the effects of autocorrelation and does not require parametric assumptions to be met (Parker et al., 2011). Bottom up methodology (see Parker & Vannest, 2012) was utilised for calculations on a case by case basis to mirror the principles of visual analysis, and omnibus Tau U scores were calculated by weighting individual scores by the inverse of their variance. A separate Tau U score was calculated for each relevant intervention, and intervention effectiveness was analysed separately with respect to fading, generalisation or follow up measures as not all interventions included these elements (see below). Some participants took part in more than one intervention meaning that they contributed more than one Tau U score to the final omnibus scores, however given that these scores refer to separate interventions (rather than multiple outcomes from the same intervention), and the small number of instances where this applied (see below), this was not considered likely to significantly affect results.

An online calculator (www.singlecaseresearch.org) was utilised to calculate individual intervention and omnibus weighted Tau U scores. Tau U scores range from 0-1 and can be interpreted as the percentage of data showing improvement (i.e., nonoverlap) between phases, with scores lower than 0.65 indicating a weak effect, 0.66-0.92 indicating a medium effect, and 0.93-1 indicating a strong effect (Parker & Vannest, 2009). For this review, improvement (i.e., a positive Tau U score) indicates a reduction in CB.

Results

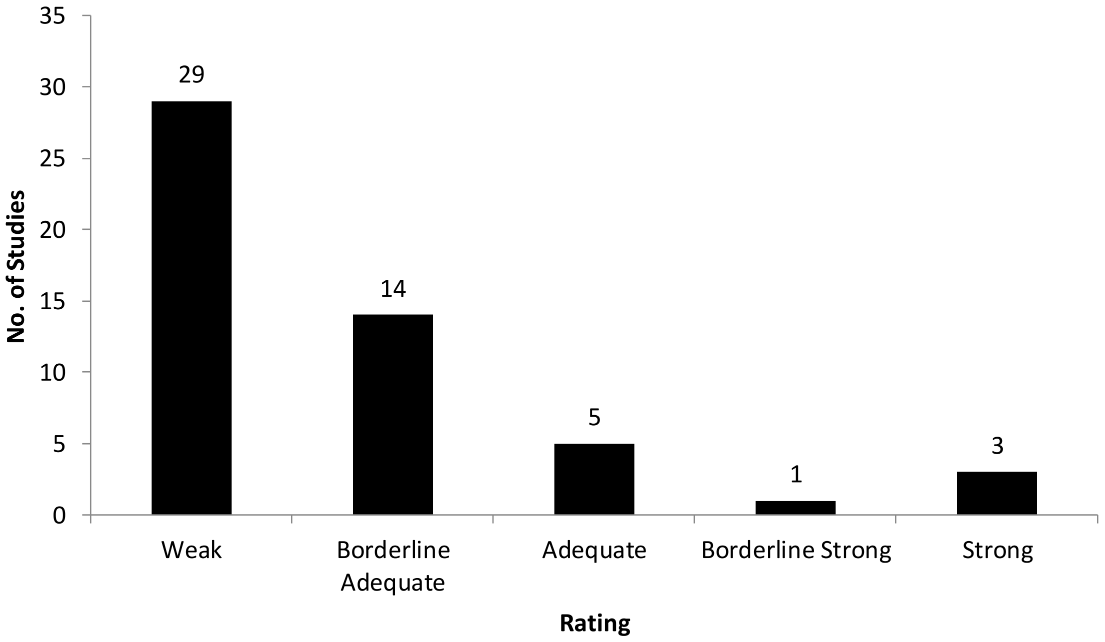
As stated above, 52 single case design articles met inclusion criteria and are included in this review. The characteristics of these studies can be seen in Appendix D.

Methodological Quality

Figure 2 displays the frequency of ratings assigned to each article for each category on the Evaluative Method (Reichow et al., 2008; Reichow, 2011), and the frequency of ratings achieved by single case designs on primary and secondary indicators can be seen in Appendix C. The majority of studies scored low ratings, however, five scored 'Adequate', one scored 'Borderline Strong', and three scored 'Strong'. Further detail about common areas of strength / weakness across ratings on the Evaluative Method is provided in the Part One Discussion below.

Figure 2

Evaluative Method Ratings for Single Case Design Studies



Sensitivity analyses were conducted to identify whether methodological quality influenced the overall weighted Tau U scores (see Table 2 below). After removal of interventions presented in articles scoring "Weak", the Tau U score improved to evidence a strong effect. However, this result was not consistent when subsequently examining Tau U scores after removing interventions from articles scoring “Borderline Adequate” or “Adequate” as the confidence intervals increased substantially suggesting greater variability. As a result, it was assumed that any influence of quality on the Tau U score was nonlinear and variable. Considering this and the large number of articles scoring “Weak”, all interventions were included in subsequent analyses. However, issues relating to methodological quality and its possible influence on conclusions are highlighted in the Part One Discussion below.

Table 2

Results of Sensitivity Analyses Using Evaluative Method Rating for Single Case Design Articles

Included interventions	**n**	**Tau U**	**95% Confidence Interval (CI)**
All	106	0.785	0.840<>0.729
‘Borderline Adequate’, ‘Adequate’ & ‘Strong’	46	0.886	0.962<>-0.805
‘Adequate’ & ‘Strong’	15	0.940	1<>-0.795
‘Strong’	4	1	1<>0.720

Participants

Ninety-two participants (64 male, 25 female, 3 where gender was not stated) were included aged 20-84 months (median = 56 months). Participants were reported to have a specific diagnosis only (*n*=28), an ID only (*n*=38) or both an ID and associated diagnosis (*n*=26). Participants had a range of diagnoses including ASCs (*n*=25), Angelman syndrome (*n*=4), Pervasive Developmental Disorder (PDD; *n*=7), Fragile X Syndrome (*n*=1) or a combination of these (*n*=12). Where participants had a reported ID (*n*=64 of which 26 also had a specific diagnosis as described above), the level of this varied with ten described as having a mild ID, seven as having a moderate ID, 17 as having a severe ID, and five having a profound ID (level of ID was not stated for 25 participants who were reported to have an ID). Participants most commonly displayed multiple response classes of interest (i.e., self-injury, aggression, or property destruction; *n*=49), with 24 displaying aggression only, 13 displaying self-injury only, and six displaying property destruction only. The identified function of each participant's behaviour varied with most having more than one function (*n*=35), however 54 had a single identified function of attention (*n*=13), tangible (*n*=14), escape (*n*=22), or automatic reinforcement (*n*=5). For three participants, no clear function was identified.

Interventions

One hundred and six interventions were implemented (eleven participants took part in more than one intervention). A range of designs were utilised including reversal (*n*=45); multiple baseline (*n*=35); alternating treatments (*n*=6); or a combination of design types (*n*=20). Interventions were implemented in either natural (*n*=56) or contrived (*n*=50) settings by therapists (*n*=62), parents (*n*=26), teachers (*n*=14), or a combination of parents and teachers / therapists (*n*=3). Interventions were categorised as being primarily skills teaching / differential reinforcement of alternative behaviour (ST / DRA: *n*=52), environmental adaptations / noncontingent reinforcement (EA / NCR: *n*=27), DRO (*n*=5), or as combining more than one of these elements (*n*=22), and 74 also included extinction procedures. The number of minutes during which data were collected was calculated for each intervention as an indicator of intervention length, with a mean length of 3.1 hours (range = .41-10.5). However, it should be noted that this refers only to data collection and it is likely that interventions were also implemented at times when data were not collected. Across all interventions, 19 included fading procedures, 20 included training and testing for generalisation, and 12 included follow up data collection after the end of the initial intervention.

Intervention Effectiveness

Table 3 displays weighted omnibus Tau U scores across all interventions and intervention types for both the main intervention and after fading, generalisation and follow up data collection. The overall weighted Tau U before fading, generalisation or follow up data collection was 0.785 (95% CI: 0.840 to 0.729) indicating a significant medium effect across all studies (according to criteria outlined in Parker & Vannest, 2009). Interventions achieving the highest Tau U scores were those that included multiple intervention elements (Tau U = 0.895, 95% CI: 1 to 0.762) with those focusing solely on ST / DRA achieving the lowest Tau U score (0.712, 95% CI: 0.784 to 0.640) though still evidencing a significant medium effect. None of the intervention types were associated with strong effect sizes of greater than 0.93 after the main intervention. However, when considering generalisation data those utilising ST / DRA and those utilising multiple intervention elements achieved strong effect sizes, and after follow up data collection those utilising multiple intervention elements also achieved a strong effect size.

Table 3

Overall Tau U Scores and Scores by Intervention Type for the Main Intervention, and After Fading, Generalisation, and Maintenance Data Collection

	Intervention			**Intervention + Fading**			**Intervention + Generalisation**			**Intervention + Follow Up**		
	n	Tau U	95% CI	n	Tau U	95% CI	n	Tau U	95% CI	n	Tau U	95% CI
Overall	106	0.785	0.840<>0.729	19	0.762	0.858<>0.665	20	0.931	1<>-0.839	12	0.911	1<>-0.791
ST / DRA	52	0.712	0.784<>0.640	11	0.678	0.808<>0.548	5	0.932	1<>0.739	3	0.695	0.896<>0.494
EA / NCR	27	0.856	0.977<>0.734	5	0.855	1<>0.686	8	0.907	1<>0.764	#	#	#
DRO	5	0.794	1<>0.548	3	0.905	1<>0.639	#	#	#	#	#	#
Multiple	22	0.895	1<>0.762	#	#	#	7	0.960	1<>0.811	9	0.997	1<>0.852

Note. # indicates that interventions in this category did not include data for this specific outcome.

Part One Discussion

The single case design interventions presented in Part One were found to be effective overall with a medium effect (Tau U = 0.785), providing good evidence for the effectiveness of FBPIs for this population though with significant methodological limitations in the evidence base as described below. Previous meta-analyses of intervention research support this finding (e.g., Heyvaert et al., 2012; Horner et al., 2002; Ma, 2009; Marquis et al., 2000) however this review is unique in examining outcomes in relation to specifically positive and function-based interventions for *young* children with a range of diagnoses and levels of ID. When considering intervention type, all interventions evidenced a medium effect, with interventions combining multiple approaches achieving the highest Tau U score (Tau U = 0.895). However, the pattern of effectiveness across intervention type varied such that interventions found to be the most effective after the main intervention were not necessarily the most effective after fading, generalisation or follow up measures. This suggests that practitioners should select interventions based not only on general effectiveness but also on important secondary outcomes. Nevertheless, all intervention types achieved at least a significant medium effect size at all stages.

Several important limitations must be considered in relation to Part One of this review. Firstly, the majority of articles received low ratings on the Evaluative Method (Reichow et al., 2008; Reichow, 2011). In particular, interventions often did not score highly for visual analysis (i.e., evidencing low variability and large changes between experimental conditions), did not evidence stable baseline data, did not include blind raters or calculate kappa, and rarely reported fidelity or generalisation and maintenance data. Whilst Tau U accounts for variability in the data, these issues nevertheless represent limitations in the methodological quality of the included studies and therefore reduces the strength of the evidence base. Sensitivity analyses suggested that methodological rigour may influence effectiveness, and this should be considered by practitioners in the field. However, the influence of methodological quality on effectiveness was not found to be linear, therefore highlighting the need for a more detailed component analysis of methodological quality indicators and their influence on intervention effectiveness. This was beyond the scope of this review and represents an area for further research. Secondly, the generalisability of the single case design evidence base is also limited. A disproportionate number of participants with mild or moderate IDs were represented which is contrary to evidence suggesting that CBs are more likely to develop if an individual has a severe or profound ID (Emerson & Einfeld, 2011). Furthermore, a high number of participants had ASC, or an unspecified developmental disability compared to other diagnoses or genetic conditions. It is therefore difficult to generalise findings to other populations.

Part Two – Group Design Articles

Methodology

Data Extraction

In most cases, the necessary data for calculation of effect sizes (i.e., the mean and standard deviation of the pre intervention measure or control group, and the mean of the post intervention measure or intervention group) was presented in the results section of each article and was extracted and recorded in a spreadsheet. In cases where the necessary data was not provided, the lead authors of the article were contacted to obtain the data. If it was not possible to obtain the data the article was excluded, as described above (this occurred in three instances).

Calculation of Effect Sizes

A standardised mean difference effect size measure was selected for the group design articles in this review to allow for comparison across studies utilising different measures; Glass's Delta (Δ: Glass, 1976). This measure is well established for use with group design methodologies where the control (or pre intervention data points) and intervention groups (or post intervention data points) have unequal standard deviations (Ialongo, 2016) as in the current review. Glass's Delta examines the difference in mean scores between two groups (or between time points) by using the standard deviation of the control group (or pre intervention data point) to standardise scores. It can be interpreted according to conventions for interpretation of difference-based effect sizes (i.e., Cohen, 1988). In this review, a positive Δ indicates reduced CB. Cis were also calculated using the formula provided for standardised mean difference measures in Ialongo (2016). Furthermore, summary effect sizes (weighted by the inverse of variance) and Cis were calculated overall and for each type of study (i.e., family carer training only, combined training, staff training only) using the formulae described in Priday, Byrne and Totsika (2017).

Results

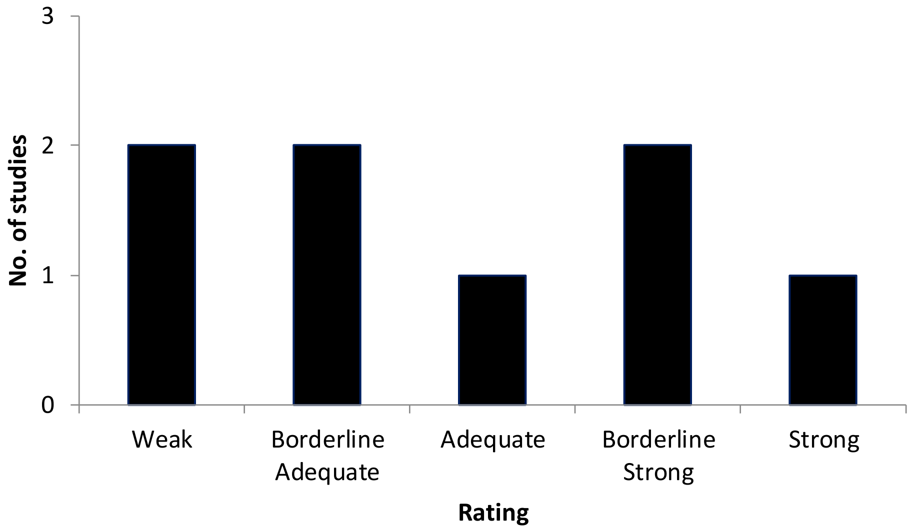
Eight group design studies met inclusion criteria and their characteristics can be seen in Appendix E.

Methodological Quality

Figure 3 displays the frequency of final rating given to group design articles on the Evaluative Method (Reichow et al., 2008; Reichow, 2011). Half of the articles scored 'Weak' or 'Borderline Adequate', with only one article scoring 'Strong'. Due to the low sample size, sensitivity analyses (as presented in Part One) were not conducted. The frequency of ratings achieved by group designs on primary and secondary indicators can be seen in Appendix C and common areas of strength / weakness on individual indicators across the articles is discussed in the Part Two Discussion below.

Figure 3

Evaluative Method Ratings for Group Design Articles



Participants and Interventions

All interventions involved training stakeholders, with four articles focusing on training family carers only, one on training staff only, and three on training both family carers and staff together. Across all interventions, 662 individuals were trained, representing 219 staff (e.g., teachers, therapists) and 443 family carers. Most interventions utilised between groups or quasi-experimental designs, with only two randomised control trials (RCTs). As a result, the majority of participants (*n*=284 family carers and *n*=219 staff) received a relevant intervention, with only 162 being placed in a control group. Interventions always involved some form of psychoeducation and training based on behavioural principles, most often delivered in a group format though some articles supplemented this with individual support for families. Two studies utilised established training programs (i.e., Brookman-Frazee & Drahota, 2010; McIntyre, 2008) whilst the remaining articles presented new programmes. Interventions targeted a range of outcomes and for the purposes of this review outcomes relevant to child CB were considered. In all cases, established questionnaires were used to measure CB (see Appendix E) and in two cases these were supplemented by observational data collection.

Intervention Effectiveness

The summary Δ effect size for all group design interventions was 0.62 (95% CI: 0.29 to 0.94) which is considered a medium effect according to Cohen (1988). This suggests that interventions presented in the group design articles were moderately effective in reducing behavioural difficulties for the participants' children. Individual intervention effect sizes ranged between -0.37 to 2.28, however, suggesting a high degree of variability in effectiveness with some evidencing a worsening in behavioural outcomes. Across intervention types (see Table 4), interventions that targeted training for family carers alone were most effective (summary Δ = 0.69, 95% CI: -1.03 to 2.42) and all such interventions evidenced an improvement in behavioural outcomes (Δ range = 0.03-2.28). Interventions which involved training both family carers and staff achieved lower effect sizes overall, though still evidencing a medium effect size (summary Δ = 0.61, 95% CI: 0.04 to 1.19).

Table 4

Summary Δ Scores by Intervention Type for Group Design Articles

Intervention type	n	Summary Δ	Δ Range	95% CI
All	8	0.62	-0.11-1.95	0.94<>0.29
Family carer training	4	0.69	0.16-1.95	2.42<>-1.03
Staff training	1	0.53[a]	#	#
Combined family carer and staff training	3	0.61	-0.11-.68	1.19<>0.04

Note. [a] Raw Δ provided as only one study utilised staff training only.

Part Two Discussion

The group design articles included in this review were found to be moderately effective overall with a summary Δ of 0.62. Three categories of interventions emerged within the group design articles (those based on family carer training, staff training, or combined training) and wide variations were found in the effect sizes for interventions within each category. Interventions based on family carer training were most effective with a medium effect size (summary Δ = 0.69) and interventions based on staff or combined training were less effective though still with medium effect sizes ($\Delta = 0.53$ and summary $\Delta = 0.61$ respectively). This result was unexpected, as interventions involving multiple stakeholders are considered best practice (Local Government Association & NHS England, 2014), however it is possible that this reflects practical difficulties in training multiple stakeholders. For example, whilst a child's main family carers can often be trained together, it may be difficult to train all members of staff who support a child, and two of the combined interventions only trained one staff member per child (i.e., Chadwick et al., 2001; Gore & Umizawa, 2011). This may mean that the intervention were not implemented with fidelity across all settings and therefore limited the extent of change in child behaviour. In addition, the most effective family carer training intervention (i.e., Durand et al., 2013) was more intensive, with one-to-one support offered to families by behavioural consultants, whereas all of the combined training interventions were group programmes delivered to family carers and staff. This may partially explain the higher effectiveness of family carer training interventions, as intensive one-to-one support is more likely to be individualised and tailored to the specific needs of the family and child. However, as statistical analyses were not conducted it remains the case that the differences between effect sizes by intervention type may be small, non-significant differences. Future research could usefully investigate this further.

Despite the overall moderate effectiveness of group design articles, the strength and generalisability of the evidence for this finding is variable. The representativeness of the study samples in some of the included articles may influence the external validity of the findings. Specifically, three of the articles (Bearss et al., 2015; Brookman-Frazee & Drahota, 2010; Reynolds et al., 2011) implemented interventions solely for participants whose children had ASC, and others included a high proportion of participants with ASC. It is therefore not known whether findings relating to these three interventions can be generalised to children with other diagnoses, or children with ID. Furthermore, some articles included only participants whose children had mild to moderate ID (McIntyre, 2008) or moderate to severe ID (Gore & Umizawa, 2011) therefore it is similarly unclear whether the findings relating to these interventions are applicable to children with a greater range of ability, or specific diagnoses. In addition to issues of representativeness, specific methodological features of some the included studies may also influence the strength of the evidence base. Whilst two articles utilised a RCT design which increases confidence in the findings, the majority of articles included no control group. As a result, for many of the articles it is not clear whether outcomes that indicate a reduction in CB are due to the intervention itself, or to another factor (e.g., maturation of the child). Furthermore, follow up data were not collected in five out of eight of the articles, therefore it is not known to what extent intervention effects were maintained over time. In general, methodological quality was variable across the studies. On the Evaluative Method, articles generally scored high for primary indicators (with the exception of the inclusion of a control group as noted above). However, no single secondary indicator was present in more than half of the studies (except for social validity), suggesting some issues in methodological quality across the group design articles.

General Discussion

Articles reporting on interventions that reflect the core features of PBS were specifically targeted for inclusion in this review to evaluate their effectiveness in reducing CB in young children with IDD. Despite variability in effectiveness and gaps in the evidence (discussed below), the results of this review provide limited support for the use of PBS based interventions for young children who display CB. Both interventions implemented directly with the child (i.e., those often presented in single case designs) and through a stakeholder training design were found to be effective overall, with effect sizes of 0.785 (based on Tau U calculations in Part One) and 0.62 (based on Δ calculations in Part Two) respectively. A wide range of intervention approaches were included in the review, and all evidenced effectiveness. In relation to the research aims, it was identified that a large number of intervention approaches used directly with children with IDD have been considered as outlined in Part One, and a small body of research has examined methods of training stakeholders to deliver such interventions as outlined in Part Two. When considering the effectiveness of intervention techniques, it was identified in both parts of the review that all interventions evidenced effectiveness. Part One further concluded that interventions evidenced effectiveness in different ways. For example, although ST / DRA interventions were the least effective initially (though still evidencing a medium effect), they were the most frequently used approaches and were amongst the most effective when considering generalisation of outcomes, which is an important consideration in applied settings. It was therefore concluded that practitioners should select interventions carefully to maximise the most important outcomes for individual children.

Despite the high levels of effectiveness noted, studies were variable in methodological quality and the evidence base for the utility of PBS for young children with IDD is therefore not robust at the time of this review. The majority of articles received a rating of 'Weak' or 'Borderline Adequate' on the Evaluative Method (Reichow et al., 2008; Reichow, 2011) which should be considered when interpreting results. Findings from Part One suggests that methodological quality may influence intervention effectiveness, though the direction and extent of this influence is unclear. Nevertheless, the finding that most articles received the lowest quality ratings reflects a limitation of the evidence base. The evidence base is also limited by the small number of studies which focus on stakeholder training and group designs in comparison to single case designs. Group design articles were rated low on the Evaluative Method and often did not include well controlled designs (e.g., RCTs). As a result, more high-quality research is needed (utilising both single case and group designs) with well controlled methodology to improve the strength and breadth of the evidence base.

A further limitation relates to the generalisability of the evidence base due to the lack of representativeness of the samples in both parts of the review. For example, as noted above a disproportionate number of participants with mild or moderate ID are represented in Part One of the review which is contrary to evidence suggesting that CBs are more likely to develop if an individual has a severe or profound ID (Emerson & Einfeld, 2011). Furthermore, a high number of participants had ASC, or an unspecified developmental disability compared to other diagnoses of, for example, a specific genetic syndrome. Whilst this is not unexpected (as genetic syndromes are generally less prevalent than ASC), the generalisability of these results to individuals with a wide range of diagnoses is not possible. Similarly, two of the articles in Part Two of the review included only participants whose children had ASC, and one article included a large proportion of participants whose children had ASC. Other articles included only participants whose children had mild to moderate ID, or moderate to severe ID. This limits the generalisability of findings relating to these particular group interventions, and of the single case design interventions more generally.

Despite limitations in the evidence base, the results of this review highlight the potential effectiveness of PBS based interventions in reducing CB in young children. It is important to note, however, that many of the interventions were based on a single procedure (e.g., differential reinforcement, stakeholder training, environmental adaptations etc.) and less than 25% of interventions were multicomponent in nature. Furthermore, the majority of the single case design interventions did not involve other stakeholders as intervention agents (e.g., family carers or teaching staff) and half were conducted in a clinic setting. The most recent conceptualisations of PBS (e.g., Denne et al., 2013; Gore et al., 2013) highlight that interventions should combine methods and involve a range of stakeholders (e.g., family carers and staff). The results of this review therefore offer some support to specific elements of PBS (such as the use of a FA, the effectiveness of techniques based on applied behaviour analysis [ABA] and stakeholder training) with young children and it is assumed that, when combined, these elements would result in even more effective interventions. However, this assertion has not yet been tested within the empirical literature and more research is needed which evaluates the use of a multicomponent, multisystem PBS framework with children aged under seven who have an IDD and display CB. This type of research is likely to involve interventions at a number of levels such as school based PBS (e.g., Horner et al., 2005), stakeholder training (e.g., for family carers), individualised support for the child, and general support for those around the child within a PBS framework (e.g., Reid et al., 2015). This will provide evidence regarding the use of multicomponent PBS, as recently conceptualised, with young children who display CB.

Limitations of the Review Methodology

Several limitations must be considered when interpreting results and formulating conclusions about the effectiveness of PBS based interventions for this population. Firstly, the influence of publication bias was not assessed as part of this review. However, publication bias has been evidenced in ABA research (e.g., Sham & Smith, 2014; Tincani & Travers, 2019) and may have influenced results here through the non-publication of less effective interventions. This may mean that, if publication bias is present, the effect sizes reported here are larger than they would be if unpublished research were also included. This possibility must therefore be considered when interpreting results. Secondly, it is not possible to compare effectiveness between Part One and Part Two of the review due to the use of different effect size measures. This was necessary given the lack of consensus about the most appropriate effect size measures in the field and lack of appropriate effect sizes that can be used with any type of design. Comparison is also limited by other factors. For example, the different nature of interventions included in both parts, with interventions in Part One utilising behavioural approaches implemented directly with the focal child whilst interventions in Part Two utilised a stakeholder training model, meaning that reductions in CB across the different parts of the review may be the result of different mechanisms. This is further reflected in the measurement of CB across the different parts of the review as interventions in Part One utilised direct observation of CB whilst most of the interventions in Part Two utilised questionnaires about CB completed by proxy informants. This additionally limits comparisons between the two parts since Part One therefore relates to direct measurement of CB whilst Part Two relates to measurement of stakeholder perceptions of CB which may have been influenced by training they received during the intervention. It is also possible that additional differences exist between the two parts of this review that were not considered within the results. The studies were grouped by design type for pragmatic purposes to enable the calculation of effect sizes. However, given that the two parts of the review reflect different interventions as described above, it is possible that other differences relating to this grouping influenced results and also limit comparisons between the two parts of the review. For example, in general the majority of the interventions in Part Two were less individualised due to their delivery within a group format, and therefore they included less comprehensive FA approaches which may mean that interventions for the focal person were based on less clear knowledge about behavioural function. These potential differences should be considered when interpreting results. Despite this, the ability to compare effectiveness across different types of intervention (e.g., those presented in Parts One and Two of this review) is likely to be of benefit to the field and should be a focus of future research. Thirdly, in relation to the group design articles, it was necessary to relax inclusion criteria to allow articles that may have included participants over the age of seven or with varying response classes of behaviour to be reviewed as few articles provided interventions specifically for young children displaying particular classes of behaviour. Conclusions relating to the group design articles must therefore be interpreted with caution as the evidence relates to a wider population of children than in Part One of the review. Finally, as the review focused on outcomes relating to a reduction in CB other important outcomes (e.g., family quality of life, functional skills for the child, stakeholder skills and confidence) have been omitted. Given the focus of PBS on improvement in quality of life (Gore et al., 2013), rather than solely on a reduction in behaviour, this is important to consider as other outcomes may have improved at a greater level than behavioural outcomes.

Directions for Future Research

Further research is needed of high quality and focusing on multicomponent interventions, as described above. In addition, more research is needed generally in relation to PBS based stakeholder training, and in particular, in relation to staff training and to different formats of training (e.g., workshop based, weekly sessions, intensive individual support etc.). Any future research should aim to recruit more representative samples by including children with a range of diagnoses and levels of ID, particularly in relation to group design interventions, in order to improve the generalisability of the findings. Research in these areas would add to the knowledge relating to PBS interventions for young children and would allow researchers and practitioners to apply best evidence-based practice when working with this population in order to prevent and reduce early CB, and therefore improve long term outcomes.

Review Update

As noted above, this review and meta-analysis was conducted in 2015. It was felt inappropriate to fully update this chapter prior to submission of the thesis as conclusions were made based on the results of the chapter, which influenced the subsequent direction and methodology of the author's research. Updating the chapter may have changed conclusions and therefore caused a lack of continuity within the thesis. Instead, a discussion of literature published since 2015 is provided here to highlight trends within the field since the completion of this review, and evaluate whether the results presented in this chapter remain consistent with the direction of contemporary research more generally.

Given the pace of the field, since 2015 a significant number of studies have been published in this area. For example, entering the review search terms into PsycINFO identified 797 new articles since 2015, similar to the number identified by PsycINFO in 2015 for the main review. This suggests that research in this area is growing and the field is developing at a considerable rate. When examining the relevant literature published since 2015, three main trends emerged. Firstly, research has focused on the refinement of FA methodology, and EFA methodology in particular, to improve the efficiency and accuracy of assessments on which intervention approaches are based. Secondly, research has continued to evaluate the use of established intervention procedures (i.e., those included in the review, such as FCT), with the majority of studies focusing on refining these in order to minimise treatment failures or resurgence of behaviour, and maintain reductions in CB over time. Fewer contemporary studies focus on the intervention procedures themselves, though some examples do exist (e.g., Heffernan & Lyons, 2016; Hodnett et al., 2018). Finally, research has attempted to promote the social validity and generalisation of interventions by examining methods for training stakeholders (e.g., family carers) in PBS based techniques. Given the focus of this meta-analysis and review on the effectiveness of PBS based interventions for young children with IDD, the subsequent discussion will therefore focus mainly on the second trend identified in the contemporary literature in order to consider the research evidence relating to interventions themselves, rather than procedures linked to this such as assessments or general stakeholder training.

It is significant that no examples of new interventions (i.e., those not included in this review) were identified in the contemporary literature, and instead research mainly focused on refinements to existing interventions, often targeting outcomes which follow an initial reduction in CB. As a result, the current chapter can be conceptualised as presenting evidence of the effectiveness of the core interventions whilst contemporary research focuses on secondary procedures used as an adjunct to these interventions. Furthermore, in line with the current review the majority of contemporary research examines interventions within a single case design with fewer utilising group design methodology, and the majority of studies focus on a single intervention approach only, rather than combined approaches or the full PBS framework (with a notable exception as discussed below). For example, contemporary research often focuses on the use of FCT with young children with IDD, as was also found in the review literature. Some of these more recent studies have examined novel techniques used to promote tolerance to delays in reinforcement, therefore reducing the likelihood of treatment failures when generalising FCT to more naturalistic schedules of reinforcement. For instance, Ghaemmaghami et al. (2016) examined the use of contingencies within delays to reinforcement phases following FCT as a method of promoting tolerance of delays. They found that the use of an alternative activity or proscribed demands during a delay to reinforcement phase can promote tolerance to delays for young children with IDD and reduce CB during such delays. Contemporary research in FCT has also sought to examine the use of various reinforcement schedules after the initial intervention, and methods of minimising resurgence. For example, Suess et al. (2020) implemented FCT via telehealth (i.e., using videoconferencing technology at a distance, see Chapter Three) with four children with IDD aged three to six years, aiming to examine whether resurgence of behaviour was influenced by the initial context in which FCT was conducted (i.e., in the stimulus context associated with CB such as a demand context, or in an alternative context such as a free play setting). They demonstrated reduced resurgence with the use of an initial alternative context for FCT followed by the introduction of FCT in the context of relevance to the child's CB. This extends FCT procedures by suggesting important methods to reduce subsequent resurgence of behaviour (in addition to describing effective methods for training family carers and conducting intervention approaches across distance). Furthermore, Fisher et al. (2018) demonstrated reduced resurgence of behaviour for a three-year-old boy with ASC by utilising behavioural momentum theory. The authors manipulated the reinforcement schedules for CBs and alternative communication behaviours within FCT, and the duration of treatment, resulting in reduced resurgence of CB. Other studies have also examined similar methods of reducing resurgence (e.g., Fuhrman et al., 2016; Gratz et al., 2019). Taken together, an emerging literature focusing on minimising resurgence of CB for young children with IDD is providing researchers and practitioners with new information with which to promote maintenance of behavioural change following an initially successful FCT intervention.

No other intervention methodologies have received similar attention in the contemporary literature relating to interventions for young children with IDD as FCT / DRA interventions, a finding consistent with the main review. In the one instance identified (i.e., Heffernan & Lyons, 2016), the focus of the paper was on the core intervention, rather than refinements to intervention procedures as in the literature described above. This is likely explained by the comparative lack of research relating to other intervention methodologies for young children with IDD and the importance, therefore, of developing this evidence base. Heffernan and Lyons (2016) utilised DRO combined with competing stimuli to reduce the severe self-injury of a four-year-old boy with autism. They also successfully faded the DRO interval such that the terminal level reached 60 minutes and subsequently demonstrated good maintenance of effects after the intervention. Whilst this study provides information about the effectiveness of a core intervention, rather than refinements to interventions as described above, it is consistent with the findings of the main review and therefore does not change conclusions. Clearly there is still a need for additional research on intervention methodologies other than FCT / DRA for this population of young children.

Finally, as noted above, there were few examples of the use of the full PBS framework with young children with IDD. Whilst some studies do describe PBS interventions for this group, it is often the case that it is not possible to separate results specifically for young children with IDD as they are aggregated with older participants (e.g., Bowring et al., 2019); an issue found in the original review also as highlighted above. In one exception, Iemmi et al. (2016) present individual outcome data for PBS interventions conducted in schools with young children with IDD, although the focus of this study was on the economic impact of PBS rather than behavioural outcomes per se meaning that the PBS intervention elements are described briefly. Despite this, this study evidenced effective reduction of CB for the two participants relevant to this review. However, more research is needed which provides operational precision relating to the PBS intervention methodology as well as detailed outcome data presented within robust experimental designs, and it remains the case that research utilising the full PBS framework for young children with IDD is scarce. One additional example was identified (i.e., Hieneman et al., 2020) in which the full PBS framework was utilised in training for family carers of children with ASC across two online training programmes. In this study, outcomes evidenced significant reductions in child CB at both post and follow up data points, supporting conclusions in the main review relating to the effectiveness of family carer training in PFBIs. However, given the low number of training based interventions identified in the both the main review and the review update, there is a clear need for further demonstrations of the effectiveness of these approaches.

In conclusion, whilst contemporary research has clearly advanced since the completion of this meta-analysis and review, the conclusions presented within the chapter appear to be valid and relevant even within the context of the advanced field, since contemporary research often focuses on refining existing intervention approaches that were included in this review rather than developing novel intervention approaches. The aims of this review, as stated above, focused on identifying the most effective intervention methodologies for young children with IDD to inform subsequent empirical work as part of this thesis. The review therefore did not consider adjunctive procedures (e.g., those aiming to minimise resurgence), and focused instead on the core interventions themselves. In addition, in line with the conclusions of the main chapter it is still difficult to determine the effectiveness of the full PBS framework since research utilising the full framework is scarce, though this does appear to be an area of emerging research given the few examples noted. As the field continues to grow and develop it is likely that additional examples of such multicomponent approaches will be published and it will, in future, be possible to consider the effectiveness of PBS in its entirety for young children with IDD.

Conclusion

As noted above, the findings of this review offer some support to the effectiveness of PFBIs for young children with IDD. Whilst further research is undoubtedly needed in a number of areas (as outlined above), and the methodological quality of the evidence base requires improvement, there is clear evidence of the utility of a range of interventions for CB for this population. All of the interventions included in the review were found to be effective and achieved substantial reductions in CB. However, for individual intervention approaches results varied according to the outcome examined. For example, the intervention evidencing the largest reductions in CB following the initial intervention was not necessarily the intervention which achieved the best generalisation or maintenance of results. As a result, it is argued that practitioners should select interventions based on overall effectiveness and any secondary outcomes that are most relevant for their client. In line with this, based on the results of this review DRA interventions (and specifically, FCT) will be used throughout this thesis since these interventions evidenced high overall effectiveness and the best results relating to both generalisation and maintenance of results, which are particularly important outcomes where interventions are delivered through training for family carers. Prior to examining the feasibility of the use of FCT and training family carers in FAs and FCT in the UK (Chapter Four), Chapter Three will consider an alternative modality for providing training, namely the use of telehealth (i.e., the use of technology across distance) since this may be particularly relevant within a UK context where behavioural expertise is sparse. Chapter Three therefore presents a systematic review of the use of telehealth for training stakeholders in behavioural approaches to inform later adaptations of training methodology as part of this thesis.

Chapter Three

Training Individuals to Implement Applied Behaviour Analytic Procedures Via Telehealth: A Systematic Review of the Literature.[1]

Chapter Overview

Chapters One and Two outlined the case and evidence for Positive Behaviour Support (PBS) based interventions when used with young children with intellectual / developmental disabilities (IDD). In Chapter Two, a range of delivery formats for such approaches were also highlighted, including delivery by different individuals (e.g., therapists, parents), in different settings (e.g., clinic, school, home). More recently, the use of technology to deliver support across distance has also been reported in the behavioural literature, as highlighted in Chapter Two. This reflects significant variation in the evidence enabling practitioners to select from a wide range of options when designing and implementing such approaches. Subsequent empirical studies within this thesis will examine the effectiveness of Functional Communication Training (FCT; the most frequently used approach according to Chapter Two) when delivered via training family carers in the UK. However, the service and support context within the UK is unique and can present challenges to working directly with individuals in situ (see Discussion below and Chapter Five for further discussion). As a result, the consideration of approaches delivered over distance via the use of technology may be important within a UK context. In order to review this literature and inform subsequent empirical studies in this thesis, the current chapter presents a systematic review of these approaches focusing on the breadth of their use, methodology, and outcomes. Given the limited literature utilising the full PBS framework identified in Chapter Two, this review focuses more broadly on approaches

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[1] A modified version of this chapter is published in: Tomlinson, S. R. L., Gore, N., & McGill, P. (2018). Training individuals to implement applied behaviour analytic procedures via telehealth: a systematic review of the literature. *Journal of Behavioral Education, 27*(2), 172-222. https://doi.org/10.1007/s10864-018-9292-0

based on Applied Behaviour Analysis (ABA: a key component of PBS, see Gore et al., 2013) in order to include all relevant literature, given the relative novelty of this area of research.

Introduction

Technology is increasingly becoming a part of everyday life, with smartphones, tablets, laptops, and high-speed internet connections becoming more accessible and affordable. Given the prominence of this technology in our society, it is not surprising that health organisations have adopted technology to provide services in innovative ways. The application of technology to providing such services has been termed '*telehealth*' and is defined as "the use of telecommunications and information technology to provide access to health [or behavioural health] assessment, diagnosis, intervention, consultation, supervision, education, and information across distance" (Nickelson, 1998, p. 527). This can include communication through the telephone, email, online chatrooms, or videoconferencing (e.g., Gerrits et al., 2007; Phillips et al., 2001; Torres-Pereira et al., 2008), computer- or internet-based interventions (e.g., Khanna & Kendall, 2008; Klein et al., 2010), and even the use of smartphone or tablet applications (e.g., Gregoski et al., 2012). Telehealth has been applied in a range of ways across several fields. For example, it has been used for collaborations between healthcare professionals (e.g., Katzman, 2013; Zollo et al., 1999), the implementation of a wide range of assessments (e.g., Loh et al., 2004; Turkstra et al., 2012), medical diagnostic services (e.g., Edison et al., 2008; Torres-Pereira et al., 2008), monitoring of long term conditions (e.g., Fatehi et al., 2014; Inglis et al., 2014), parent training (e.g., Reese et al., 2015; Xie et al., 2013), speech and language therapy interventions (e.g., Georgeadis et al., 2004; Grogan-Johnson et al., 2011), and mental health support (e.g., Klein et al., 2010; Mitchell et al., 2008). Delivering services via telehealth may have a number of practical advantages for clinical practice in that it may enable increased access to populations that are hard to reach (e.g., those with rare conditions or those living in rural areas), reduce travel related costs, make scheduling appointments easier, and even increase family carer participation in interventions with their child as the clinician is not physically present (see, for discussion, Hilty et al., 2002; Meadan & Daczewitz, 2015). In relation to psychiatric services, telehealth support has been reported to be reliable, acceptable to both the individuals receiving telehealth and the individual delivering the service, and associated with a range of positive outcomes such as reduced costs and less medication errors (Hilty et al., 2002). Telehealth and its application to psychological and behavioural support services is therefore an important area of study.

Whilst the use of telehealth is relatively well established in psychiatric and psychological services, with 98% of psychologists reportedly using some form of telehealth in 2000 (Vandenbos & Williams, 2000), the field of ABA and PBS has evidenced less use of telehealth. Some early work involved the use of telephone support during parent training (e.g., Patterson, 1974; Patterson et al., 1982), or 'bug-in-ear' technology to provide real-time coaching (e.g., Bowles & Nelson, 1976; Stumphauzer, 1971), however articles reporting more extensive use of telehealth in ABA / PBS are relatively novel. This disparity between fields may be due to key differences between general psychological or health support, which is often delivered directly to a client, and behaviour analytic support which often involves training others in specific techniques (e.g., Deliperi et al., 2015; Downs & Downs, 2013; Wacker et al., 2017) or using a more formal behavioural consultation model (see, for example, Sheridan et al., 1996; Sheridan & Kratochwill, 2007; Watson & Robinson, 1996; Wilkinson, 2006). These training and consultation approaches have been shown to be effective in enhancing consultee skills and fidelity (e.g., Collier-Meek & Sanetti, 2014; Deliperi et al., 2015; McKenney et al., 2013) and improving child behaviour or academic and social skills (e.g., Garbacz & McIntyre, 2016; Sheridan et al., 2006; Sheridan et al., 2013; Wacker et al., 2017). However, some authors highlight barriers to this type of support due to the amount of consultant time needed and difficulties providing training or behavioural consultation to clients in rural areas, suggesting that telehealth may be a useful alternative method of providing such support (e.g., Bice-Urbach & Kratochwill, 2016; Fischer, Dart, Radley et al., 2016; Fischer, Dart, Leblanc et al., 2016).

Despite this, conducting training primarily via telehealth may present more barriers than providing training in-person in relation to role playing skills, observing practice, monitoring implementation fidelity, and collecting data. This may partially explain the slower uptake of telehealth within ABA / PBS, and early examples often used initial in-person training supplemented by telehealth support (e.g., Patterson, 1974; Patterson et al., 1982). However, there is some evidence that general parent training or parenting interventions can be effectively delivered via telehealth. For example, Reese et al (2015) reported comparable results for both parents and children when a parenting intervention was delivered via telehealth or in-person, suggesting that training a consultee to support a client may be possible via telehealth. Similarly, Xie et al (2013) reported comparable findings for parents of children with Attention Deficit Hyperactivity Disorder (ADHD), and greater improvements in hyperactivity for those whose parents were trained via telehealth rather than in-person. Whilst this evidence may have implications for behaviour analytic support, the parenting interventions presented in these articles were not (explicitly) based on ABA / PBS meaning that these results may not be easily generalisable to support provided within such services.

Given the recent emergence of articles relating to the use of telehealth for training consultees in ABA / PBS, a review of the literature is timely and important in order to identify the breadth of application of telehealth methodology, indicators of effectiveness, and any limitations or difficulties encountered in its use. Furthermore, during the 2020 global coronavirus pandemic, telehealth was rapidly adopted by a range of services including behaviour analytic services. Whilst this was a necessary approach to ensure that support could still be provided to clients in the absence of in-person appointments, in the field of ABA this was unlikely to be well informed by empirical literature as there is currently no known review focusing solely on behaviour analytic research, with previous reviews focusing on other fields (e.g., psychotherapy Gros et al., 2013; palliative care, Kidd et al., 2010; speech pathology, Mashima & Doarn, 2008), or more broad training interventions for parents of children with disabilities (e.g., Meadan & Daczewitz, 2015). Boisvert et al. (2010) reviewed literature relating to the use of telehealth for providing support to individuals with an Autism Spectrum Condition (ASC), including five studies focusing solely on ABA techniques. The review included articles where support was provided in relation to behaviour and educational goals to teaching staff and parents, or psychological support provided directly to individuals with ASC. They found that this support provided via telehealth was deemed to be effective for the client in seven out of eight cases, with technical difficulties influencing conclusions in one case. In addition, a review by Neely et al. (2017) focused on the fidelity with which individuals were able to implement techniques when trained via telehealth to support individuals with ASC. They reported that trainee fidelity increased throughout the intervention, however results were mixed and often did not maintain in the absence of direct training or coaching. Whilst some of the studies included in these reviews involved the use of ABA techniques, the focus on ASC alone, specific outcomes (i.e., fidelity) and the inclusion of support provided within other disciplines means that the findings are not easily generalisable to the field of ABA / PBS more widely.

As a result, the current review aims to synthesise the literature relating specifically to training an individual in ABA / PBS techniques via telehealth in order to provide an overview of the state of the evidence and highlight gaps in research relating to this method of providing support. This will inform the design and methodology of empirical work within this thesis utilising a telehealth approach (see Chapter Five). The review seeks to answer the following research questions:

1. How has telehealth methodology been utilised for training individuals in ABA approaches, including the context in which it is adopted, the training focus, methodology used, and characteristics of those involved?
2. How effective is the use of telehealth for training individuals in ABA approaches in relation to improving trainee skills or fidelity, and / or changing client behaviour?
3. Is the use of telehealth for training in ABA approaches socially acceptable and are there any obstacles reported that researchers and practitioners in the field should consider when utilising such methodology?

Methodology

Inclusion / Exclusion Criteria

Original empirical articles published in peer reviewed journals were included if they met the following criteria. Firstly, the study involved training an agent (e.g., a parent, therapist, teacher) in a specific behavioural procedure (e.g., preference assessments, functional assessments (Fas), teaching techniques such as discrete trial teaching, FCT). Studies which involved delivering support directly to a client or delivering broader parenting-based programs (i.e., those focusing on more general parenting skills or focusing on knowledge about behavioural approaches more generally rather than specific techniques) were excluded. Similarly, due to the focus on direct training, articles which involved self-directed study with no additional support from a trainer were not included. Secondly, articles included data relating to behavioural outcomes for the trainee (e.g., increased skills / fidelity of implementation) and / or the client. Thirdly, all of the training relating to implementing the techniques was provided through telehealth methodology (e.g., videoconferencing, telephone, email) to ensure that the focus was on telehealth training, rather than the telehealth role being supplementary to that provided in-person. There were no criteria relating to the date of publication to ensure that all relevant articles were included, as it is not possible to pinpoint when telehealth methodology was first adopted.

Search Strategy

A three-phase search strategy was adopted, and all searches were conducted in July 2017. Firstly, a search string was entered into PsycINFO, Web of Science, and PubMed databases using the search terms listed in Table 5 below such that each group 1 term was combined with each group 2 term.

Table 5

Databases and Search Terms

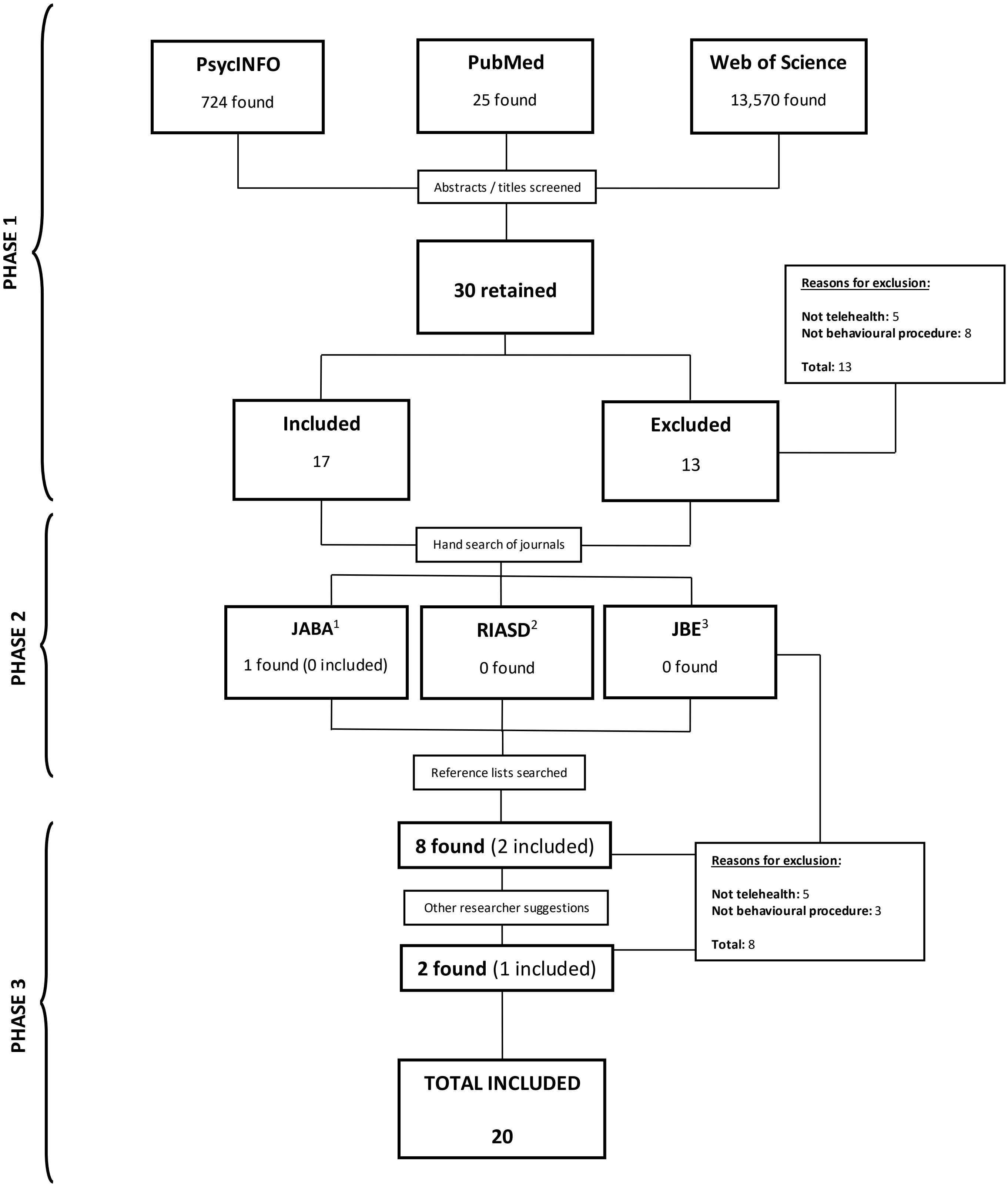
	Search Terms	
Databases Searched	**Group 1**	**Group 2**
PsycINFO	Telehealth	Applied behav* anal*
Web of Science	Tele*	Behav* anal*
PubMed	Videoconferenc*	Positive behav* support

The use of these terms aimed to identify the majority of telehealth-based ABA research. Given evidence from Chapter Two indicating that a large proportion of PBS research may not be multicomponent and may instead focus on specific behavioural techniques, the inclusion of the term "positive behav* support" aimed to identify those articles that may be labelled primarily as PBS, rather than applied behaviour analytic. Furthermore, as noted above the use of ABA is a core component of PBS (Gore et al., 2013) and may therefore mean that studies utilising PBS also involve training an agent in behavioural techniques. As stated above, articles were only included if training related to a clearly defined behavioural procedure, rather than multicomponent behavioural support plans. In addition, given that several recent articles focus on the use of videoconferencing in training agents to conduct behavioural techniques, "videoconferenc*" was included to ensure that this group of articles was explicitly searched for.

A total of 14,002 original articles were identified from the database searches and the titles / abstracts of these articles were screened, resulting in 30 articles being retained for further review. After applying inclusion criteria to the retained articles, 17 were included in the review. Secondly, a hand search was conducted of the three journals that published the highest number of included articles (Journal of Applied Behavior Analysis, Research in Autism Spectrum Disorders, Journal of Behavioral Education). One additional article was identified, which did not meet inclusion criteria after full text review. Finally, the reference lists of all included articles were searched which resulted in an additional nine articles being identified, of which two were included. An additional two articles were reviewed that had not been found via the searches described above but had been brought to the authors' attention by other researchers. One of these articles met inclusion criteria and was included in the review. A total of 20 articles were included in the review with 17 of these utilising single case designs. An overview of the search strategy and reasons for exclusion of articles at each stage can be seen in Figure 4 below.

Figure 4

Search Strategy and Number of Articles Included at Each Stage



[1] Journal of Applied Behavior Analysis, [2] Research in Autism Spectrum Disorders, [3] Journal of Behavioral Education.

Methodological Quality Evaluation

In order to evaluate the methodological quality of included articles, the Evaluative Method (Reichow et al., 2008; Reichow, 2011) was used as in Chapter Two, with the same modifications as detailed in Chapter Two. The tool was applied to each article in this review with reference to the outcomes reported. This meant that for some articles, the tool was applied twice (i.e., for outcomes relating to the trainee such as fidelity / skills, and for assessment / intervention outcomes relating to the client due to the trainee implementing behavioural techniques with them). Where applicable, criteria for assigning ratings were considered in relation to the specific outcomes being assessed (e.g., participant ratings where trainee outcomes were assessed were evaluated in relation to details reported about trainees, rather than clients). A second rater independently applied the tool to 50% of the articles (10 articles). This reflects a higher percentage of studies reviewed for reliability purposes than in Chapter Two. This higher percentage was included given the initially low levels of reliability identified in Chapter Two; it was therefore felt appropriate to rate a higher percentage of articles to ensure reliability of the use of the tool for this review. Percentage agreements across indicators and final ratings was calculated and was 81.45% across indicators, and 60% across final ratings. The low agreement for final ratings is reflective of the higher weighting of primary indicators on the final rating, meaning that disagreements on these indicators often resulted in disagreements on the final ratings assigned (as was also the case in Chapter Two). Disagreements were discussed and consensus was reached on ratings, and, where necessary, ratings for all articles were reviewed in light of agreements following discussion. This procedure was adopted as in Chapter Two in order to ensure that the tool had been applied consistently across the articles and that disagreements between raters were resolved.

Coding

Information was extracted from each included article about the context and background to adopting telehealth methodology given by the researchers, trainer / trainee / client characteristics, telehealth methods used including characteristics of training (e.g., methods and technology used, dosage of training, format of training), the behavioural focus of the training (e.g., type of assessments, skills, or interventions used), and outcomes (for trainer, trainee, client, social validity, obstacles experienced). Given the novelty of the research, and the broader focus and more variable outcomes included here than in Chapter Two, it was not felt appropriate to conduct statistical analyses to quantify effectiveness. Instead, the research is outlined descriptively to provide an overview of the evidence base and answer the research questions above.

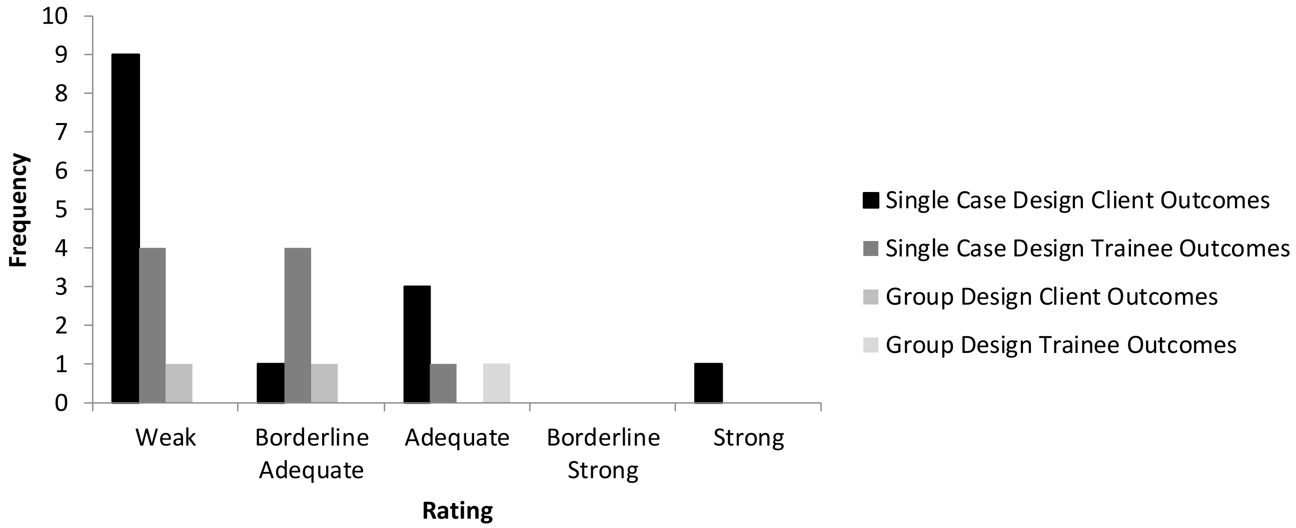
Results

Methodological Quality

The Evaluative Method (Reichow et al., 2008; Reichow, 2011) was applied 23 times for the 17 single case design articles (i.e., six articles included outcomes related to both the trainee and client) and once for each group design article as none of the group design articles presented outcome data relating to both the trainees and clients. The most common ratings were 'Weak' or 'Borderline Adequate' with only one single case design article rated as 'Strong' in relation to outcomes for the client (see Figure 5 below).

Figure 5

Evaluative Method Ratings for Single Case and Group Design Articles for Trainee and Client Outcomes



Appendix F provides an overview of the individual indicator ratings and final rating given to each article. Single case designs most often did not score highly on evidencing a stable baseline across at least three data points (16/23 instances) or having stable data that varied with implementation of the intervention (18/23 instances for visual analysis criteria relating to stability of data and overlap between conditions, and 15/23 for experimental control criteria relating to number of reversals and variation in data based on implementation of the independent variable). In addition, none of the single case designs included Kappa statistics, only one used blind raters, and most did not collect data on the fidelity of implementation or meet fidelity criteria where data were presented (for either the main trainer related to implementing the training, or the trainee for implementation of the intervention: 17/23 instances). Group designs did not score highly for the use of appropriate statistical analyses with adequate sample size and power (2/3 instances), did not use blind raters (2/3 instances), and did not collect data on the fidelity of intervention implementation (for either the main trainer related to implementing the training, or the trainee for implementation of the intervention: 3/3 instances), or on generalisation/maintenance (2/3 instances). They also did not include effect sizes calculations (2/3 instances).

Breadth and Context

An overview of each included study can be found in Appendix G. As stated above, 20 articles were identified. Across these 20 articles, 113 agents were trained in behavioural techniques via telehealth by at least 27 trainers (it was not possible to determine the number of trainers for three articles: Alnemary et al., 2015; Lindgren et al., 2016; Wainer & Ingersoll, 2015), and 104 children received support from someone who had been trained via telehealth. In some cases, additional individuals were also trained including four trainees as part of a wait list control group (Fisher et al., 2014), and 53 individuals who were trained via in-person methods as a comparison group (Hay-Hansson & Eldevik, 2013; Lindgren et al., 2016).

Studies were conducted by research teams primarily located in the United States, with one study conducted in Norway. Where information was reported on the distance over which telehealth support was provided, distances varied from a different room in the same building (Higgins et al., 2017; Machalicek et al., 2009b), a different location under 100 miles away (Barretto et al., 2006; Gibson et al., 2010; Lindgren et al., 2016; Machalicek et al., 2009a; Machalicek et al., 2016; Neely et al., 2016), between 100 and 200 miles away (Barretto et al., 2006; Lindgren et al., 2016; Suess et al., 2016), or over 200 miles away (Knowles et al., 2017; Lindgren et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). In three cases training was provided for trainees in a different country located 300 (Wainer & Ingersoll, 2015), 5863 (Barkaia et al., 2017), and 8333 (Alnemary et al., 2015) miles away from the trainer.

The context in which telehealth methodology was employed varied. Some researchers cited practical difficulties with offering support in-person, such as large waiting lists for support or costs and time involved with travelling around rural areas (Barretto et al., 2006; Gibson et al., 2010; Hay-Hansson & Eldevik, 2013; Knowles et al., 2017; Machalicek et al., 2009a; Machalicek et al., 2010; Machalicek et al., 2016; Neely et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel,

& Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013; Wainer & Ingersoll, 2015). Alnemary et al. (2015) and Barkaia et al. (2017) further cited a lack of behavioural expertise and support available internationally in Saudi Arabia and Georgia respectively. Other researchers cited knowledge gaps relating to effectiveness, efficiency or agent fidelity when training is conducted via telehealth (Fischer, Dart, Radley et al., 2016; Suess et al., 2014). Finally, some researchers highlighted the need to compare delivery formats (Lindgren et al., 2016), or evaluate the use of particular training techniques and behavioural procedures (Higgins et al., 2017; Neely et al., 2016; Wainer & Ingersoll, 2015), whilst others cited methodological considerations relating to telehealth research including the use of a randomly controlled or multiple baseline design (Fisher et al., 2014; Higgins et al., 2017), the incorporation of telehealth into existing support models (Suess et al., 2016), or the use of specific technology and software (Fischer, Dart, Radley et al., 2016; Machalicek et al., 2009b).

Trainer Characteristics

In three cases (Alnemary et al., 2015; Barretto et al., 2006; Wainer & Ingersoll, 2015) the characteristics of the trainer were not stated and in some instances the trainer was listed only as one or more of the authors or a researcher / experimenter, with no further details provided. Where the characteristics of the trainer were stated, these individuals were most commonly professionals who had prior experience or training in behaviour analytic approaches. For example, in six articles (Higgins et al., 2017; Machalicek et al., 2009a; Machalicek et al., 2009b; Machalicek et al., 2010; Machalicek et al., 2016; Neely et al., 2016) it was explicitly stated that trainers were Board Certified Behaviour Analysts. Trainers were often Doctoral or Master's students (Fischer, Dart, Radley et al., 2016; Higgins et al., 2017; Knowles et al., 2017; Lindgren et al., 2016; Machalicek et al., 2009a; Machalicek et al., 2009b; Machalicek et al., 2010; Suess et al., 2014; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) and trainees had varying levels of experience using behavioural approaches, ranging from one (Fischer, Dart, Radley et al., 2016) to 20 years' experience of implementing behavioural techniques (Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013).

Trainee Characteristics

Of the 113 individuals trained via telehealth, 72 were family carers, 26 were teaching staff, nine were students / graduates, and six were ABA therapists or direct care staff. In many cases trainees had no prior experience or knowledge of behavioural techniques. Three trainees in one study had some prior experience although it was not possible to determine whether these received training via telehealth or in-person (Hay-Hansson & Eldevik, 2013), and in one study therapists were used who had reportedly taken a class relating to ABA (Barkaia et al., 2017). In five studies (15 trainees), it appeared that agents may have had prior experience in behaviour analytic techniques, but had no experience in the specific technique used in the study (Higgins et al., 2017; Machalicek et al., 2009a; Machalicek et al., 2009b; Machalicek et al., 2010; Machalicek et al., 2016), and in three articles (seven trainees) it was not clear how much prior experience the trainees had (Barretto et al., 2006; Gibson et al., 2010; Suess et al., 2014).

In some cases, other individuals were also present during the sessions to offer logistical support to trainees. Parent assistants with no prior experience of behavioural techniques were used in three studies (Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) and received training via telehealth as part of the study. These individuals assisted parents during the sessions in relation to setting up the room, ensuring materials were available, and providing physical assistance. Similarly, Barkaia et al. (2017) involved an additional psychologist in situ for trainees during implementation of procedures, however it was not clear what type of support this individual provided. Additional individuals known to the client were also present in one study (Barretto et al., 2006) and included a school psychologist, a physical therapist, biological parent, special education teacher, social worker, nurse, and paediatrician. These individuals were not involved in the sessions, except for the school psychologist who acted as a coach for one parent, and the physical therapist who carried out physical activities as demand activities for one child.

Client Characteristics

As noted above, 104 individuals received support from someone who had been trained via telehealth, and in almost all instances (with the exception of one child in Fischer, Dart, Radley et al., 2016; and two children in Knowles et al., 2017) these individuals were children with IDD, most commonly ASC. Children were aged between 12 months and 16 years (where it was possible to determine age) and in thirteen studies (78 children) children reportedly displayed challenging behaviours (CB) such as self-injury, property destruction, aggression or noncompliance (Alnemary et al., 2015; Barretto et al., 2006; Fischer, Dart, Radley et al., 2016; Gibson et al., 2010; Knowles et al., 2017; Lindgren et al., 2016; Machalicek et al., 2009b; Machalicek et al., 2010; Machalicek et al., 2016; Suess et al., 2014; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). Only seven studies (Barkaia et al., 2017; Gibson et al., 2010; Machalicek et al., 2009b; Machalicek et al., 2010; Machalicek et al., 2016; Neely et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013) reported on clients' communication abilities. However, across these studies they had a range of abilities from no spoken language to fluent speech.

Training Focus

In most cases training focused on assessments such as experimental functional analyses (EFAs: Alnemary et al., 2015; Lindgren et al., 2016; Machalicek et al., 2009b; Machalicek et al., 2010; Machalicek et al., 2016; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013) or preference assessments (Higgins et al., 2017; Machalicek et al., 2009a). Fewer studies focused on training for specific intervention strategies: in seven cases trainees were supported to develop and implement FCT or differential reinforcement interventions (Fischer, Dart, Radley et al., 2016; Gibson et al., 2010; Lindgren et al., 2016; Machalicek et al., 2016; Suess et al., 2014; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) and in one case each trainees were taught to implement Reciprocal Imitation Training (Neely et al., 2016), mand and echoic training (Barkaia et al., 2017), or classroom management approaches within a positive behaviour interventions and supports (PBIS) model (Knowles et al., 2017). Three studies focused on improving trainee skills relating to implementing behavioural teaching techniques such as discrete trial teaching or incidental teaching (Fisher et al., 2014; Hay-Hansson & Eldevik, 2013; Wainer & Ingersoll, 2015).

Training Methods

In all cases, training was provided via videoconferencing (i.e., real-time communication across a distance using an internet connection with video and audio facilities) with the trainer providing training and / or coaching from a different location, using a computer, webcam, and microphone (see Appendix H for technical set up and difficulties reported in each article). However, the specific methods used to conduct training varied. In most cases, initial training was provided using a variety of methods. Some researchers provided extended training sessions, lasting between 15 minutes and three hours, which involved a combination of presentations relating to the techniques, direct instruction, modelling, or role playing (Alnemary et al., 2015; Barkaia et al., 2017; Fisher et al., 2014; Gibson et al., 2010; Hay-Hansson & Eldevik, 2013; Higgins et al., 2017; Machalicek et al., 2016; Suess et al., 2014; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). This initial training was usually provided via videoconferencing and was provided via telephone in one study (Barretto et al., 2006). In other cases, trainees undertook self-instruction using online modules or videos (Fisher et al., 2014; Knowles et al., 2017; Neely et al., 2016; Wainer & Ingersoll, 2015), or written explanations of the techniques and individual practice (Machalicek et al., 2009a).

In some cases, training was provided solely through live coaching via videoconferencing during implementation of procedures. However, in nearly all of these instances trainees or individuals who supported trainees in situ appeared to have prior knowledge of behavioural techniques (Barretto et al., 2006; Lindgren et al., 2016; Machalicek et al., 2009a; Machalicek et al., 2009b; Machalicek et al., 2010). Other researchers used live coaching to supplement initial training (Alnemary et al., 2015; Barkaia et al., 2017; Suess et al., 2014; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013; Wainer & Ingersoll, 2015), and in two studies delayed feedback was provided based on videos made during earlier clinical sessions (Knowles et al., 2017; Neely et al., 2016). In all cases, feedback involved providing praise and corrective feedback. Where live coaching was used this was usually provided for all sessions. However, some researchers also conducted sessions in which trainees were not directly coached in order to test their skills or evaluate whether behavioural change had maintained at follow up (Fisher et al., 2014; Hay-Hansson & Eldevik, 2013; Higgins et al., 2017; Neely et al., 2016; Wainer & Ingersoll, 2015). Sessions without coaching were also used to assess whether trainees could perform as well when not coached (Machalicek et al., 2010; Suess et al., 2014). In addition to this direct training / coaching, trainees were explicitly asked to independently practice techniques or complete homework in five instances (Lindgren et al., 2016; Machalicek et al., 2009a; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013; Wainer & Ingersoll, 2015)

A supplemental trainee manual was described in four articles (Suess et al., 2014; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013; Wainer & Ingersoll, 2015), and an additional parent assistant manual containing information about the techniques, data recording forms, and scripts for use with parents was used by Wacker and colleagues (Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). Some studies also reported the use of written protocols for trainers to use during coaching / training (Fischer, Dart, Radley et al., 2016; Fisher et al., 2014; Hay-Hansson & Eldevik, 2013; Higgins et al., 2017; Knowles et al., 2017; Machalicek et al., 2010; Suess et al., 2014).

Training often continued until trainees had met predetermined criteria for fidelity or accuracy (Barkaia et al., 2017; Fisher et al., 2014; Gibson et al., 2010; Machalicek et al., 2010; Machalicek et al., 2016; Neely et al., 2016; Suess et al., 2014). However, in many studies training procedures were fixed and not responsive to fidelity (Barretto et al., 2006; Fischer, Dart, Radley et al., 2016; Hay-Hansson & Eldevik, 2013; Knowles et al., 2017; Lindgren et al., 2016; Machalicek et al., 2009a; Machalicek et al., 2009b; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013; Wainer & Ingersoll, 2015), and in three instances training was supplemented with individual feedback or additional training based on fidelity (Alnemary et al., 2015; Fischer, Dart, Radley et al., 2016; Higgins et al., 2017).

Outcomes

A range of outcomes were included in the articles for both the trainee themselves and the client. Only two studies compared outcomes of training conducted via telehealth with in-person methods (Hay-Hansson & Eldevik, 2013; Lindgren et al., 2016), and both found comparable results between delivery formats suggesting that delivery of training via telehealth may be as effective as delivery via traditional in-person methods. Additionally, Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al. (2013) anecdotally reported comparable outcomes for clients between their current project, in which trainees were trained via telehealth, and previous projects, in which trainees were trained via in-person methods.

Trainee Outcomes

Outcomes reported for trainees related in most cases to trainee fidelity or skills, with only one article examining changes in trainee knowledge about the procedures and reporting large increases (Wainer & Ingersoll, 2015). In eight articles no outcomes data were presented for trainees with outcomes presented only for the client (Barretto et al., 2006; Gibson et al., 2010; Lindgren et al., 2016; Machalicek et al., 2009b; Machalicek et al., 2016; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). Where data were presented on trainee fidelity / skills mastered, results were variable. Some studies reported very high fidelity across trainees. For example, Machalicek et al. (2009a) reported 100% accuracy for teachers completing preference assessments and Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron (2013) reported averages of 96% (without corrections) and 97% (with corrections) fidelity across 24% of sessions for all trainees. Despite this, whilst all studies reported increases in fidelity for those who were trained (with some significant increases over time or relative to a control group: Fisher et al., 2014; Hay-Hansson & Eldevik, 2013), in the majority of cases trainees failed to meet criterion fidelity, with only four articles reporting that criterion fidelity was met by all trainees across all session types or experimental phases (Fisher et al., 2014; Machalicek et al., 2009a; Neely et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013). Hay-Hansson and Eldevik (2013) did, however, report comparable fidelity between individuals trained via telehealth and those trained in-person, suggesting that variable fidelity may be a common finding regardless of delivery format. However, the small number of studies directly comparing delivery formats precludes a more detailed analysis of the relative fidelity with which trainees can implement procedures when trained or coached via telehealth.

Client Outcomes

A range of outcomes were reported in relation to the client, however five articles included outcomes for the trainee only (Alnemary et al., 2015; Fisher et al., 2014; Hay-Hansson & Eldevik, 2013; Higgins et al., 2017; Machalicek et al., 2010). Outcomes for the client were usually presented where individuals were trained to undertake assessments or specific intervention techniques. Only one of the studies which focused on teaching techniques presented client outcomes, reporting large increase in children's use of mands (Neely et al., 2016).

Where trainees implemented EFAs a social function was identified for the client's behaviour in the majority of cases (Barretto et al., 2006; Lindgren et al., 2016; Machalicek et al., 2009b; Machalicek et al., 2016; Suess et al., 2014; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013) with the exception of one client in Suess et al. (2016) and two in Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron (2013) for whom no function was identified. The results of the analysis were directly verified using a function based intervention (FBI) in five articles (Lindgren et al., 2016; Machalicek et al., 2016; Suess et al., 2014; Suess et al., 2016), and Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron (2013) verified results using FCT presented in a subsequent article for 13 clients (Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). In one article (Barretto et al., 2006) analysis results were not verified by a subsequent intervention. Only one article (Machalicek et al., 2009a) presented results of preference assessments conducted by trainees for three children. In this instance, preferred items were identified for each child and these preferences were subsequently verified using an instructional intervention in which children were observed to choose the task associated with access to the items identified as preferred.

Some articles focused on training agents to implement specific interventions such as FCT or differential reinforcement, Reciprocal Imitation Training, PBIS approaches, or mand and echoic training. FCT and differential reinforcement interventions were found to be generally effective when implemented by trainees. For example, Gibson et al. (2010) reported that elopement occurred only 5% of the time following FCT compared to over 90% of the time during baseline sessions. Several studies (Fischer, Dart, Radley et al., 2016; Lindgren et al., 2016; Suess et al., 2014; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) similarly reported large reductions in CB for the majority of clients. However, results were variable with less than 80% reductions for some clients and additional intervention elements were required in some cases. Results were particularly variable with an average of only 65.1% reduction in CB in Suess et al. (2016), despite CB being found to be significantly lower during the intervention than baseline. Of note, however, is that telehealth training for EFAs and FCT was implemented in this study in order to examine whether it could be delivered within the same time frame (i.e., two hours) as existing clinical support systems. As a result, the authors highlight that the findings offer preliminary evidence that telehealth training for EFAs and FCT can be incorporated into existing systems, with questions remaining about ways to maximize intervention effects within a short timeframe. In relation to Reciprocal Imitation Training (Wainer & Ingersoll, 2015) or echoic and mand training (Barkaia et al., 2017) outcomes were variable but with moderate increases in children's spontaneous imitation or overall communication.

Social Validity

Fourteen of the 20 articles included data relating to the social validity of the training / coaching delivered via telehealth. In most cases, social validity ratings were very high and nearly at ceiling levels on the measures used. For example, Fisher et al. (2014) developed a 14-item social validity questionnaire (utilising a seven point Likert scale from one [strongly disagree] to seven [strongly agree]) relating to the use of web-based technology, the content of the online modules, the interactions with the trainee, and their overall satisfaction. Mean ratings assigned to each of the items ranged from 5.4 (for use of web-based technology) to 7 (for overall satisfaction) indicating high social validity. Other researchers evidenced similarly high social validity with a range of standardised and novel questionnaires (Barkaia et al., 2017; Fischer, Dart, Radley et al., 2016; Gibson et al., 2010; Higgins et al., 2017; Knowles et al., 2017; Machalicek et al., 2016; Neely et al., 2016; Suess et al., 2014; Wainer & Ingersoll, 2015), with one article highlighting that scores were comparable to other interventions provided in-person (Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). However social validity scores were variable in one study (Alnemary et al., 2015) with low scores assigned to aspects of the videoconferencing, indicating technical difficulties experienced (see Appendix H and discussion below). Despite this, trainees stated that they would recommend the training to others, a finding that was replicated by Fisher et al. (2014) and Higgins et al. (2017). Trainees reported across the studies that they found telehealth simple, valuable, unobtrusive, and convenient as it allowed more frequent meetings with the trainer and immediate feedback. Although the use of telehealth was generally rated highly, two individuals in separate studies stated that they felt the training would have been easier or preferable in-person (Alnemary et al., 2015; Neely et al., 2016) and another expressed concerns about the possibility of technical difficulties (Gibson et al., 2010).

In addition to assessing social validity, some researchers also examined costs relating to the use of telehealth in comparison to in-person support. For example, Wacker and colleagues (Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) estimated that the weekly costs of providing an EFA would have been $335.09 per client if training were delivered in-person (when including costs related to the behavioural consultant's time and travel) versus $57.95 when training was delivered via videoconferencing. Similarly, the combination of an EFA and FCT would have resulted in total costs per client of $55,872 if delivered in-person, versus $11,500 when delivered via videoconferencing. Lindgren et al. (2016) similarly evidenced large cost savings as a result of the use of telehealth, and particularly when telehealth support was provided in clients' homes rather than regional clinic settings (due in part to the exclusion of costs relating to families' travel to the clinics, additional staff support, and use of other resources). Despite this, the use of telehealth was found to result in increased family costs due to the equipment necessary for families to access training, although the authors highlight that these costs were offset by reduced professional costs.

Obstacles Relating to Telehealth

Several obstacles were identified in the articles relating to the use of telehealth for training. These often related to technical difficulties (see Appendix H). However, in most cases authors reported that technical issues did not significantly affect the training and were easily resolved. Issues relating to the logistics of using the equipment were also highlighted, including the possibility of needing support to set up equipment prior to sessions, or transferring large video files (Fischer, Dart, Radley et al., 2016), and issues with protecting clients' confidentiality or obtaining informed consent

(Barkaia et al., 2017; Fischer, Dart, Radley et al., 2016). Some authors discussed issues with software being blocked by local firewalls (Hay-Hansson & Eldevik, 2013), and with insurance companies not covering the cost of support delivered via telehealth (Barretto et al., 2006). Finally, researchers also highlighted potential limitations of support provided via telehealth, such as whether it can be used with all types of behaviour or techniques (Machalicek et al., 2010; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) and whether some trainees may need more direct modelling which is not possible via telehealth (Suess et al., 2014).

Discussion

The results of this review provide initial support for the use of telehealth to effectively train individuals to implement ABA / PBS techniques including assessments, teaching procedures and specific interventions. In some cases, training via telehealth was found to produce comparable results to traditional in-person training and resulted in behavioural change or useful assessment outcomes for clients. Furthermore, telehealth training was rated as highly socially valid, and, in preliminary analyses, resulted in significant financial savings for organisations and reduced travel burdens for trainees. Providing training via telehealth may therefore be a promising method of supporting behavioural change for clients and increasing access to behavioural support.

Methodological Quality of the Evidence Base

Whilst these initial results are promising, a key limitation of the evidence base for telehealth training in ABA / PBS procedures relates to the methodological quality of the studies. The articles included were most commonly rated as ‘Weak’ or ‘Borderline Adequate’ on the Evaluative Method (Reichow et al., 2008; Reichow, 2011), indicating that they lacked key indicators of methodological quality. This finding replicates earlier findings by Boisvert et al. (2010) who similarly found that research relating to telehealth support for people with ASC had key methodological flaws. Only five studies in the current review were rated as ‘Adequate’ (one relating to trainee outcomes: Knowles et al., 2017; four relating to client outcomes: Lindgren et al., 2016; Machalicek et al., 2009b; Neely et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013), and one as 'Strong' (relating to client outcomes: Gibson et al., 2010).

Due to the low number of articles utilising a group design included in the review, it is not possible to examine the methodological quality of these articles in depth. However, the most common cause of low ratings for single case design studies related to graphical representations of the data which suggested unstable data in the baseline or intervention conditions, poor experimental control, insufficient replication of independent variable manipulations, or a lack of adequate data to evidence an effect. This may suggest that variables other than the training (for trainee outcomes) or behavioural techniques (for client outcomes) influenced results. When considering trainee outcomes, it is unclear whether these elements are due to difficulties in training individuals via telehealth or other aspects of the study design. However, for client outcomes only some of these elements (i.e., number of independent variable manipulations, amount of data collected) are likely to be within the control of the researcher, with others likely to be influenced by the fidelity with which trainees implement the techniques which was found to be variable when examined by the studies included in this review and in a previous review (Neely et al., 2017). Despite this, additional research examining whether issues in these areas of experimental design are common amongst interventions utilising a training or behavioural consultation model is warranted to identify whether this is unique to the use of telehealth. Furthermore, the low ratings for single case design studies may be in part explained by the emphasis given to different elements of study design by the Evaluative Method (Reichow et al., 2008; Reichow, 2011). Wendt and Miller (2012) suggested that elements such as interobserver agreement (IOA) and fidelity may also be key indicators of internal validity in single case design, but are currently considered only as secondary indicators on the Evaluative Method with less influence on the overall rating. This may be particularly relevant in the current review, as only two studies (Barretto et al., 2006; Neely et al., 2016) did not evidence acceptable levels of IOA across all measures, conditions, and participants. Nonetheless, whilst the studies reviewed here often did not score highly on the existing measures of internal validity on the Evaluative Method, their external validity is supported where comparisons were conducted to training provided in-person, as findings were often reported to be comparable. This is a key strength of the evidence base to date. It is also important to consider that research relating to training individuals in behavioural procedures via telehealth is a relatively new in the field, and therefore should be considered in light of this. Further studies that evidence high methodological quality are undoubtedly needed, however the positive outcomes reported here remain a promising indication of the potential effectiveness and utility of this type of support.

Limitations and Directions for Future Research

Some additional limitations of the evidence base must also be considered. Firstly, the vast majority of research included in this review was conducted by research teams located primarily in the United States, therefore it is unclear whether such methodology could be integrated into the support systems of other countries. In addition, there are only a few direct comparisons of training provided via telehealth with training provided via in-person methodology. Whilst this is in an important omission and requires further study, in some contexts it may be sufficient to demonstrate that training provided via telehealth is effective more generally given that it may not be possible to provide in-person support to some trainees / clients (e.g., in very rural areas in which there are no professionals with expertise in behaviour analysis). This limitation may therefore relate to the theoretical understanding of telehealth-based support, rather than its clinical utility. However, the rapid adoption of telehealth during the coronavirus pandemic has highlighted the importance of developing and evaluating methods of providing support via telehealth given that its use was widespread and represented the only method of supporting clients. As a result, whilst comparison of in-person and telehealth methodologies may be primarily a theoretical consideration, this will also be important more generally to ensure that, should telehealth be used on a large scale out of necessity (e.g., during a global pandemic), its effectiveness can be maximised. Secondly, the variable results relating to trainee fidelity warrant further study to identify the determinants of this and ways to improve trainees' implementation of techniques, as well as the impact of this on client outcomes.

Many studies included in the review did not report fidelity data which is a key methodological limitation, although this limitation is also applicable to behavioural research more widely (e.g., Gresham et al., 1993; Ledford & Wolery, 2013). Comparisons with fidelity when trainees receive training via in-person methodology would again be useful, given one study in this review finding that variable fidelity was common across both training modalities (Hay-Hansson & Eldevik, 2013). Finally, some technical difficulties were reported in the studies, suggesting a need to document and refine the technological requirements for successful telehealth interventions. This is likely to be a common concern for telehealth interventions across several fields and Lee et al. (2015) provide an initial analysis of the particular considerations for training relating to FCT interventions. More demonstrations of sufficient technology for conducting telehealth and troubleshooting guidelines are undoubtedly needed if practitioners are to adopt such methodology within their practice.

In addition to limitations in the evidence base, there are also limitations relating to the current review which must be considered when interpreting results. Firstly, it was beyond the scope of the review to consider interventions that did not include additional support from a trainer (e.g., those based solely on self-directed learning such as Jang et al., 2012), or interventions relating to more broad behavioural methodology rather than defined procedures (e.g., Heitzman-Powell et al., 2014; Vismara et al., 2009; Vismara et al., 2013; Vismara et al., 2012), therefore the utility of telehealth in these contexts cannot be inferred from this review. In addition, due to the nature of systematic review methodology some relevant articles may not be included if they were not identified as part of the search strategy and it was not possible to include grey literature such as unpublished manuscripts, dissertations, or book chapters. As a result, some relevant evidence may not have been included in the review. Despite this, the methodology of a systematic review requires adherence to tight inclusion criteria, and this is therefore a limitation of systematic reviews in general. Finally, due to the small number of studies identified the ability to evaluate the effectiveness of interventions quantitatively was limited. The relative infancy of the research in this area also rendered the quantitative evaluation of effectiveness a secondary focus, with a more important aim deemed to be the in-depth description of the evidence base for use by practitioners and researchers in the field. As a result, conclusions relating to effectiveness are only tentatively made.

Despite limitations, this review has highlighted several specific areas that require further study. Any future research should aim to overcome methodological limitations highlighted in this review and be conducted in a range of countries and contexts in order to demonstrate the applicability of telehealth to ABA / PBS support internationally. Additional research is also needed for wider target populations, as nearly all studies in this review focused on children with disabilities, for a greater range of outcomes (e.g., trainee knowledge and confidence), and on other ABA / PBS techniques and interventions. Finally, a component analysis of telehealth training would add to the evidence base by determining which elements of training are necessary or sufficient for behavioural change, as many studies used multiple approaches including initial training, real-time coaching, accompanying manuals, and logistical support from other individuals during sessions.

Broader Considerations Relating to Telehealth

Some wider issues relating to the use of telehealth also warrant further discussion and will require investigation and clarification if the field of ABA / PBS is to adopt telehealth methodology more widely. The articles included in this review often contained only limited details about the characteristics of the trainer, trainee, and clients, with no evaluation of the characteristics of those who would be most able to deliver training via telehealth or benefit from the use of this technology. Some authors highlighted a need to investigate this further (Suess et al., 2014; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) and this may be a key consideration for professionals wishing to use telehealth methodology. It is possible that some individuals may have difficulty engaging with or benefiting from support provided via telehealth due, for example, to difficulty accessing or using the technology required, cultural and language barriers, or preferences for support provided in a particular way. Identifying the characteristics of those who would benefit most and engage with telehealth support would ensure that such methodology is used when it is most appropriate and useful. On a related note, there is debate within other fields around the extent to which support provided via telehealth alters the therapeutic relationship between the therapist / trainer and the recipient (see, for example, Kaplan & Litewka, 2008; McCarty & Clancy, 2002; Swinton et al., 2009). Whilst a full overview of this debate is beyond the scope of this review, there may be important implications relating to this for behaviour analytic support provided via telehealth. For example, if the therapeutic relationship is indeed altered, it may imply that behaviour analytic telehealth support will be most appropriate for individuals who are more emotionally resilient and require less therapeutic / emotional support from trainers alongside the training. These implications will need to be investigated and considered when implementing support via telehealth.

Other limitations relating to the use of telehealth in ABA / PBS may also exist, with some authors highlighting that use of the methodology may be limited to particular types of target behaviours (Machalicek et al., 2010), or particular procedures as training relating to highly specific procedures may be more suited to delivery via telehealth than training for less easily defined procedures (Machalicek et al., 2010; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). Whilst some authors have applied telehealth methodology to more broad training (see, for example, Heitzman-Powell et al., 2014; Reese et al., 2015; Vismara et al., 2009; Vismara et al., 2013; Vismara et al., 2012; Xie et al., 2013), an analysis of the factors related to the effectiveness of telehealth for different types of support and with different behavioural targets is warranted. Finally, the motivations and context for adopting telehealth support in ABA / PBS services must be considered. Whilst providing support via telehealth has preliminarily been shown to reduce costs or travel burdens (Gibson et al., 2010; Lindgren et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013), it can be argued that this should be a secondary focus, with clinical need taking precedence. Furthermore, there is some evidence that despite reduced professional costs, client related costs may increase as a result of the use of telehealth (see Lindgren et al., 2016) which may present a barrier to participation for some families. It may be important, therefore, to ensure that services do not adopt telehealth methodology solely to reduce professional costs where in-person training is possible, but instead adopt telehealth to support populations who may be unable to otherwise access support (e.g., in rural settings) or who would specifically benefit from the use of such technology.

Implications for Practice

Whilst these broader issues require further investigation and the methodological quality of articles included in this review presents a significant limitation, the findings presented here and the literature relating to telehealth more generally may have important implications for clinical practice. In early evaluations, telehealth methodology was effective for training individuals in a number of ABA / PBS techniques. Whilst more high quality research is warranted, these findings suggest that telehealth support may have the potential to improve the reach and scope of behaviour analytic support and enable professionals to effectively support populations that would otherwise struggle to access such support. This may be particularly important in contexts where expertise in behaviour analysis is scarce such as the UK, where only 275 professionals are registered with the Behaviour Analyst Certification Board as Board Certified Behaviour Analysts or Board Certified Assistant Behaviour Analysts (Behavior Analyst Certification Board, 2017). This is equivalent to one certified professional per 235,525 people and is much lower than other countries such as the USA, where there is one certified professional for every 12,776 people (based on total population data as of 1st July 2017: United States Census Review, 2017). Telehealth support in ABA services also necessitates a focus on training stakeholders as it may be difficult to provide direct behavioural interventions to a client using telehealth due to the need to be able to deliver reinforcement and manipulate aspects of the environment directly. Training stakeholders is consistent with best practice in PBS (Gore et al., 2013) and is also likely to improve stakeholder skills and promote the sustainability of behavioural support for the client over time. In addition to this, telehealth-based interventions were considered highly socially valid by trainees which is another important determinant of the likelihood that the intervention will be continued in the absence of direct professional support (Baer et al., 1987). Finally, in initial investigations telehealth training appears to be an efficient and cost effective way to provide support, given evidence of potentially large cost savings overall and reduced travel burdens (Gibson et al., 2010; Lindgren et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). Whilst caution should be exercised in solely using financial benefits to justify the adoption of telehealth methodology as discussed above, this may be an important consideration for the field in the current economic and political climate.

Conclusion

This chapter has outlined the evidence base for the use of telehealth in ABA interventions. Whilst this evidence base is currently small and limited in scope, it provides promising emerging evidence of the feasibility, utility, effectiveness, and acceptability of such approaches within behavioural work. The focus of this chapter was not explicitly on young children with IDD who display CB. However, a high number of included articles focused on this population, suggesting that telehealth may be particularly useful with this population. The evidence indicated good initial outcomes for this population in relation to both assessments and interventions for CB when delivered by someone trained via telehealth. Despite this, as in Chapter Two there were no examples found in the review that were conducted within the UK, highlighting an important omission. As argued within this chapter, telehealth may be particularly relevant for a UK context given the small number of behaviourally oriented professionals in the UK, making in-person support for all families challenging. As a result, later chapters in this thesis will examine the feasibility (Chapter Five) and acceptability (Chapter Six) of the use of telehealth approaches within behavioural support in the UK.

Chapter Four

Study One - Training Family Carers in Functional Assessment and Function-Based Interventions In-Person for Young Children with Intellectual / Developmental Disabilities who Display Challenging Behaviour

Chapter Overview

This chapter describes the results of study one, which focused on training family carers to conduct functional assessments (FAs) and implement Functional Communication Training (FCT: Carr & Durand, 1985) interventions for their child aged under 7 years with an intellectual or development disability (IDD). Differential reinforcement of alternative behaviour (DRA) interventions, which include FCT, were highlighted in Chapter Two as the most common type of function-based intervention procedures (FBIs) used for young children with IDD who display challenging behaviour (CB), with promising maintenance and generalisation of outcomes. FCT is also identified as a "well-established"[2] approach for supporting children with IDD who display CB (Kurtz et al., 2011) and was therefore selected as the intervention strategy for study one. This study aimed to firstly examine the feasibility of implementing FCT procedures within a UK context, as no known examples of this exist in the literature, and secondly to examine the feasibility of training families in implementing these procedures with their children.

Introduction

As noted in earlier chapters, children with IDD are at a higher risk of developing CBs such as self-injury, aggression, or property destruction. It is estimated that at least 41,547 children with intellectual disabilities (IDs) in England display CBs (Emerson et al., 2014) with 19,409 of these children being under seven years of age. Amongst young children with IDD, as many as 24% to 36% aged 0-3 years display behavioural difficulties including CBs (Emerson & Einfeld, 2011). Without

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[2] Defined by the American Psychological Association's taskforce (Task Force on Promotion and Dissemination of Psychological Procedures, 1995) as including at least two good quality between group and nine single case studies finding statistically significant results in comparison to another intervention (see Kurtz et al., 2011)

intervention, these behaviours are known to persist into adulthood (Murphy et al., 2005) and can have detrimental impacts on the wellbeing and quality of life of both the child themselves and their family. Displaying CBs can result in children being at a higher risk of experiencing injury or restrictive treatment (Adams & Allen, 2001; Allen, D. et al., 2006) and may lead to the child being placed in a residential school that is located far away from their family (Alborz, 2003; McGill, Tennyson et al., 2006). In addition, family carers often experience stress and other emotional difficulties as a result of their child's behaviour (Baker et al., 2003; Hastings, 2002). Early intervention for children who display CB is therefore important to prevent and reduce behavioural difficulties and improve outcomes for the child and their family (Gore et al., 2014).

As noted in Chapter Two, some of the most common FBIs used to support young children with IDD who display CB were identified as DRA approaches. DRA involves identifying a functionally equivalent alternative behaviour to a CB and teaching the individual to use this to access reinforcement, whilst withholding reinforcement for CB (see for review, Petscher et al., 2009). For example, Flynn and Lo (2016) implemented DRA with six children with Autism Spectrum Conditions (ASCs). They identified an alternative behaviour that was functionally equivalent to each child's CB, such as raising their hand to request attention, and arranged contingencies such that this alternative behaviour received reinforcement whilst the CB was placed on extinction. The authors trained teachers to conduct the FA and implement DRA with each student and demonstrated a reduction in CB for all children and an increase in use of the alternative behaviours. FCT (Carr & Durand, 1985) is a specific form of DRA that has been widely used (mainly in the USA) with children with IDD who display CB. The alternative behaviour taught during FCT is a functionally equivalent communication response such as a word / phrase, manual sign, or picture exchange. In order to ensure that the alternative response is functional in nature, FCT is always preceded by a FA identifying the relevant functions of the child's CB. The reinforcement that had previously maintained the child's CB is then provided contingent on the alternative communication response, with reinforcement often withheld for CB (i.e., CB is placed on extinction). In the first application of FCT, Carr and Durand (1985) found that the aggressive, self-injurious, and oppositional behaviour of four children with developmental disabilities functioned to gain attention from adults or to escape from difficult tasks. As a result, the children were taught to request attention or help from adults verbally and their CBs subsequently reduced to near zero levels. The use of FCT, rather than another form of DRA, with young children with IDD is likely to be particularly useful given that young children's communication skills will naturally be less well developed (and even more so if the child's IDD is associated with communication difficulties), making a communication-based intervention particularly appropriate. Such interventions for young children with IDD have the potential to improve communication skills (alongside reductions in CB) and may therefore have more long-term benefits for the child, and influence outcomes beyond CB.

FCT has been widely used with young children in the USA in order to teach alternative communication skills including speech, signing, and alternative and augmented communication (e.g., Fisher et al., 2000; Hanley et al., 2005; Harding, Wacker, Berg, Winborn-Kemmerer et al., 2009; Mildon et al., 2004; Schieltz et al., 2011), however there are no known published examples of FCT being used with young children with IDD in the UK. This is a significant omission given the different cultural contexts in the UK and the USA. For example, there is more experience and widespread usage of behavioural approaches in the USA. No figures exist relating to the number of professionals utilising behavioural approaches in different countries. However, as an indicative measure, in 2018 (when this study was completed) there were 30,161 individuals certified with the Behavior Analyst Certification Board in the USA (Behavior Analyst Certification Board, 2018), equal to one certified professional per 12,528 people in the population. In comparison, there were only 336 individuals certified with the Behavior Analyst Certification Board in the UK (Behavior Analyst Certification Board, 2018), equal to one certified professional for every 198,679 people in the population.

Despite wider spread use of and evidence for behavioural approaches (including FCT) in the USA, it is not known how well these approaches would fit within a UK context and any influence that the different context would have on implementation of approaches, acceptability amongst stakeholders, and outcomes. In addition, support offered to families is likely to differ between the UK and the USA given the different service contexts that operate within each country. Whilst behavioural support is often provided in clinics or as part of medical interventions funded through insurance within the USA, support is more typically offered in a range of settings (e.g., homes, schools, clinics) and by a variety of professionals in the UK. As a result, there may be additional considerations relating to the practical application of behavioural approaches within the UK, and despite support for approaches that are consistent with Positive Behaviour Support (PBS, e.g., FCT) in the UK (e.g., NICE, 2015) there is a notable lack of examples of such approaches being used. As a result, demonstrations of the applicability and feasibility of PBS based interventions such as FCT in the UK are needed.

Furthermore, consideration of ways to ensure these approaches fit within the support context and culture of the UK is also needed. This may, for example, emphasise the involvement of stakeholders in the design and delivery of support, which is a key component of UK definitions of PBS (e.g., Gore et al., 2013). Furthermore, the involvement of key stakeholders is consistent with the social model of support used within the UK, and may also lead to more effective and socially valid interventions which can more easily be incorporated into naturalistic settings, promoting maintenance and generalisation of outcomes. However, in addition to the lack of examples of PBS based interventions generally in the UK, there are no accounts in the literature of training family carers to implement specifically FAs and FCT interventions in the UK. As a result, it is not known whether family carers can be trained to act as intervention agents and implement FCT with their children within this context. Within the UK this gap in knowledge may be particularly significant, as constraints on time and resources may prevent professionals from offering intensive support to children and families. Training family carers in assessment and implementation techniques is therefore a highly important focus of professional work with families, as it may empower families with knowledge and skills to support their children over the long term and after professional input has ended (see Chapter One for further discussion). As a result, supporting family carers in this way is not only likely to be empowering for families and supported by best practice, but may also be cost effective and beneficial within the current UK context.

This study therefore aimed to examine the feasibility of implementing FAs and FCT with young children with IDD in the UK. A key focus of study one was on ensuring that the length of assessment and intervention procedures was kept short in order to maximise both contextual fit (i.e., the extent to which the procedures fit within the family context) for families, ensuring that burden on families was kept low, and also the likelihood that such support could be adopted within existing services in the UK, such as the NHS where available sessions with a family are often limited. As a result, the number of available sessions within each phase of the study was fixed in line with the study's ethical approval and to keep procedures short. An additional focus was on whether it is feasible to train family carers to implement procedures, therefore maximising family carer skill and empowerment and reducing professional input. As a result, the majority of family carer participants in study one were trained by the researcher to implement procedures themselves for their own children, whilst two children received all procedures delivered by the researcher rather than their family carer in order to trial the methodology prior to training families in the procedures.

The specific aims of study one were to answer the following feasibility questions within a UK context:

1) Is it feasible to recruit families to take part in the study and retain their participation for all study procedures?
2) Is it feasible for all study procedures to be trialled by the researcher with two children with IDD prior to training other family carers to implement the procedures themselves with their child?
3) Is it feasible (within two training and four assessment sessions) to train family carers to complete a FA (including descriptive assessment and experimental functional analyses [EFA]) with their child, with an acceptable level of fidelity?

4) Is it feasible to, in conjunction with family carers, design an FCT based intervention for each child based on the FA results?
5) Is it feasible to (within two training and four intervention sessions) train family carers to implement the intervention with their child, with acceptable fidelity?

Methodology

Participants

Participant Inclusion Criteria

Child participants were required to be under nine years of age with an identified ID or condition usually associated with ID (e.g., Fragile X Syndrome) who displayed either property destruction, self-injury or aggression at home. An initial age range criterion of 0-7 years was selected given evidence described above that approximately 19,409 children aged 0-7 with ID in England display CB, with over 75% of these being aged under five years (Emerson et al., 2014). Focusing on children aged 0-7 therefore increased the likelihood that intervention within the study would be provided early in the development of CB. However, due to recruitment difficulties (see below) it was necessary to expand the age range to nine years to facilitate participant recruitment. In addition, child participants were required to use no more than phrase speech due to the focus on FCT as the intervention strategy. If participants had more fluent speech it was anticipated that FCT may not be the most appropriate intervention given their advanced communication skills, as there are few examples in the literature of the use of FCT with young children with IDD who have fluent speech. Participants who were fully deaf / blind or who had medical conditions associated with fluctuating pain (e.g., uncontrolled gastrointestinal problems) were excluded due to the increased complexity of supporting these populations. Participants were also excluded if they were currently receiving support from a professional in relation to their behaviour to minimise cross intervention interference. Family carer participants were required to be over 18 years of age with capacity to consent and not be in receipt of support from a professional in relation to their child's behaviour to minimise cross intervention interference.

Participant Recruitment

Recruitment was facilitated by staff from local NHS Child Development Centres (CDCs) or specialist schools, and by circulating advertisements (see Appendix I) on social media platforms and via charitable organisations involved in supporting children with IDD and their families. Recruitment procedures at CDCs or schools involved professionals (e.g., clinical psychologists, keyworkers, teachers) who were already involved with the family providing information sheets (see Appendix J) and reply slips to families to introduce them to the study and enable them to contact the researcher if they were interested in taking part. Professionals were also provided with follow up letters to send to families two weeks after providing the initial information pack. Four CDCs and two specialist schools in East Kent supported recruitment, and each was provided with at least fifteen information packs to give to families. It was expected that most participants would be recruited via direct contact from professionals in this way. In addition to this, twelve charities also circulated advertisements to their networks and via social media. All participating families were recruited via CDCs except for one family who contacted the researcher independently after seeing an advertisement.

Despite extensive recruitment efforts, significant recruitment challenges were experienced for this study. The first family was recruited ten months after the start of recruitment, with the final family recruited two years after the start of recruitment, at which point recruitment efforts were terminated. Despite this extended recruitment period, only five families were recruited (one who later withdrew from the study). The researcher made several attempts to facilitate recruitment during this period. The main professional involved in supporting recruitment at each CDC was provided with information packs and follow up letters on multiple occasions and encouraged to hand all information packs out to families. Staff in schools were asked to circulate information packs and follow up letters only once since all eligible families in the school were provided with information on the first occasion. In addition, the researcher attended meetings at CDCs and schools to discuss the study with wider staff groups and encourage their support with recruitment. Advertisements circulated by charities were repeated where possible. Seventeen charities who supported families of young children with IDD were initially contacted in Kent, East Sussex and South Surrey, of which twelve agreed to support recruitment (and the remainder did not respond to contact).

In addition, several modifications were made to the procedures and ethical approval for the study in order to facilitate recruitment. Firstly, the study location was expanded to include South Surrey and East Sussex with charities in these areas then asked to circulate advertisements. Approval was also obtained for procedures to take place in the family carer's home (rather than at a CDC only), or the University of Kent in order to remove potential barriers to participation relating to the location of study activities. In addition, the upper age limit for child participants was increased from seven to nine years as outlined above, and approval was obtained to contact families who had recently been involved in other research. Based on feedback from professionals at the CDCs about recruitment, approval was also obtained for professionals to send information packs to families on their waiting list, rather than only those who were actively on the professional's caseload. Despite these efforts, recruitment remained a significant challenge for this study and this is discussed further in Results below.

Participant Characteristics

Participants were five children with IDD and one family carer per child (in all instances, this was the child's mother), none of which had had specialist input in relation to their child's behaviour. Child and family carer participants are described below, and pseudonyms have been assigned to all participants to protect their confidentiality.

Billy (aged three years) had been diagnosed with an ASC and global developmental delay. He was ambulatory with no additional medical concerns. He communicated using some single signs and phase one of the Picture Exchange Communication System (PECS: Frost & Bondy, 1994). During his involvement in the study, he attended both a specialist and a mainstream nursery before transitioning to a primary school for children with special educational needs towards the end of his involvement with the study. He displayed aggression (biting, kicking, hair pulling) and self-injury (self-biting).

Millie (aged three years) had a diagnosis of global developmental delay, cerebral palsy, and sensory processing disorder. She also experienced a number of health conditions including gastro-oesophageal reflux, eczema and food intolerances (all of which were said to be well controlled with medication or lifestyle changes, with the exception of reflux which was described as being more difficult to control in the evenings only). She was ambulatory with the aid of a walker. Millie could talk in simple sentences and used Makaton signing. During her involvement in the study Millie attended a mainstream nursery. Millie displayed self-injury (self-pinching and biting) and aggression towards others (slapping, pinching, hair pulling, biting, scratching, pushing / pulling, hitting with objects).

The researcher implemented all procedures with Billie and Millie throughout the study (i.e., family carers were not trained in procedures). This enabled the researcher to trial the study procedures prior to training the family carers of all other participants (as described above).

Gary (aged seven years) had an unspecified genetic syndrome affecting his cognitive and physical development. He had hypermobility of his joints but was ambulatory with the aid of ankle splints. He also had several additional health concerns including epilepsy, constipation, and various allergies, all of which were reported to be well controlled through medication or lifestyle management. He communicated using idiosyncratic vocalisations and some Makaton signs. He attended a primary school for children with special educational needs and used a picture board to communicate at school. His CB included aggression (pulling hair, biting, scratching, grabbing), self-injury (self-biting), and property destruction (throwing items). Gary's mother *Kelly* (47 years old) also took part in the study and was trained by the researcher to implement the study procedures.

Jack (aged four years) was diagnosed with ASC and a severe expressive language disability. He was ambulatory and had no additional health concerns. He communicated using phrase speech and was receiving intermittent speech and language therapy support to improve his pronunciation. He attended a mainstream nursery throughout his involvement in the study. He displayed aggression (biting, head-butting, kicking, pinching), self-injury (self-biting, head-butting the floor, self-scratching), and property destruction (throwing items). Jack's mother, *Kylie* (44 years old) also took part in the study and was trained by the researcher to implement the study procedures.

Donna (aged five years) was diagnosed with ASC and an ID. She was ambulatory and had no additional health concerns. She communicated using single signs and used PECS phase one at school (Frost & Bondy, 1994). She attended a specialist primary school for children with special educational needs. Her CB included aggression (biting, pinching, scratching, kicking, throwing items, hitting others with objects) and self-injury (self-biting, hitting body on objects, hair pulling, head banging, hitting self, kicking self, pinching self, scratching self, stamping foot). Donna's mother *Nancy* (aged 49 years) also took part in the study and was trained by the researcher to implement the study procedures.

Data Collection

Behavioural Data

The primary outcome measures in the study were observed CB, communication responses, and implementation fidelity, therefore observational data were collected as described below.

Response Definitions. Target behaviour and communication response definitions were individualised for each child. A specific response class (aggression, self-injury or property destruction) was selected as the focus of assessment and intervention procedures for each child in consultation with their mother during the descriptive FA (see below). *Aggression* included any behaviour that could cause physical injury to another person, *self-injury* included any behaviour that could cause physical injury to the child themselves, and *property destruction* included any behaviour that could result in damage to items in the child's environment.

In the absence of consensus on the most appropriate mand (i.e., request) topography for use during FCT (e.g., Kunnavatana et al., 2018; Ringdahl et al., 2009), mands for each child were selected in consultation with the child's family carer, a speech and language therapist, a Board Certified Behaviour Analyst, and the researcher's supervisors. Mands were designed to be simple responses, low in response effort, congruent with the child's existing communication repertoire, and with functional equivalence to the target behaviours as identified by the FA. For some participants (i.e., Billy, Gary), new mands were designed as the participant had no existing functionally equivalent mands in their repertoire, and for other participants (i.e., Jack, Donna), existing mands were identified to be strengthened. Whilst there is some suggestion that the use of existing mands may be associated with increased CB during FCT (Winborn et al., 2002), this research is conflicting and some studies find no association between these variables (e.g., Matter & Zarcone, 2017). Given that this study aimed to evaluate the procedures implemented within a short period of time, the use of an existing mand where possible functioned to ensure that the teaching phase was kept short. As noted above, mands were selected in consultation with several stakeholders therefore mitigating against the possibility of unanticipated issues with using an existing mand. Mand selection did not occur for Millie due to her withdrawal from the study prior to the completion of any intervention procedures (see below).

Gary and Donna's targeted mands were modifications of Makaton signs for 'play' and 'more' respectively. Gary's modified sign involved performing the sign with his palms facing down rather than up, due to concerns reported by his mother about his ability to turn his palms up given his hypermobility. On consultation with the speech and language therapist, it was agreed that this was likely to be understandable by others who supported him. Donna's modified sign involved touching both fists together horizontally. Donna already used this modified sign and this was reportedly understood by those who supported her. Additionally, her mother reported that she was resistant to physical prompting and it was therefore felt inappropriate to attempt to modify the sign as this would increase response effort for Donna as well as being difficult to modify via vocal or imitative prompts alone. For Billy, two communication responses were targeted. Initially, a picture card exchange was selected but due to Billy's interest in posting the communication card this was switched to a Makaton sign as he was reported and observed to use either topography of communication. Jack's target communication response was a vocal mand as he was observed to use phrase speech exclusively.

CB response classes and the communication response selected for each child can be seen in Table 6 below.

Table 6

Challenging Behaviour Response Class and Communication Response for Each Participant

Participant	***CB Response Class* (Individual Topographies)**	**Communication Response**
Billy	*Aggression* (biting, hitting, kicking, hair pulling)	Picture card exchange: "want" and Makaton sign: "want"
Millie	*Aggression* (biting, pinching, slapping, pushing, hair pulling, hitting with an object)	N/A due to withdrawal from the study
Gary	*Aggression* (biting, hitting, hair pulling, scratching, throwing items at another person)	Modified Makaton sign: "play"
Jack	*Aggression* (biting, hitting, hitting with an object, kicking, hair pulling, head-butting, throwing items at another person, scratching)	Vocal phrase: "I want"
Donna	*Self-injury* (head banging, hitting self, kicking self, pinching face, scratching self, foot stamping, arm banging, self-biting, pulling own	Modified Makaton sign: "more"

Participant	*CB Response Class* (Individual Topographies)	Communication Response
	hair)	

Response Measurement. Due to the use of latency based EFA methodology (see below), latency to any targeted CB and targeted mand (from the start of the EFA condition or FCT trial) was collected using a stopwatch. In addition, frequency data were also taken as an indicator of the number of CBs or targeted mands occurring in each baseline, teaching and intervention session (frequency data were not recorded during EFA sessions due to the latency methodology which would have resulted in frequency being one in all sessions). However, frequency data for targeted mands were not recorded during communication training sessions since this value would be influenced by the number of trials presented and duration of prompting. Data were also collected during communication training on prompt level (full, partial, or none), and during all procedures on procedural fidelity (see below). All experimental sessions were video recorded to aid data collection.

Procedural Fidelity. Fidelity data were recorded for the researcher's / family carer's implementation of procedures using a task analysis of procedures (see Appendix K for examples) and 10-second partial interval recording. Data were collected by scoring an interval as accurate if the task analysis component was completed accurately each time it was required within the interval. Steps that were not required during a given interval were scored as not applicable. The average percentage of intervals implemented correctly was then calculated for each appointment (i.e., each visit with the family) if the appointment contained only one session type, or for each block of session types within a given appointment. For example, if the appointment included three baseline conditions and five teaching conditions a percentage was calculated for the baseline and teaching conditions separately to enable examination of fidelity across different condition types.

Interobserver Agreement. Second raters independently collected data across a percentage of all sessions for all variables (i.e., CB latency / frequency, prompt type during communication training trials, fidelity) to calculate interobserver agreement (IOA) data. For latency measures, total duration IOA was calculated by dividing the smaller duration observed by the larger duration and multiplying by 100. For fidelity and frequency measures, total count IOA was calculated by dividing the smaller count observed by the larger count and multiplying by 100. Where this was calculated for fidelity variables, count includes only those steps implemented accurately (as opposed to including those steps completed inaccurately or omitted) since data presented below focuses on percentage of steps implemented correctly (i.e., also does not include data relating to steps completed inaccurately or omitted). For teaching prompt data, trial-by-trial agreement IOA was calculated by dividing the number of trials in which observers agreed on the prompt type by the total number of trials and multiplying by 100.

Table 7 below provides information about the number of sessions IOA data were collected for across each participant and variable, IOA average percentage, and IOA range. IOA data were collected for 22.58% of all sessions for Billy, 30.95% of all sessions for Gary, 35% of all sessions for Jack, and 33.33% of all sessions for Donna (percentage of sessions by session type for which IOA data were collected for each participant can be seen in Table 7 below).

Table 7

IOA Data for All Participants

Participant	**Variable**	**No. of Sessions (%)**	**IOA Average %**	**IOA Range**
Billy	EFA CB latency[a]	5 (31.25)	98.08	95-100.00
	EFA fidelity[b]	5 (31.25)	90.89	77.78-100
	Baseline CB latency[a]	1 (100)	100	-
	Baseline fidelity[b]	1 (100)	98.36	-
	Baseline CB frequency[c]	1 (100)	100	-

Participant	Variable	No. of Sessions (%)	IOA Average %	IOA Range
	Teaching session prompts[d]	1 (7.14)	60	-
	Teaching session fidelity[b]	1 (7.14)	90.48	-
	Teaching session CB frequency[c]	1 (7.14)	50	-
Gary	EFA CB latency[a]	6 (30)	72.88	6.34-100
	EFA fidelity[b]	6 (30)	86.31	42.86-100
	Baseline CB latency[a]	1 (33.33)	6	-
	Baseline fidelity[b]	1 (33.33)	5.88	-
	Baseline CB frequency[c]	1 (33.33)	0	-
	Teaching session prompts[d]	6 (31.58)	71.18	33.33-100
	Teaching session fidelity[b]	6 (31.58)	82.12	62.96-100
	Teaching session frequency[c]	6 (31.58)	91.67	50-100
Jack	EFA CB latency[a]	5 (31.25)	99.83	99.50-100
	EFA fidelity[b]	5 (31.25)	97.31	94.34-100
	Baseline CB latency[a]	2 (50)	100	-
	Baseline fidelity[b]	2 (50)	98.53	97.06-100
	Baseline CB frequency[c]	2 (50)	100	-
Donna	EFA CB latency[a]	5 (33.33)	90.86	60-100
	EFA fidelity[b]	5 (33.33)	90.27	71.43-100
	Baseline CB latency[a]	1 (33.33)	77.78	-
	Baseline fidelity[b]	1 (33.33)	100	-

Participant	Variable	No. of Sessions (%)	IOA Average %	IOA Range
	Baseline CB frequency[c]	1 (33.33)	80	-
	Teaching session prompts[d]	3 (33.33)	95.83	87.50-100
	Teaching session fidelity[b]	3 (33.33)	86.56	77.78-94.74
	Teaching session CB frequency[c]	3 (33.33)	66.67	0-100

Note. [a] Total duration IOA. [b] Total count IOA (for steps completed accurately). [c] Total count IOA. [d] Trial-by-trial agreement IOA.

Questionnaire Data

In addition to behavioural measurement as described above, several questionnaires were used to facilitate the FA and to evaluate secondary outcomes.

Functional Assessment Interview (FAI). The FAI (O'Neill et al., 2014) is a structured interview used to gather information about variables relevant to the child's behaviour. The interview was modified during the study to remove questions that were not required (and therefore shorten it overall to reduce burden on families), and to incorporate items from the Challenging Behaviour Checklist (CBC: Harris et al., 1994). Items from the CBC were added to expand the information collected about the CB and ensure that all topographies were captured as part of the interview, and to provide a method of scoring the child's CB that could be compared at different time points during the study. The modified FAI can be seen in Appendix L. The FAI was completed in full during the FA with the child's family carer and took between one hour and ninety minutes to complete. Information gathered during the interview was used to write preliminary target behaviour definitions and develop summary statements about the possible function of the child's behaviour, which were subsequently confirmed with family carers. Sections A (including items from the CBC: Harris et al., 1994) and G (relating to communication) of the FAI were also completed at each participant's withdrawal point as an indicator of change in non-targeted behaviours and communication.

Functional Assessment Observation Form (FAOF). The FAOF (O'Neill et al., 2014) was used during the FA to collect data during a structured observation (see below) completed by the researcher / family carer. The form was typically completed from the video footage of the observation. The form provides a system for recording the antecedents, target behaviours, and observed consequences of behaviour during an observation and was simplified for use in the current study to facilitate use by family carers. This involved removing the 'initials' column (as only one person would be completing the form) and the event recording system (as the form would be used for only one observation period). Instead, events were listed on the form sequentially and were defined as any instance of a target behaviour that occurred more than ten seconds after the previous instance (i.e., with more than a 10-second inter-response time). The data obtained from the FAOF were used to suggest possible functions for the child's behaviour and examine correspondence with the summary statements developed from the FAI. The observation was also used to refine target behaviour definitions developed during the FAI.

Parenting Tasks Checklist (PTC). The PTC (Sanders, M. R. & Woolley, 2001; Sanders, M. R. & Woolley, 2005) was used to assess family carer confidence in dealing with their child when they are displaying CB. The PTC contains 28 items in two 14-item subscales relating to family carer confidence in dealing with difficult behaviours (behavioural self-efficacy subscale, Cronbach's alpha = 0.97) and dealing with these behaviours in a range of settings (setting self-efficacy subscale, Cronbach's alpha = 0.91) (Sanders, M. R. & Woolley, 2005). Items are rated between 0 ('Certainly I can't do it') and 100 ('Certainly I can do it'). This scale was modified to 0-10 in the current study in order to simplify the rating procedures. A total score and subscale scores can be calculated by summing ratings, with higher scores indicating greater confidence. Where necessary, the language of the items was modified to ensure consistency with UK terminology and ensure that items did not imply that the child had fluent speech. Four items were removed from the behavioural self-efficacy subscale that were irrelevant to the target population as the children did not have fluent speech, resulting in a ten-item subscale. The questionnaire was completed at the beginning of the study and at each participant's withdrawal point.

Beach Centre Family Quality of Life Scale (FQOLS). The FQOLS (Hoffman et al., 2006; Park et al., 2003) was used to assess family quality of life at the beginning of the study and at each participant's withdrawal point. The questionnaire contains 25 questions about variables identified as important to family quality of life for families of children with IDD (e.g., "my family has the support we need to relieve stress" and "my family member with a disability has support to accomplish goals at school or at their workplace"). The 25 items are split into five subscales (see Hoffman et al., 2006): family interaction (six items, Cronbach's alpha = 0.85); parenting (six items, Cronbach's alpha = 0.81); emotional well-being (four items, Cronbach's alpha = 0.83); physical / material well-being (five items, Cronbach's alpha = 0.64); and disability-related support (four items, Cronbach's alpha = 0.70). Items are scored on a five point Likert scale (one - very dissatisfied to five - very satisfied) and subscale and total scores are calculated, with higher scores indicative of higher levels of satisfaction.

Treatment Acceptability Rating Form-Revised (TARF-R). The TARF-R (Reimers & Wacker, 1988) was completed at each participant's withdrawal point (see below) to assess the acceptability of the study procedures to participants. The wording of the items was modified to ensure questions were applicable to the procedures of the study. The questionnaire contains 20 questions (e.g., "how clear is your understanding of the assessment techniques?" and "given your child's behavioural problems, how reasonable do you find the assessments and training techniques?") each rated on relevant a seven point Likert scale. A final score is calculated, with higher scores indicative of higher treatment acceptability. Although the questionnaire examines acceptability as a single dimension, 19 of the items can be grouped for clinical utility in order to examine seven individual variables relevant to treatment acceptability, with the final item providing an indication of the participant's understanding of the procedures (see Reimers et al., 1992). The individual variables include: reasonableness (three items, Cronbach's alpha = 0.88); effectiveness (three items, Cronbach's alpha = 0.86); side-effects (three items, Cronbach's alpha = 0.62); disruptive/time (three items, Cronbach's alpha = 0.65); cost (two items, Cronbach's alpha = 0.54); willingness (three items, Cronbach's alpha =

0.84); and severity (two items, Cronbach's alpha = 0.93). Due to the modifications made to the TARF-R as described above, only total score is examined as part of this study.

Data Analysis

Behavioural data were graphed and analysed through visual analysis to evidence change and facilitate decisions to transition between study phases as described below. All decisions about transition between study phases were made in consultation with a Board Certified Behaviour Analyst, the researcher's academic supervisors, and the participant's family carer. EFA data were graphed by condition and analysed by identifying which condition type was associated with the shortest average latency to target behaviour, indicating function. During baseline, communication training and intervention sessions target behaviour and communication responses were graphed per appointment or per session block as described above and analysed by trend, level and variability to evidence change.

Questionnaire data (for the FQOLS, PTC and TARF-R) were used to calculate total scores and subscale scores as described above. Where applicable, changes in average scores for all participants were examined across time points. Data from the CBC (incorporated into the FAI as described above) were analysed by examining the number of behaviours identified for each participant and average scores for frequency, management difficulty, and severity across behaviours. This allowed for examination of changes in these values over time. Finally, section G of the FAI was analysed by assigning a sequential score to each communication method from one (self-injury) to 18 (complex speech) listed on the communication table in section G. The highest score attained for each communicative function was then recorded and used to calculate an average highest score attained for each participant at each time point. Inferential statistics were not used to analyse questionnaire data due to the low sample size.

Setting and Materials

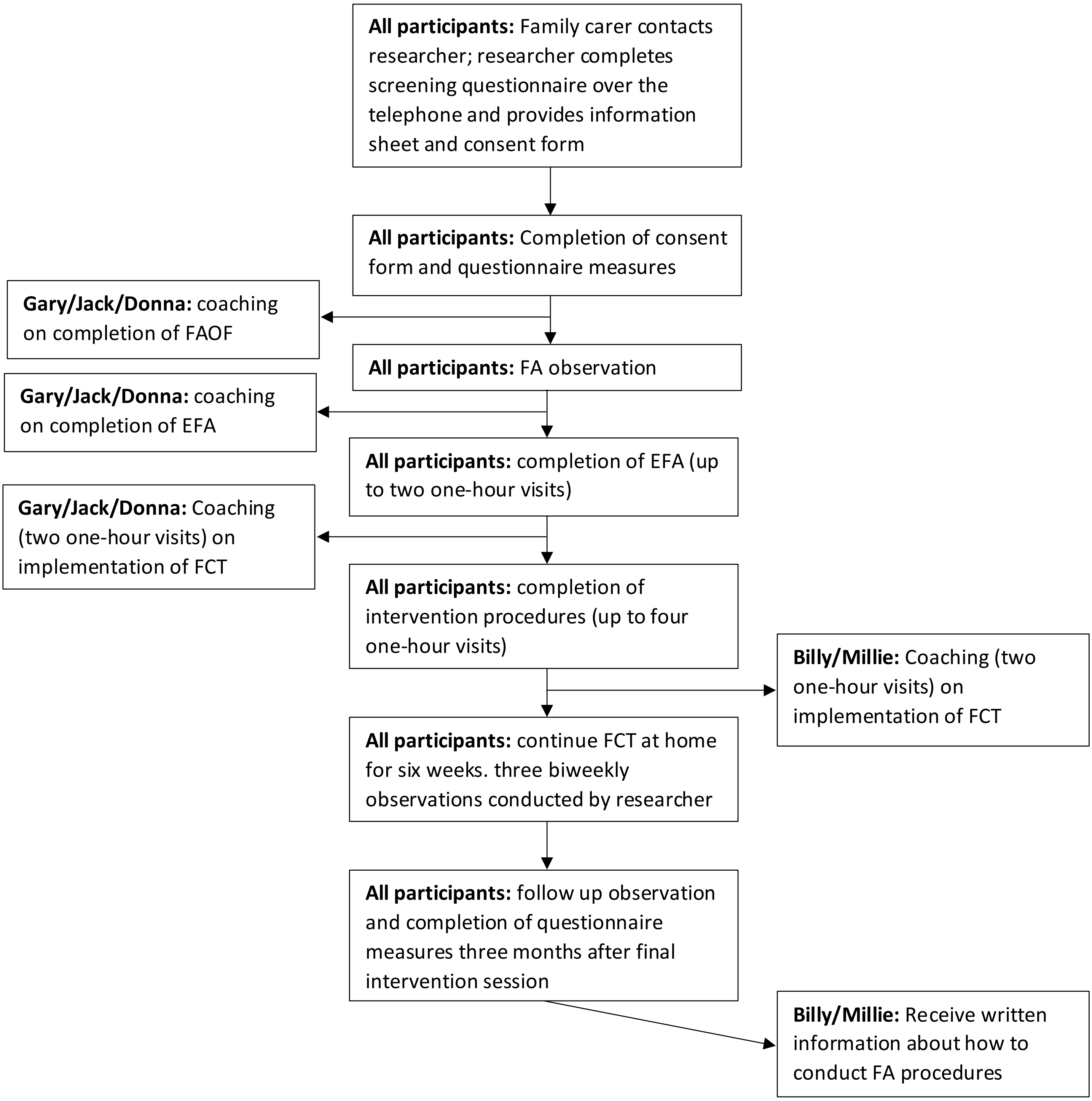
All experimental procedures took place in an NHS clinic setting (Billy, Millie, Jack, Donna) or the participant's home (Millie, Gary, Jack, Donna). Materials varied depending on the session type (see below) and involved a range of toys, food items and work tasks (block stacking, tracing, shape sorting, bead threading). A video camera and tripod were used to record sessions, and data were collected using a stopwatch, tally counter, and paper data sheets. Where needed (i.e., Billy) communication cards were supplied during sessions. A detailed study manual was used to support training (see Appendix M) along with response prompt cards produced to guide researcher / family carer behaviour during sessions. In addition, the researcher used a task analysis to guide procedures during training sessions (see Appendix N for examples).

Procedure

The study involved a number of planned procedures as illustrated in Figure 6 below, with further detail provided in the subsequent sections. These varied slightly according to whether participants received procedures complete by the researcher (Billy / Millie) or their family carer (Gary / Jack / Donna) as outlined in Figure 6.

Figure 6

Planned Study Procedures for All Participants



After receiving contact from a family carer, the researcher completed a screening questionnaire by telephone with families to confirm eligibility for the study and an initial meeting was scheduled to complete consent procedures, the PTC and FQOLS prior to FA procedures as described below.

Functional Assessment

A FA was conducted for each participant consisting of both descriptive and experimental procedures.

Descriptive Functional Assessment. The descriptive FA involved the completion of a modified version (as described above) of the FAI (O'Neill et al., 2014) followed by a structured observation using a simplified version (as described above) of the FAOF (O'Neill et al., 2014). This observation was conducted during a time / activity identified in the FAI to have a high likelihood of evoking the target behaviour and lasted up to 30 minutes. For all participants (with the exception of Billy and Millie for whom the researcher attempted the observation at their homes), the participant's family carer was provided with a video camera and asked to record the observation and complete the FAOF independently. This served to minimise the likelihood of observer effects on the participant's behaviour due to the presence of the researcher. The researcher then retrieved the video and completed the FAOF from the video to compare to the family carer's FAOF and assess degree of agreement for observed variables and hypothesised function. This information was then fed back to family carers in the next training session.

Experimental Functional Analysis. A brief latency based EFA (Thomason-Sassi et al., 2011) was completed for all participants within a multi-element design, either by the family carer (Gary, Jack, Donna) or the researcher (Billy, Millie). A brief EFA (i.e., with conditions lasting no longer than five minutes) was designed in order to minimise the number and length of required study sessions, in line with the study aims. Furthermore, use of a latency measure was selected as the procedures for such an EFA are simpler than in a traditional EFA (e.g., Iwata et al., 1982) as sessions are terminated on the first instance of behaviour and do not require repeated presentation of the establishing operation (with the exception of the demand condition). It was therefore thought that this would facilitate family carer training. Latency based EFAs have also been shown to have good levels of agreement with traditional EFAs (Thomason-Sassi et al., 2011) and involve less risk to participants as behaviour is emitted only once per condition.

The analysis was designed to explicitly test hypotheses developed as a result of the FAI and structured observation about the function of the child's CB, and in particular, to test common functions identified in the literature (i.e., Iwata et al., 1982). Each EFA consisted of attention, tangible, demand and play conditions lasting a maximum of five minutes (alone conditions were not conducted as there was no suggestion from the descriptive FA of an automatic reinforcement function for any participant). Conditions were conducted in a random order and terminated on the first occurrence target behaviour, meaning that many of the conditions were shorter than five minutes in length. Each condition was conducted at least four times for all participants except Donna, for whom only three attention conditions were possible due to noncompliance and distress during the final EFA appointment. The EFA was conducted over a series of one-hour appointments with multiple conditions conducted per appointment separated by a short free play break in between conditions.

Play. During play sessions, a range of toys were available to the child, including those identified by family carers as preferred. No demands were placed, and attention was delivered at least every 30 seconds or more frequently if requested by the child. There were no programmed consequences for the target behaviour, however if the target behaviour occurred the session was terminated one-minute later. This one-minute change over delay has also been used in other examples of latency EFAs (e.g., Thomason-Sassi et al., 2011) and served to ensure both that the session did not last longer than necessary, since latency data were collected, and that adventitious reinforcement of the target behaviour would be unlikely to occur. This condition acted as a control condition.

Tangible. During tangible sessions, a preferred toy or edible item (identified by the family carer) was provided to the child for approximately 30 seconds (or the child was allowed to consume a small piece of an edible item) prior to the start of the session. The researcher / family carer then removed access and made a statement signalling the termination of access (e.g., "you can have some more in a minute"). Contingent upon any instance of the target behaviour, the item was returned, and the session terminated. This condition was designed to test whether the target behaviour was sensitive to social-positive reinforcement in the form of access to tangibles.

Demand. During demand sessions the child was instructed to complete a task that was reported by family carers to be difficult or non-preferred. Tasks included: threading beads (Donna, Billy, Millie); shape sorting (Donna); block stacking (Gary); tracing (Jack); and, completing puzzles (Billy). A three-step prompt procedure (vocal, model/gestural, physical) was utilised to occasion task completion. Contingent upon any instance of the target behaviour, the task items were removed, the researcher / family carer signalled that the task was finished, and the session was terminated. This condition was designed to test whether the child's behaviour was sensitive to social-negative reinforcement in the form of escape from demands.

Attention. During attention sessions, a range of toys (not including those that had been reported by family carers to be highly preferred) were available to the child. The researcher / family carer stated that they had some work to do and instructed the child to play with the toys. The researcher / family carer pretended to work and ignored all non-target behaviour. Contingent upon any instance of the target behaviour, attention in the form of a disapproving statement was delivered and the session terminated. This condition was designed to test whether the child's behaviour was sensitive to social-positive reinforcement in the form of access to attention.

Intervention

Following completion of the FA, a mand was selected for each child (as described above) and teaching procedures were designed. An FCT intervention was also designed for each child, however none of the participants progressed to the final intervention sessions as described below.

Communication training and intervention procedures were designed to be implemented in up to four one-hour appointments with each child using either an AB or ABAB design (dependent on child progress within the appointments).

A – Baseline. Prior to communication training, three five-minute baseline sessions were conducted using the same procedure as the EFA condition associated with the identified function of the child's behaviour, with the exception that sessions were not terminated on the first instance of behaviour and were instead continued for the full five minutes (unless the safety criteria were met as described below). This enabled the collection of frequency data relating to the target behaviour and mand, to facilitate comparisons during intervention sessions. There were no programmed consequences for target behaviour or mands during these sessions.

Communication Training. Communication training was implemented following the three baseline sessions as described above. Communication training was conducted in a series of trials using the same procedure as the EFA condition relevant to the identified function of the child's behaviour. Trials involved immediately prompting the child to use the targeted mand when the establishing operation was initially set up and providing the reinforcer for approximately 30 seconds following completion of the response, whether prompted or independent. For participants whose targeted mand was a manual sign or a picture exchange, physical guidance was used and faded using graduated guidance, with the exception of Donna for whom physical prompting was reported to be aversive. Instead, Donna was provided with a vocal and model prompt, which was to be faded to vocal prompt only and then removed. As Jack's targeted mand was a vocal response, teaching procedures were designed using an echoic prompt that was to be gradually faded by reducing the amount of the word / phrase spoken by the family carer. However, Jack did not progress to communication training as he was withdrawn from the study prior to this (see below). Communication training was conducted in five-minute sessions in which multiple trials were conducted per five-minute session and was terminated following three consecutive five-minute sessions in which at least 80% of communication responses were independent (i.e., unprompted).

Multiple sessions were conducted per appointment and separated by a short free play break. Prior to each communication training session for Billy, a contrived free operant preference assessment was conducted due to difficulties identifying preferred items from family carer report alone during this part of the study. This involved providing free access to ten items for a five-minute period and recording item engagement (i.e., touching an item) using ten second partial interval recording. Further details are provided below.

B – FCT. Although no participant progressed to FCT sessions as described below, procedures during FCT were designed to be identical to those used during communication training with the exception that no prompts would be provided to occasion the communication response and extinction would be programmed for the target behaviours. Participants would therefore be using the communication response independently (as opposed to during communication training in which the response was prompted) and provided with reinforcement for this response, with reinforcement for CB being withheld. If during three consecutive five-minute sessions the target behaviour occurred at a rate that was 80% lower than during baseline sessions, a three-session return to baseline would be conducted before reinstating FCT sessions to evidence experimental control.

Follow up. Although no participant progressed to follow up as described below, procedures for maximising maintenance and generalisation were designed. Specifically, after the four one-hour appointments had been completed in which at least some FCT sessions were conducted, family carers would be asked to continue implementing FCT sessions at home for 15 minutes per day, at least five days per week for six weeks in order to facilitate maintenance and generalisation. They would be asked to film these sessions and complete session logs containing a self-rated fidelity checklist in order to support them to identify areas of implementation that they should review in the manual or discuss in more detail with the researcher. The researcher planned to meet with family carers fortnightly to conduct a 30-minute videotaped observation for data collection and to provide additional coaching and support to family carers. One final observation would be scheduled approximately three months after the final intervention appointment in order to conduct a final 30-

minute observation, provide family carers with advice for continuing FCT and complete final questionnaires (the FAI sections A and G, PTC, FQOLS and TARF-R). As participants did not progress to the follow up stage, all questionnaires were instead completed at their withdrawal point.

Family Carer Training.

Where family carers completed study procedures (Donna, Gary, Jack) they were trained by the researcher in four one-to-one training sessions, and via coaching during sessions.

One-to-One Training. A detailed manual (Appendix M) was developed to support family carer training. This manual provided a written description of the procedures, as well as background information about the functions of behaviour. The manual formed the basis of training sessions and provided a reference point for family carers to return to if they needed to revisit procedure descriptions. Of the four one-to-one training sessions, two related to procedures for the FA. The first of these sessions focused on understanding behaviour, the functions of behaviour, and the purpose and procedures for the structured observation. The second focused on how to conduct the EFA. A further two training sessions were completed relating to the intervention procedures. The first of these provided an overview of FCT and the study procedures for each of the baseline, communication training, and FCT session types. The second of these sessions provided another opportunity to review the procedures and allowed the family carer to briefly trial the communication training procedures with their child and receive feedback from the researcher. Behavioural Skills Training (BST: see Miltenberger, 2008) was utilised to teach the family carer to accurately implement key procedures (the structured observation, EFA conditions, baseline sessions, communication training, FCT sessions). BST involved providing instructions (both using the written manual and vocally), video modelling of procedures being implemented with another child, role-play practice, and both positive and corrective feedback based on the family carer's performance during the role-play. In order to keep sessions short in line with the study aims, BST was not continued to a predetermined criterion and was completed once or twice for each key session type. Since the research did not aim to train family carers to complete procedures independently (i.e., all procedures were designed to be completed in the presence of the researcher), it was not felt necessary to continue BST to pre-determined criterion for this study.

In-Session Coaching. During implementation of procedures (with the exception of the structured observation when the researcher was not present), the researcher provided real-time coaching in the form of vocal instructions about how to implement procedures, praise for elements completed accurately and corrective feedback for any errors made. Response prompt cards were also provided to participants for use during study procedures. These cards contained brief step-by-step procedures for each session type which the family carer could review prior to appointments and use during the appointment to guide their implementation of the procedures.

Ethical considerations

Ethical approval was obtained from the NHS London-Bromley ethical review committee (reference: 15/LO/2024). In order to maintain participants' safety during all study procedures, detailed individualised safety criteria were developed in consultation with each family carer which specified when a session should be terminated based on the frequency and / or intensity of the participant's behaviour. These criteria were regularly reviewed and modified as needed during the study. A support plan was also developed for each participant to be used by the family carer / researcher if sessions were terminated due to the participant's behaviour to ensure that the behaviour de-escalated quickly. Sessions during the study were never terminated due to the safety criteria for Millie, Jack, or Gary. One baseline session each was terminated due to the safety criteria for Donna and Billy due to the frequency (not intensity) of the behaviour. In these instances, the behaviour terminated very quickly when the support plan was implemented, and it was possible to subsequently continue the appointment. In addition, two appointments were terminated early for Donna due to noncompliance and distress. In these instances, although Donna's behaviour did not reach the safety criteria, Donna's mother reported that she did not think Donna would reengage with the materials and opted to reschedule the appointment.

Results

The results will firstly be discussed in relation to the feasibility questions outlined above, followed by a more detailed discussion of results for individual participants.

Feasibility Questions

Is it Feasible to Recruit Families to Take Part in the Study and Retain Their Participation for all Study Procedures?

As noted above, significant difficulties were encountered in recruitment for this study. Recruitment attempts lasted two years and only five families were enrolled into the study during this time (with few other enquiries about the research). This was following extensive efforts to facilitate recruitment as described above, including repeated contact with professionals involved in supporting recruitment and recirculation of advertisements via a variety of platforms.

Following recruitment, most participants were retained in the research until the natural endpoint of their involvement, and their subsequent withdrawal was related to the appropriateness or effectiveness of the intervention procedures rather than participant drop out prior to the commencement of assessment and intervention procedures. The only exception to this was Millie who was withdrawn from the study due to lack of contact and inability to arrange appointments (as described below). This suggests that although initial recruitment may be difficult, it is comparatively easier to retain families for this type of study and may indirectly suggest that the procedures were considered acceptable by families.

Is it Feasible for all Study Procedures to be Trialled by the Researcher with Two Children with IDD Prior to Training Other Family Carers to Implement the Procedures Themselves with Their Child?

The researcher was able to complete most of the study procedures with one child with IDD (i.e., Billy) and some of the descriptive FA procedures with another child (i.e., Millie) as part of this study (see below). Acceptable average fidelity was achieved for the EFA and baseline session with Billy, although fidelity was lower for communication training sessions. This is likely due to a range of difficulties encountered in the communication training procedures in Billy's case (see below). Difficulties were also encountered in the EFA for Millie as described below. However, in both cases difficulties were unrelated to the procedures themselves and did not suggest that modifications were needed to procedures prior to training other family carers in the procedures. Whilst the final intervention sessions were not explicitly trialled the procedure during these sessions was closely linked to the procedure used during communication training sessions (as described above) which were trialled with Billy, therefore it was not felt necessary to recruit a third child with IDD to enable these sessions to be trialled. As a result, it was feasible for the researcher to trial the majority of study procedures with one child with IDD and assessment procedures with a second child with IDD prior to training family carers in the procedures, and no modifications were identified as necessary during this process.

Is it Feasible (Within Two Training and Four Assessment Sessions) to Train Family Carers to Complete a FA (Including Descriptive Assessment and EFA) with Their Child, with an Acceptable Level of Fidelity?

Three of the five participants in this study were trained by the researcher to implement FA procedures with their child. Of these, all three completed the EFA within the specified number of sessions with acceptable overall fidelity (i.e., greater than 80% fidelity on average – see individual participant results below) suggesting that training relating to the EFA procedures was effective. Fidelity varied by condition type and participants often achieved lower fidelity for the demand condition of the EFA (which is more complex and involves more steps than other condition types) therefore suggesting that training in this area could be improved. In addition, individual participant factors which may have impacted fidelity are discussed in the individual participant results below. However, the high overall fidelity suggests that it is feasible to train families in this methodology and achieve acceptable fidelity. Furthermore, all participants took part in descriptive FA procedures including an interview involving the FAI (O'Neill et al., 2014) and an observation.

The results from the FAI suggested potential functions for the participant's target behaviour in all cases. However, observational procedures were unsuccessful in one of the three cases (i.e., Jack) due to difficulties capturing the target behaviours on video. It is therefore not known in this case whether Jack's family carer would have been able to complete observational procedures and data collection as intended. For the other two participants (Gary and Donna) observational procedures were completed by the family carer and there was high congruence between researcher and family carer completed observation forms (see below) suggesting that the training in this area was effective. This provides tentative evidence of the feasibility of training family carers in the observational procedures, although it is not clear whether the failure to capture the target behaviour on video for Jack was related to ineffective training (i.e., ineffective communication of appropriate times and contexts in which to video) or child reactivity to the videoing equipment. This requires further investigation. Overall, results suggest that it was feasible to train family carers in FA methodology including descriptive and experimental procedures within a defined number of sessions.

Is it Feasible to, in Conjunction with Family Carers, Design an FCT Based Intervention for Each Child Based on the FA Results?

For all participants who completed FA procedures (i.e., excluding Millie) an FCT based intervention was designed for the child in conjunction with the child's family carer and a speech and language therapist. In all cases, at least one clear function was identified following the FA enabling the design of an FBI. No difficulties were encountered in designing the FCT intervention procedures and families were generally keen to be involved in this process. Modifications to procedures were made based on family carer involvement (e.g., the use of modified signs for Gary and Donna) and enhanced contextual fit was evident due to the family carer's involvement as they were able to express their preference for the most important functions to target (where multiple functions were identified) and the context within which intervention procedures were conducted. These results therefore suggest that it was feasible to design an FCT based intervention for each child based on FA results and in conjunction with the child's family carer, and that the involvement of family carers is imperative to this process.

Is it Feasible to (Within Two Training and Four Intervention Sessions) Train Family Carers to Implement the Intervention with Their Child, with Acceptable Fidelity?

As described below, none of the participants completed final intervention sessions for various reasons. However, two of the three participants who were trained by the researcher (i.e., Gary and Donna) completed some initial communication training procedures and therefore took part in the early stages of the intervention. In these instances, high levels of fidelity were achieved (i.e., above 80% on average – see below) suggesting that it was feasible to train family carers in these techniques. Despite this, it was not possible to complete communication training according to predefined criteria (as outline above) and progress to the next stages of the intervention for any of the participants. The reasons for this varied and are discussed below but are unlikely to be related to the family carer's implementation of communication training given the high fidelity noted. Nevertheless it is not possible to ascertain whether family carers would have been able to implement the full intervention procedures with acceptable fidelity and it was not possible for this to occur within the defined number of sessions set out as part of the study. This is discussed further in the individual participant results and General Discussion below.

Individual Participant Results

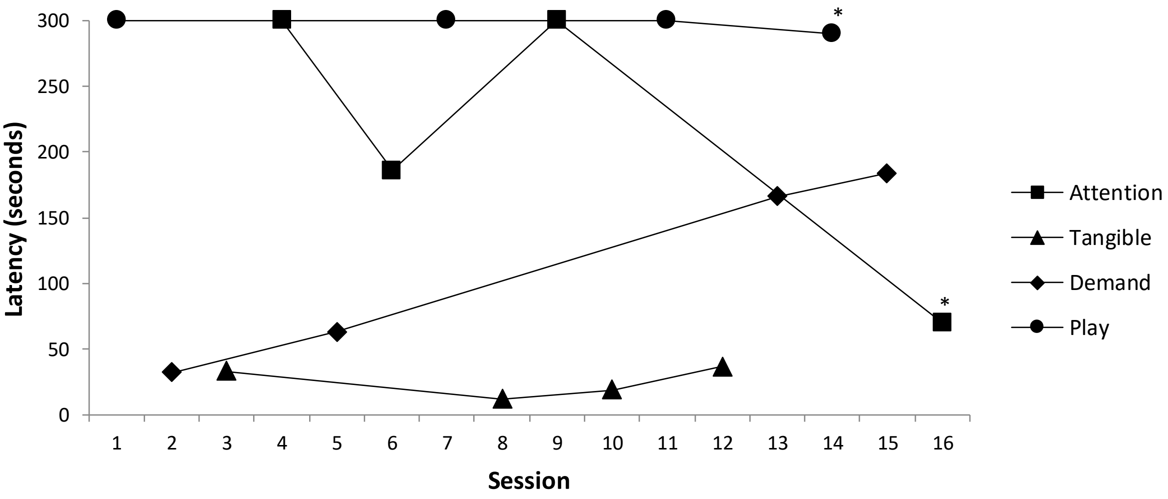
Billy

Descriptive Functional Assessment. The modified FAI (O'Neill et al., 2014), completed with Billy's mother, identified potential tangible and escape functions for Billy's aggressive behaviours, and that these were more likely to occur when Billy was tired. Two structured observations (using the FAOF: O'Neill et al., 2014) were attempted at Billy's house. However, on these occasions the target behaviours did not occur. In order to minimise potential observer effects as a result of the researcher's presence in the home, Billy's mother was instead provided with a camera and asked to record for approximately 30 minutes at times when the behaviour frequently occurred. However, this was also unsuccessful at capturing instances of the target behaviour on video. Despite this, as the FAI had identified clear potential functions for Billy's behaviour it was possible to test these in the EFA without confirming these hypotheses via direct observation.

Experimental Functional Analysis. Billy's EFA was conducted by the researcher in a clinic-based setting. The results of this analysis can be seen in Figure 7 below.

Figure 7

Results of Billy's Experimental Functional Analysis



*Behaviour directed towards Billy's mother rather than the researcher.

Billy's EFA confirmed the hypotheses that the target behaviours functioned to access tangible items and escape demands. Average latency to target behaviours during tangible and escape conditions was 25.25 seconds (range = 12-37 seconds) and 111.25 seconds (range = 32-184 seconds) respectively, compared to average latencies of 214 seconds (range = 70-300 seconds) and 297.50 seconds (range = 290-300 seconds) during attention and play conditions. Given that the tangible conditions evoked behaviour much more quickly and consistently than the demand conditions, the subsequent FCT intervention was designed for a tangible function.

Intervention. It was only possible to complete one valid baseline session with Billy as two earlier baseline sessions were invalid due to a technical failure (meaning that no video was available for data collection). The study's ethical approval did not allow for additional baseline sessions, meaning that data were available for only one baseline session. The completed baseline session identified that the target behaviours occurred 17 seconds after the start of the session (i.e., a similar latency to the tangible conditions of the EFA) and at a rate of 3.20 instances per minute under extinction conditions prior to any teaching or intervention procedures. The picture card was not available to Billy, and he did not independently sign "want" during the baseline session.

Communication Training. Fourteen teaching trials (see Figure 8 and Figure 9 below) were implemented with Billy across the course of the four available one-hour appointments. Trials initially began using a picture exchange mand as described above, however progress was highly variable and it was difficult to successfully fade prompts when teaching Billy to exchange the picture. It was hypothesised that there were two main reasons for this. Firstly, a range of difficulties were encountered in identifying reinforcers and engaging Billy with different activities during the sessions. Billy was noted to have few available reinforcers (with the exception of biscuits which his mother did not want to use more than once per appointment), and it was difficult to identify highly preferred items from caregiver report alone. As noted above, to identify a wider range of reinforcers, five-minute contrived free operant preference assessments were conducted at the start of each appointment. The items identified as highly preferred (i.e., with the highest percentage of intervals with engagement) were used during teaching trials. However, Billy was also noted to become satiated quickly on each item and he engaged in repetitive play (i.e., posting items behind furniture), and ritualised behaviour that involved lining up or arranging items. Billy displayed highly intense aggressive behaviour when these ritualistic/repetitive behaviours were interrupted, and this prevented the researcher from prompting the mand prior to the occurrence of the target behaviours. As a result, motivation to access items was hypothesised to be highly variable during teaching trials and few teaching trials were completed per appointment (mean = 3.50 sessions per appointment). The study protocol and ethical approval did not allow for procedures designed to establish new reinforcer, therefore it was not possible to completely overcome these difficulties.

Secondly, as noted above, Billy displayed repetitive play that involved posting items behind furniture in the room, and he showed a strong motivation for engaging in this behaviour with the picture card used for the mand. This had not been anticipated at the outset of teaching as he was reported to successfully use PECS both at nursery and home. As a result, the mand topography was changed to a manual sign for the final appointment (indicated with a dashed line in Figure 8) as he had also been observed to independently sign. During this appointment, more progress was made in fading prompts to enable Billy to sign independently. This was also the first appointment after Billy had begun attending a specialist school and he was noted to be motivated to access many more items and displayed less stereotypic play than in previous appointments. This, in combination with the modified mand topography, likely resulted in the increased success during this appointment. However, all four available one-hour appointments during this phase of the study had been used for Billy therefore it was necessary to withdraw him from the study at this point.

Figure 8

Percentage of Trials with Each Prompt Type During Teaching Sessions for Billy

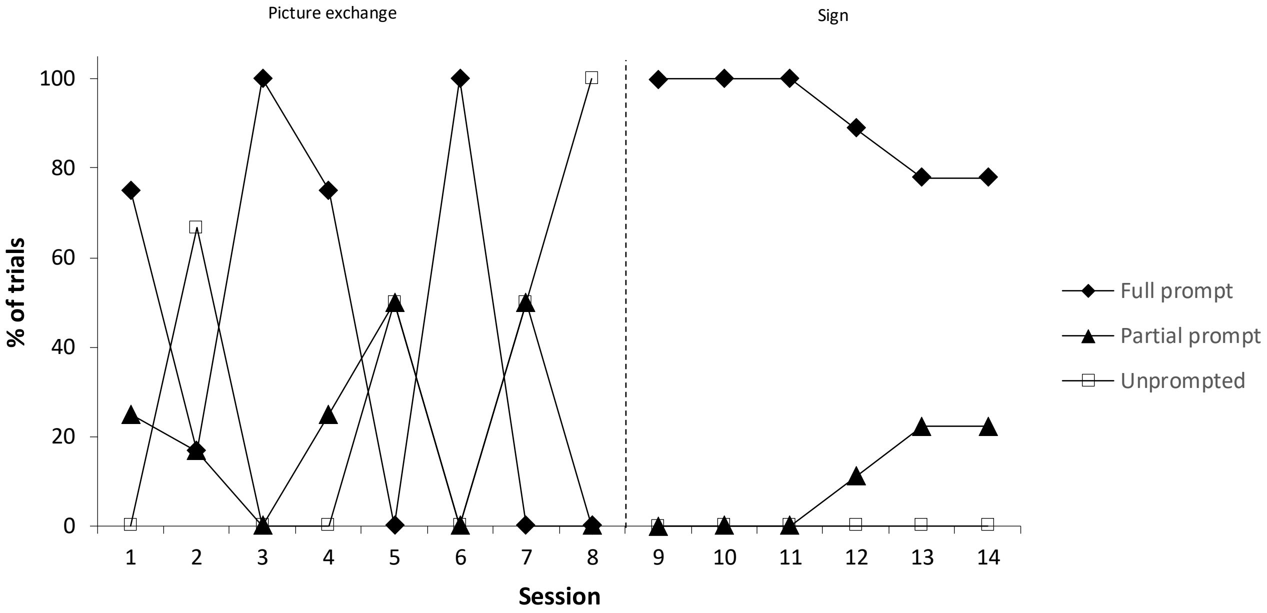
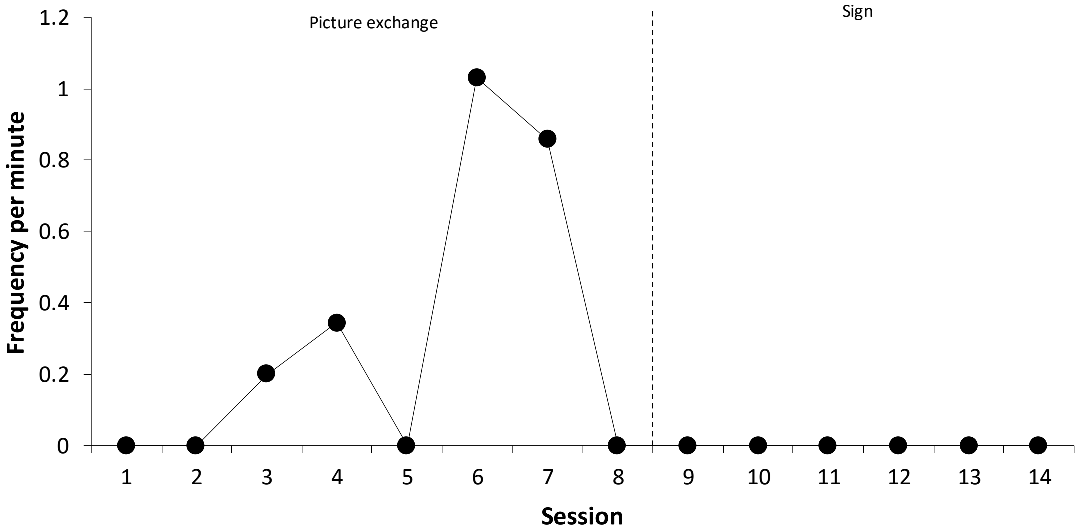


Figure 9

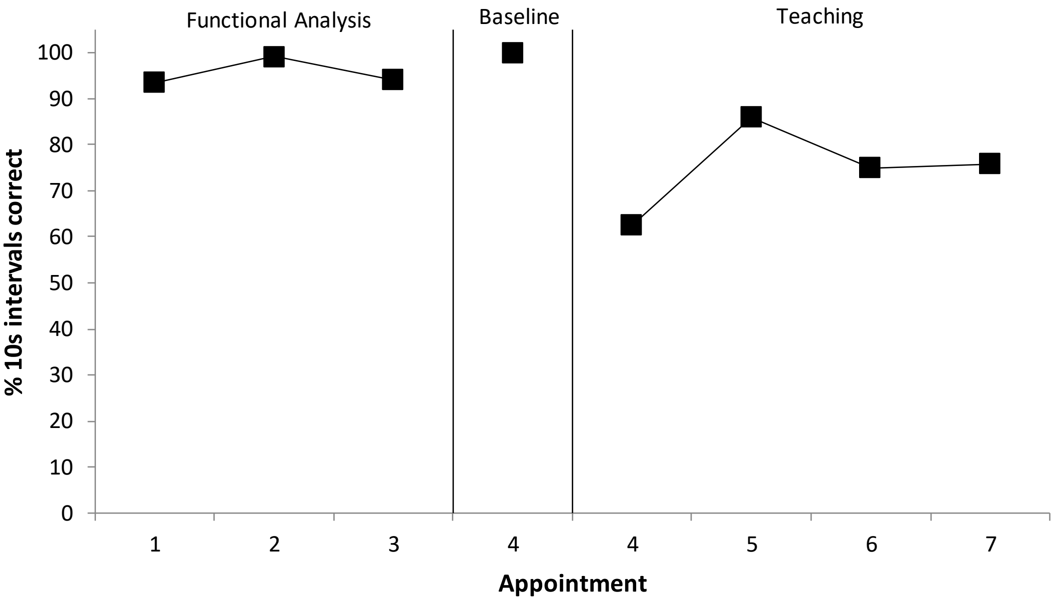
Frequency of Challenging Behaviour per Minute During Teaching Sessions for Billy



Fidelity. Figure 10 displays fidelity data for the researcher's implementation of all procedures for Billy. As noted above, fidelity data are graphed as the percentage of opportunities correct per session type per appointment, meaning that in Figure 10 appointment four is represented twice as it involved two types of session. Fidelity was above 80% on average across all data points (mean = 85.76, range = 62.50-100.00).

Figure 10

Fidelity of Researcher Implemented Procedures for Billy



A further breakdown of fidelity by session type can be seen in Table 8 below. All session types were associated with greater than 80% average fidelity except for communication training sessions which evidenced lower fidelity overall.

Table 8

Breakdown of Fidelity Data by Session Type for Billy

Session type	**No. of sessions**	**Mean % of 10s intervals correct**	**Range % of 10s intervals correct**
EFA overall	16	94.88	71.43-100.00
Play condition	4	99.11	98.21-100.00
Demand condition	4	81.69	71.43-100.00
Tangible condition	4	100	-

Attention condition	4	97.22	88.89-100.00
Baseline	1[a]	100	-
Teaching	14	76.65	45.45-90.00

Note. [a] Data were available for only one baseline session due to a technical failure as noted above.

Interim Discussion – Billy. Whilst it was necessary to withdraw Billy from the study prior to the FCT intervention being implemented, it was possible to complete a full FA with Billy and use the results to design an FCT intervention. However, several extraneous variables likely influenced the speed with which the communication training was successful for Billy and additionally influenced the fidelity with which procedures were implemented. As noted above, difficulties were initially encountered in prompting the picture exchange mand due to intense episodes of aggression and repetitive play. This had not been anticipated as Billy had been reported to use picture exchanges at nursery. It is possible that several variables related to the study contributed to this disparity with the nursery setting. For example, the study was conducted in a novel clinic setting, with a researcher as the interventionist rather than someone Billy was familiar with (e.g., a family member or nursery worker). In addition, Billy's mother reported that he did not have favourite toys that she could bring to the sessions and therefore the researcher provided new toys. These toys may not have been preferred by Billy and may not therefore have provided sufficient competing reinforcement to posting the communication card. These variables in combination may have increased Billy's motivation to engage in repetitive play with the picture card due to the absence of alternative sources of reinforcement that he typically accessed in other settings (e.g., alternative toys). Alternatively, it is possible that discriminative stimuli present in the nursery setting evoked picture exchange responses and that these stimuli were not present in the clinic setting. As it was not possible to conduct nursery observations this could not be verified and rectified as part of the study.

Billy's mother was resistant to the researcher conducting sessions at home with Billy and it was therefore not possible to reduce the contrived nature of the procedures. However, when the mand topography was changed to a manual sign, progress in the next session was much more rapid. If more appointments had been available, it is likely that teaching trials would have been completed, and FCT trials could have been implemented. However, this session was also the first session after Billy started at a new school and he was observed to engage with more items during the session and display less noncompliance or stereotypical behaviour. His mother confirmed that this was also the case at home and that his behaviour had improved considerably since starting school. It is therefore possible that the improved progress during the final teaching sessions was a result of maturation.

In addition to this, scheduling difficulties were encountered when working with Billy which meant that sessions were not conducted at regular intervals. This was often due to clinic room availability or availability of the family. It is therefore possible that progress was slower than anticipated due to the extended time between sessions. Whilst this is a common occurrence in clinical work, it is particularly problematic in this context as it may result in slower progress overall, and outcomes may be more likely to be influenced by changes in participant's lives (e.g., starting school, maturation). The nature of the context of a research study may have exacerbated these difficulties as participants may have been less motivated to engage with the procedures regularly given that they were not provided as part of routine clinical support, and it was not possible for the researcher to insist on more regular sessions as this may have resulted in participants withdrawing from the study. In addition to this, personal difficulties encountered by Billy's family made it difficult to attend sessions regularly and two long breaks were needed. As a result, the researcher had to prioritise the family's needs over the experimental needs of the study, and this may have limited progress.

Millie

Descriptive Functional Assessment. The modified FAI (O'Neill et al., 2014) completed with Millie's mother suggested that Millie's targeted behaviours may have multiple functions including escape from demands, access to attention, or access to tangibles. An observation using the FAOF

(O'Neill et al., 2014) was attempted at Millie's home, however no instances of the target behaviour were observed in this appointment. Millie's mother also attempted to record the behaviour on video but was unsuccessful. However, given that the FAI had identified clear potential functions for Millie's behaviour, it was possible to test these functions within an EFA.

Experimental Functional Analysis. The researcher attempted to conduct EFA procedures with Millie in two one-hour appointments. However, in these appointments no instances of the target behaviour were observed. Following discussion with Millie's mother, modifications were made to procedures which were felt likely to evoke behaviour and more closely mimic contingencies thought to maintain Millie's behaviour at home. These included: conducting the sessions at home (rather than in a clinic setting); extending the session length to 15 minutes (as in Iwata et al., 1982); and collecting data on frequency rather than latency of behaviour (Iwata et al., 1982). However, it was not possible to arrange appointments to conduct the modified EFA despite repeated attempts to contact the family. It was therefore necessary to withdraw Millie from the study at this point.

Interim Discussion – Millie. Whilst it was not possible to progress through the full study procedures with Millie, a descriptive FA using the FAI (O'Neill et al., 2014) was conducted and identified target behaviours and potential functions for Millie. It is unclear why none of these target behaviours were then observed during structured observation or EFA sessions. However, anecdotally Millie's mother reported that Millie's behaviour was often directed towards siblings and animals (and less frequently, adults). As it would have been unethical to include other children or animals in sessions it is therefore possible that the study procedures did not effectively mimic stimulus control conditions related to Millie's behaviour. It is not known whether planned modifications to EFA procedures would have more effectively evoked behaviour as it was not possible to schedule additional appointments and Millie was therefore withdrawn from the study as described above.

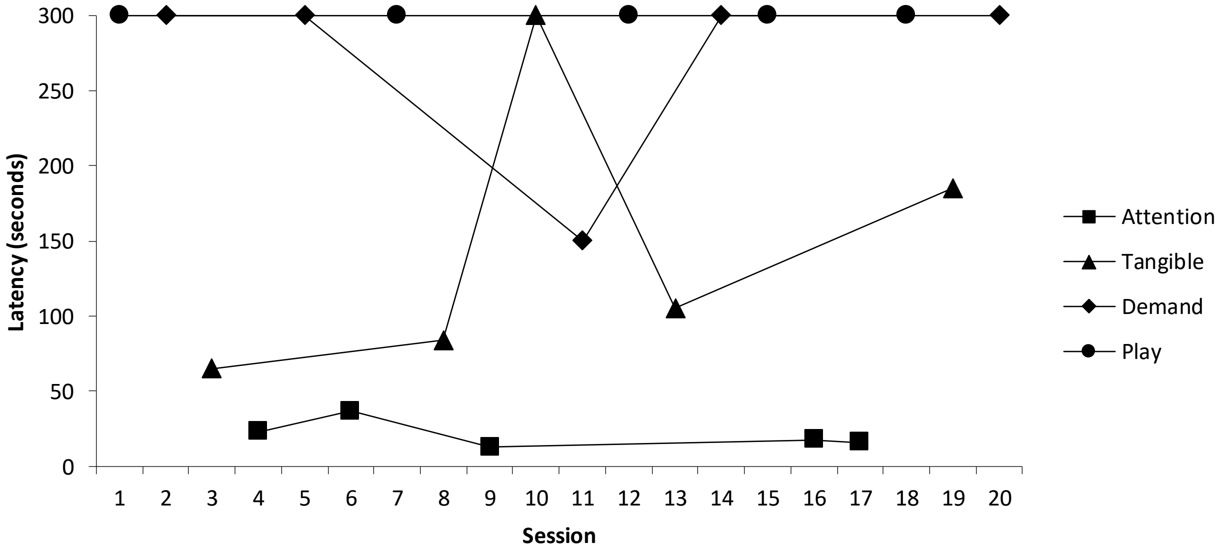
Gary

Descriptive Functional Assessment. The modified FAI (O'Neill et al., 2014) completed with Gary's mother indicated multiple potential functions for Gary's aggressive behaviours, including access to attention, tangibles, or escape from demands. Gary's mother was able to successfully record instances of the behaviour on video and complete the FAOF (O'Neill et al., 2014). Both Gary's mother's and the researcher's FAOF findings indicated clear tangible and attention functions, though with some minor disagreement about the number of instances indicating these functions. None of the instances identified an automatic reinforcement function (although this is not unexpected as the videos were recorded in contexts when other people were present and interacting with Gary), and no consistent escape function was identified. As a result, the FAOF partially confirmed findings from the FAI of possible multiple functions for Gary's behaviour.

Experimental Functional Analysis. Gary's EFA was completed by his mother at home, with coaching from the researcher as described above. The results of Gary's analysis can be seen in Figure 11 below.

Figure 11

Results of Gary's Experimental Functional Analysis



An additional session of each condition type was conducted to confirm hypotheses due to the extraneous results for sessions 10 (tangible) and 11 (demand), both of which had been conducted in the same appointment. Gary's analysis suggested both an attention and tangible function for the target behaviours, with average latencies of 21.40 (range = 13-37 seconds) and 147.80 (range = 65-300 seconds) seconds respectively. The target behaviour never occurred during play conditions and occurred in only one demand condition with a latency of 150 seconds. Due to the shorter latencies in the attention condition this function was selected to be targeted during FCT. However, Gary's mother also reported that situations in which tangible items are unavailable were particularly problematic at home. Gary's highly preferred tangible items were a football which he exclusively played with alongside another person, or an iPad which he required support to operate. This meant that the tangible condition also involved a degree of attention delivery during the EFA. As a result, both attention and tangible functions were targeted during teaching trials in which both reinforcers were removed, and Gary was prompted to sign for both using the modified Makaton sign for "play". The use of synthesised conditions during EFAs and a generalised mand during intervention has recently been demonstrated as an effective approach to assessment and intervention for CB (e.g., Hanley et al., 2014; Jessel et al., 2016; Jessel et al., 2018; Slaton et al., 2017), and was therefore felt appropriate for Gary.

Intervention. Three baseline sessions (see Figure 12 and Figure 13 below) were conducted with Gary in which he never used the targeted communication response and displayed target behaviour with an average latency of 4 seconds, at an increasing rate and on average 0.80 times per minute.

Figure 12

Frequency per Minute of Challenging Behaviour and Independent Targeted Signs During Baseline Sessions for Gary

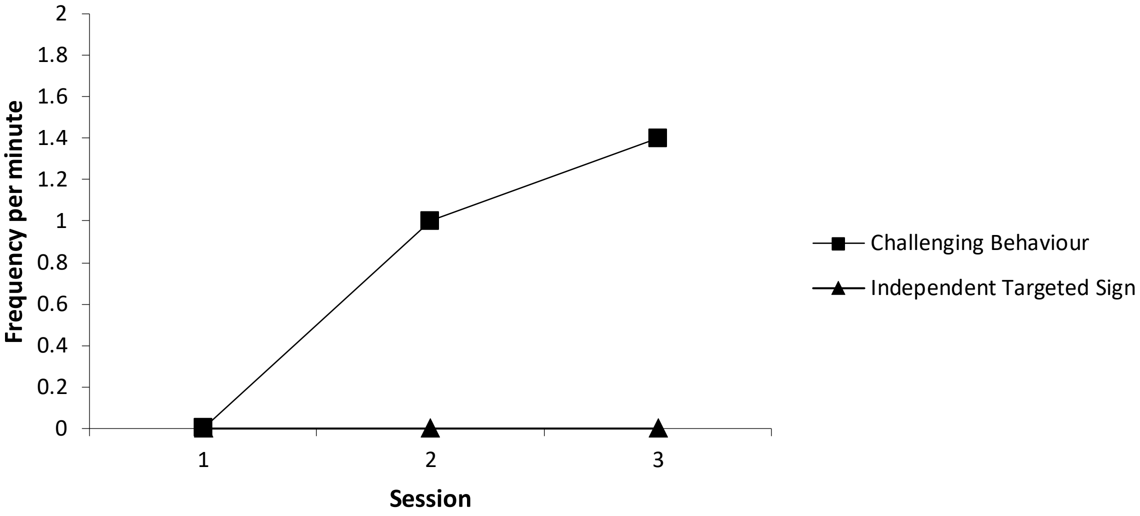
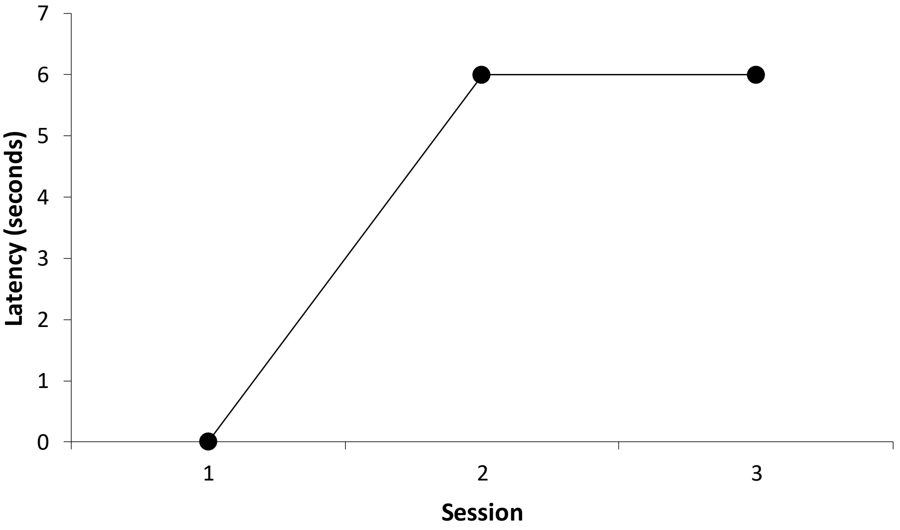


Figure 13

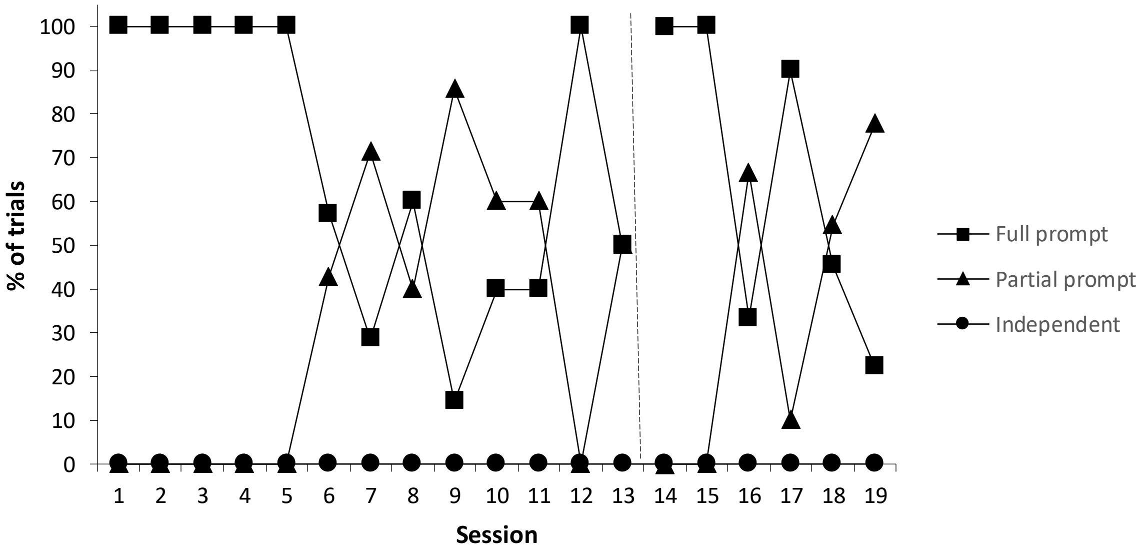
Latency (Seconds) to Challenging Behaviour During Baseline Sessions for Gary



Communication Training. Nineteen teaching trials (see Figure 14 and Figure 15 below) were conducted with Gary by his mother over the course of the available appointments. As noted above, these trials were conducted in the context of both attention and tangible reinforcement, which was delivered contingent on the targeted mand (the modified Makaton sign for 'play'). Following removal of the reinforcers, Gary was physically prompted to complete the sign, with prompting faded using most to least prompting. No consensus exists in the literature about the relative effectiveness of most to least or least to most prompting (Libby et al., 2008), and therefore most to least prompting was selected to minimise the possibility for erroneous responses. However, significant difficulties were encountered in fading the prompts for Gary as he would only perform the beginning of the response (i.e., raising his hands) independently and required prompts to complete the response. As a result, prompting procedures were restarted during session fourteen (indicated by a dashed line in Figure 14 and Figure 15) in order to ensure that the entire response was prompted and that there was no gap in the response. This was implemented in the final available appointment with Gary, however progress was still highly variable. As all available one-hour appointments had been completed it was necessary to withdraw Gary from the study at this point.

Figure 14

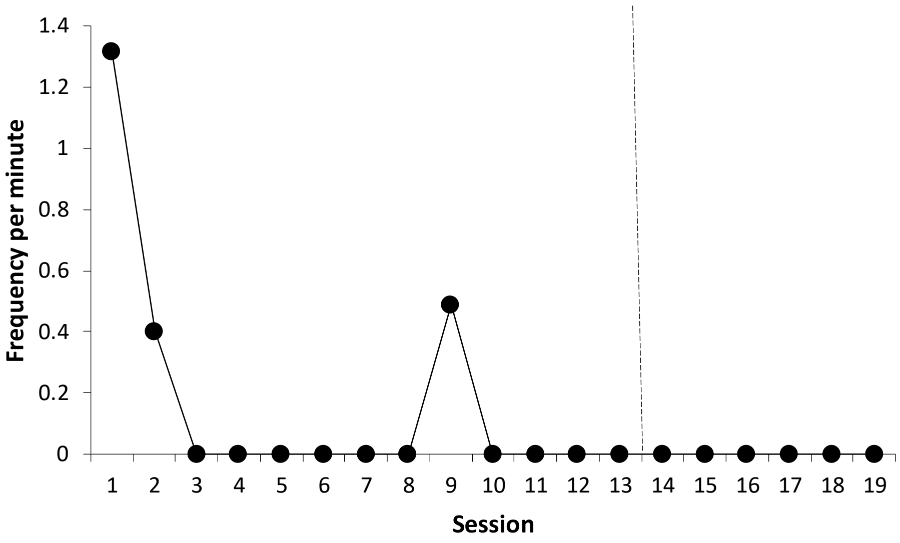
Percentage of Trials with Each Prompt Type per Teaching Session for Gary



Dashed line indicates restarting of prompt fading procedure.

Figure 15

Frequency per Minute of Challenging Behaviour During Teaching Sessions for Gary

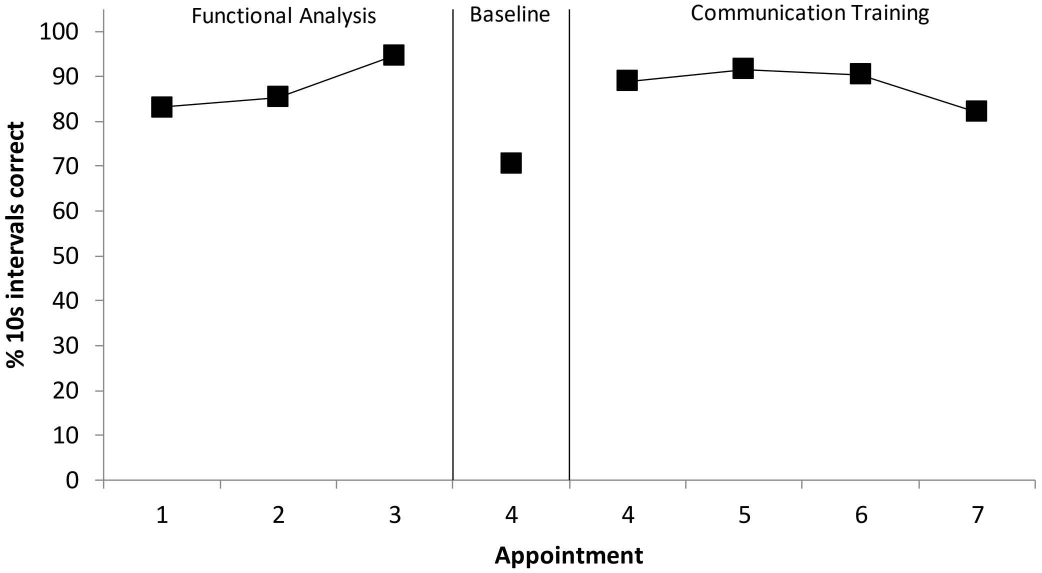


Dashed line indicates restarting of prompt fading procedure.

Fidelity. Figure 16 displays fidelity data for all procedures for Gary. As noted above, fidelity data were graphed as percentage of 10-second intervals correct per session type per appointment, meaning that appointment four is represented twice in Figure 16 as it involved two session types. Across all appointments, fidelity was above 80% (mean = 84.74, range = 70.48-94.74) with the exception of the baseline sessions.

Figure 16

Fidelity of Family Carer Implemented Procedures for Gary



A more detailed breakdown of these fidelity results can be seen in Table 9 below. Whilst Gary's mother implemented the majority of procedures with greater than 80% fidelity, she implemented demand conditions of the EFA with less fidelity, achieving only 68.37% on average (range = 55.26-87.18) across demand sessions. This is perhaps not unexpected given that the demand condition of an EFA involves the most steps due to the inclusion of a prompting hierarchy.

Table 9

Breakdown of Fidelity per Session Type for Gary

Session type	No. of sessions	Mean % of 10s intervals correct	Range % of 10s intervals correct
EFA overall	19	87.19	55.26-100
Play condition	5	99.62	98.08-100
Demand condition	5	68.37	55.26-87.18
Tangible condition	4[a]	100	-

Session type	**No. of sessions**	**Mean % of 10s intervals correct**	**Range % of 10s intervals correct**
Attention condition	5	83.33	75-100
Baseline	3	70.48	40-100
Teaching	19	88.25	70.91-100

Note. [a] Fidelity data were unavailable for one tangible session due to a camera failure.

Interim Discussion – Gary. As with Billy, it was possible during the study to complete a full FA with Gary. Gary's mother was trained in the assessment techniques and implemented these with high fidelity, resulting in differentiated outcomes that facilitated the design of an FCT intervention. However, the communication training sessions were unsuccessful within the timeframe allowed for the study and it was therefore necessary to withdraw Gary from the study prior to the final stages of the FCT intervention being implemented. There are several reasons that this may have been the case for Gary. Firstly, difficulty was encountered in fading the physical prompts used to teach Gary to use the targeted mand. Whilst Gary's mother generally implemented the teaching sessions with high fidelity, some sessions were less accurately implemented than others and this may have influenced the fading procedure. A structured procedure was used for fading but at times it was difficult for the researcher to coach the family carer in this as it was not possible to tell whether Gary was beginning to complete any of the response independently, and the researcher relied on his mother reporting this. It is therefore possible that the coaching provided to Gary's mother was not sensitive to Gary's performance which may have influenced the fading procedures. More research is needed to identify effective training and coaching methods for physical prompt fading.

In addition, Gary was anecdotally observed to become satiated with the available reinforcers during the sessions and the motivating operation for access to these may not have been strong enough to evoke independent mands. The sessions necessitated a degree of attention when prompting the mand and it is therefore possible that he became satiated with this quickly. Attempts were made to overcome this with differential reinforcement (through the provision of presumed higher quality attention following the mand) and ensuring that minimal attention was provided during the prompting itself, however these strategies appeared to be unsuccessful. It is possible that using another person to teach the response may have proved more successful as it would minimise the extraneous attention provided by his mother during the sessions. An alternative approach could have utilised more frequent and shorter appointments to minimise potential satiation, however this was not possible within the ethical approval granted to the study. Finally, as with Billy, scheduling sessions regularly was difficult for Gary's family and there were often long breaks between sessions during the study. This may have similarly influenced outcomes and is discussed further below.

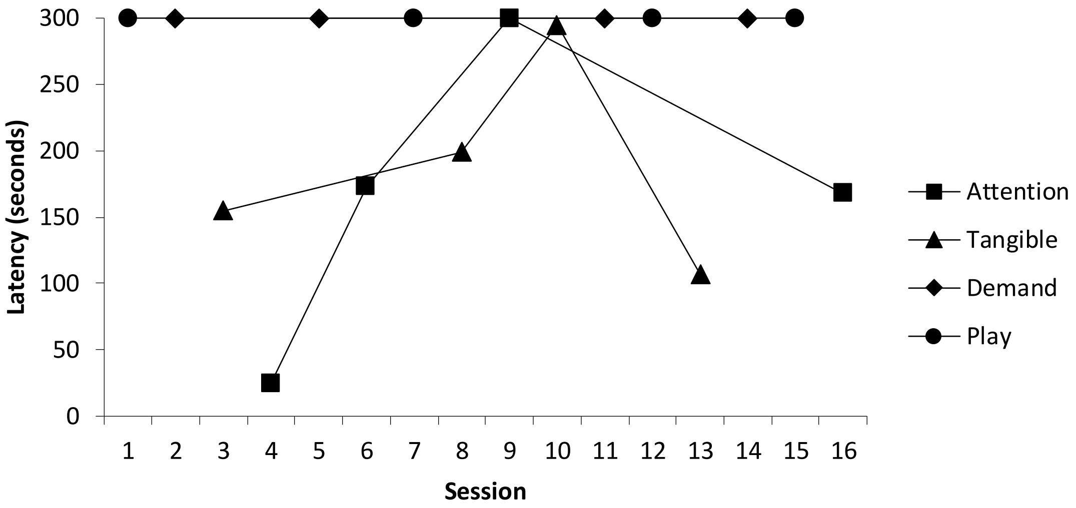
Jack

Descriptive Functional Assessment. The modified FAI (O'Neill et al., 2014) was completed with Jack's mother and identified possible attention, tangible and escape functions for his aggressive behaviours. Jack's mother attempted two structured observations (using the FAOF: O'Neill et al., 2014) however on these occasions the target behaviours did not occur. Despite this, as the FAI had identified clear potential functions for Jack's behaviour it was possible to test these in the EFA without confirming these hypotheses via direct observation.

Experimental Functional Analysis. Jack's EFA was completed by his mother at home, with coaching from the researcher as described above. The results of Jack's analysis can be seen in Figure 17 below.

Figure 17

Results of Jack's Experimental Functional Analysis



The target behaviours never occurred during the demand or play sessions. They occurred at similar average latencies during the attention (mean = 166.50 seconds, range = 25-300 seconds) and tangible (mean = 189 seconds, range = 107-295 seconds) sessions. As a result, the EFA suggested both a tangible and attention function for Jack's behaviour. Jack's mother reported that she would prefer to focus on the tangible function and therefore the subsequent FCT intervention was designed for a tangible function.

Intervention. Baseline sessions were attempted with Jack at his home, within the same context as the tangible session of the EFA. However, only one instance of the target behaviour was observed during these sessions. Jack's mother suggested using an alternative location as Jack was observed to engage in other non-target behaviours at home (e.g., jumping on the sofa, rubbing a fur rug) that appeared to be automatically reinforced and may therefore have been competing with the motivating operation to access tangible items. It was not possible to use an alternative room at home, therefore sessions were relocated to a CDC. Despite this, no target behaviours were observed during sessions at the CDC. This result was somewhat unexpected for Jack given that the initial EFA sessions had been conducted at home and had evoked behaviour during tangible conditions. Possible explanations for this finding are described in the interim discussion below. Due to the study's ethical approval it was not possible to undertake additional baseline sessions and it was therefore necessary to withdraw Jack from the study at this point.

Fidelity. Figure 18 displays the percentage of 10-second intervals correct per session type per appointment for Jack. Fidelity was above 80% for all appointments (mean = 89.74, range = 81.03-100).

Figure 18

Fidelity of Family Carer Implemented Procedures for Jack

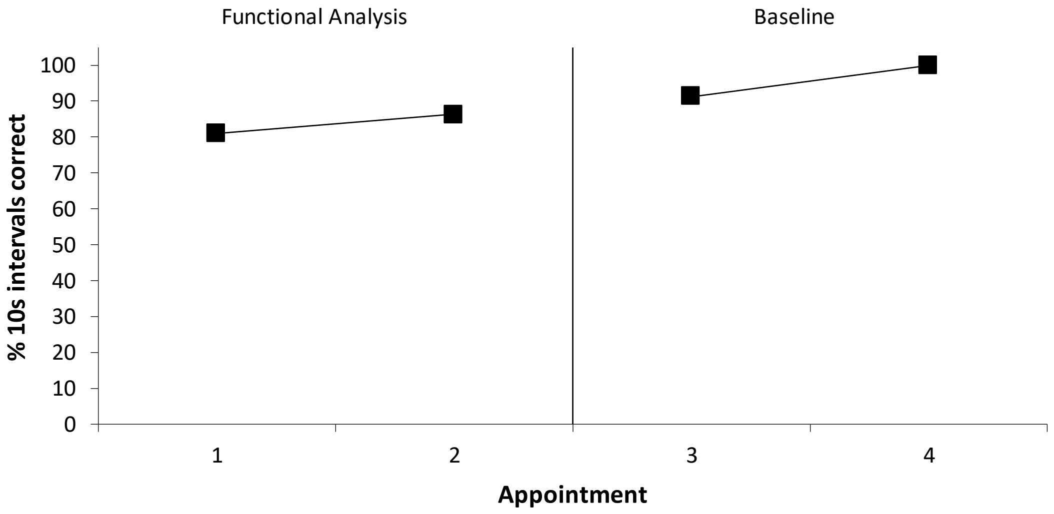


Table 10 displays a breakdown of fidelity data per procedure for Jack's mother. Similar to Gary's mother, Jack's mother achieved high fidelity for all session types with the exception of the demand condition of the EFA for which average fidelity was 70.23% (range = 65.28-73.13).

Table 10

Breakdown of Fidelity Data per Session Type for Jack

Session type	No. sessions	Mean % of 10s intervals correct	Range % of 10s intervals correct
EFA overall	16	89.78	65.28-100

Play condition	4	98.68	93.18-100
Demand condition	4	70.23	65.28-73.13
Tangible condition	4	97.83	94.44-100
Attention condition	4	94.40	80-100
Baseline	4	93.55	74.19-100

Interim Discussion – Jack. Similar to Billy and Gary, it was possible to complete a full FA with Jack and use the results of this to design an FCT intervention. Jack's mother was trained in assessment procedures and implemented these with a high degree of fidelity. However, despite differentiated EFA outcomes, no target behaviours were observed during baseline sessions. These sessions used the same procedure and context as the EFA session linked to the identified function of Jack's behaviour, therefore it is unclear why the targeted behaviours did not occur during these sessions. As with other participants, scheduling difficulties meant that sessions were not completed at regular intervals with Jack and it is therefore possible that, in the interim, the topography and / or function of Jack's CB changed. His mother anecdotally reported that the topography and context surrounding the behaviour had altered and that her main concern was now related to instances of elopement when in the community. This suggests that the original targeted behaviours (i.e., aggression) had ameliorated.

There are several possible reasons for this. Jack's communication had developed significantly since the EFA which may have expanded his repertoire of adaptive skills and replaced CB in the response class. It is therefore possible that the CB reduced as a result of maturation, as noted for other participants above. At the outset of the study, Jack spoke in phrase speech with poor articulation, therefore suggesting that a communication intervention may be useful. However, by the end of the study he was talking in full sentences with clearer pronunciation. Furthermore, during baseline sessions the targeted mand (“I want”) was observed frequently (mean = 3.55 times per minute across sessions, range = 3-4.80 times per minute across sessions) and no CB was observed, supporting the conclusions that his improved communication skills may have contributed to the reduction in CB. It is possible that the target behaviours may still have occurred had baseline sessions been longer, given evidence that resurgence is common if an alternative mand is placed on extinction (Volkert et al., 2009; Wacker, Harding et al., 2013) however the ethical approval for the study did not permit extended baseline sessions and it was therefore not possible to examine this assumption. A final possibility is that other people’s responses (e.g., his mother’s) to Jack’s behaviour may have changed during the study as a result of learning a functional understanding of behaviour, therefore influencing the frequency with which it was displayed. Whilst it is not possible to test this assumption within this study, this represents a potential side effect of the training and is discussed further below. In the absence of the target behaviours during the baseline sessions, and given his mother’s reports that the intervention was no longer needed, it was necessary to withdraw Jack from the study as described above.

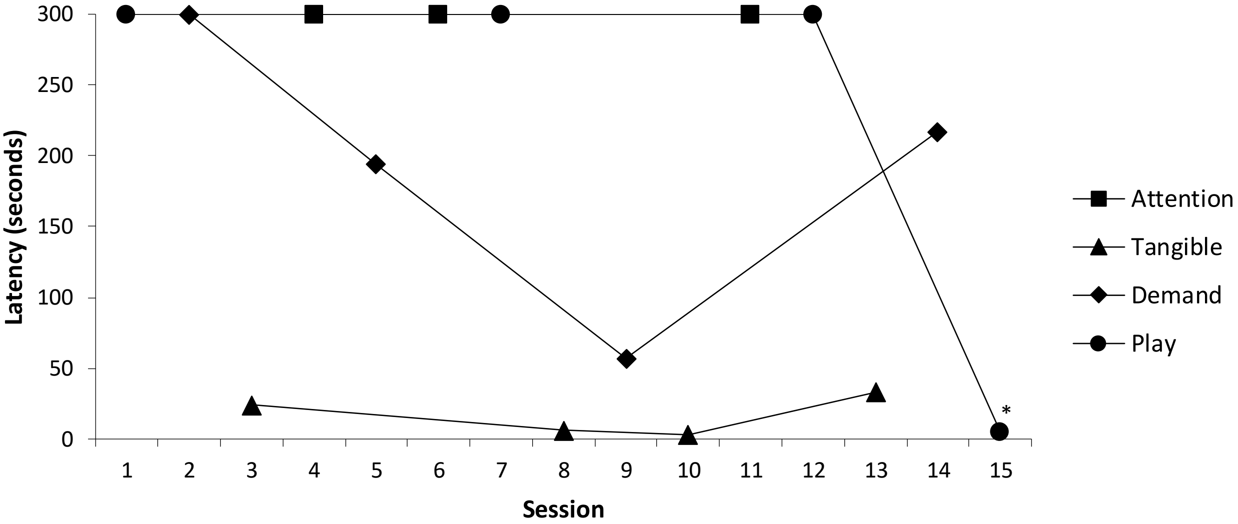
Donna

Descriptive Functional Assessment. The modified FAI (O'Neill et al., 2014) was completed with Donna’s mother and identified possible tangible and escape functions for her self-injurious behaviours. Donna’s mother also completed three brief observations (using the FAOF: O'Neill et al., 2014) which indicated an escape function. The researcher’s completion of the FAOF from the videos also confirmed this and identified an additional potential attention function. However, these videos were very short and often began during the behaviour (limiting analysis of the antecedents) or terminated during the behaviour (limiting analysis of the consequences). As a result, the FAOF results for Donna should be interpreted with caution.

Experimental Functional Analysis. Donna’s EFA was completed by her mother in a clinic setting with coaching from the researcher as described above. The results of Donna’s EFA can be seen in Figure 19 below.

Figure 19

Results of Donna's Experimental Functional Analysis



*Critical fidelity error made (see below).

Only three attention sessions were conducted with Donna due to distress during the appointment. However, no target behaviour occurred in any of these attention sessions. The target behaviours occurred in only one play session with a very short latency of 5 seconds. However, a critical fidelity error occurred during this session, in which Donna's mother interrupted Donna's play immediately prior to the target behaviour occurring, which may have evoked the target behaviour in this instance. During demand and tangible sessions, the target behaviours occurred at average latencies of 192 seconds (range = 57-300 seconds) and 16.50 seconds (range = 3-33 seconds) respectively. As a result, the tangible function was selected as the focus of the FCT intervention.

Intervention. Three baseline sessions were conducted with Donna (see Figure 20 and Figure 21 below) and during these sessions the targeted mand was never observed. The target behaviour occurred at an increasing rate (with an average latency of 20.20 seconds, range = 0-15.50 seconds) and resulted in the early termination of the third baseline session due to safety criteria relating to the frequency of behaviour being met. Despite termination as a result of the safety criteria, Donna did not sustain any injuries during this session and calmed quickly, enabling the appointment to continue as planned with the introduction of the communication training sessions.

Figure 20

Frequency per Minute for Challenging Behaviour and Independent Targeted Signs During Baseline Sessions for Donna

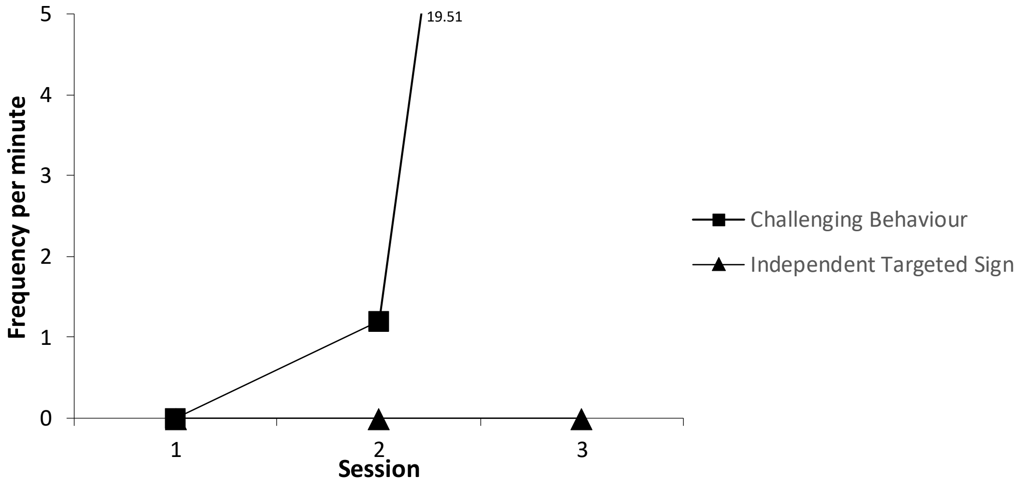
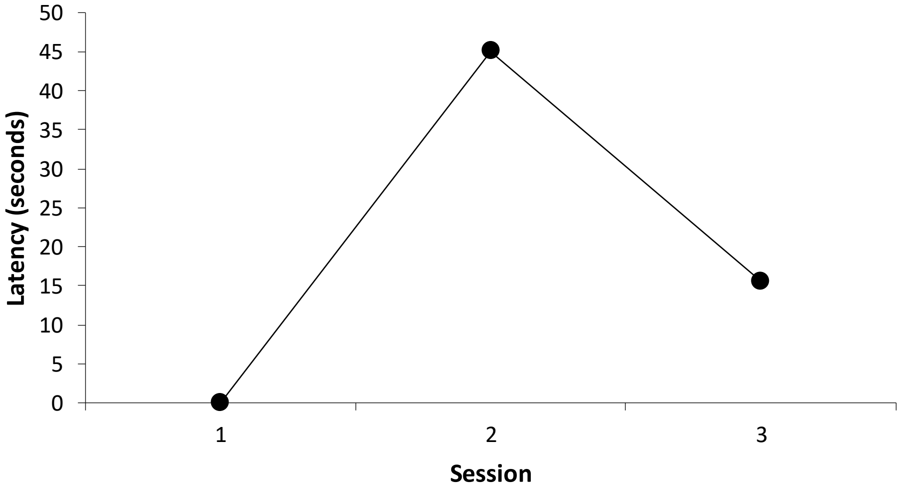


Figure 21

Latency (Seconds) to Challenging Behaviour During Baseline Sessions for Donna



Communication Training. Following baseline sessions, nine communication training sessions were conducted with Donna before her withdrawal from the study (see Figure 22 and Figure 23 below). Prompt fading initially progressed rapidly in the first appointment (sessions one to four), with unprompted mands increasing to 85.70% of responses by session four. However, at the next appointment, Donna required full prompting again and prompt fading was much slower in subsequent sessions. Donna appeared to lose motivation quickly for accessing the items from session five, despite a range of reportedly highly preferred items being used during sessions. As a result, the motivating operation may not have been strong enough to evoke independent mands. The target behaviour also did not occur during these sessions, supporting this conclusion (see Figure 23). Donna's mother reported that this typically occurred with other professional appointments (e.g., speech and language therapy, portage) in that Donna quickly lost interest in the activities conducted during sessions. She expressed concern that the study procedures would not be successful with Donna for this reason and requested that she be withdrawn from the study at this point.

Figure 22

Percentage of Trials with Each Prompt Type During Communication Training Sessions for Donna

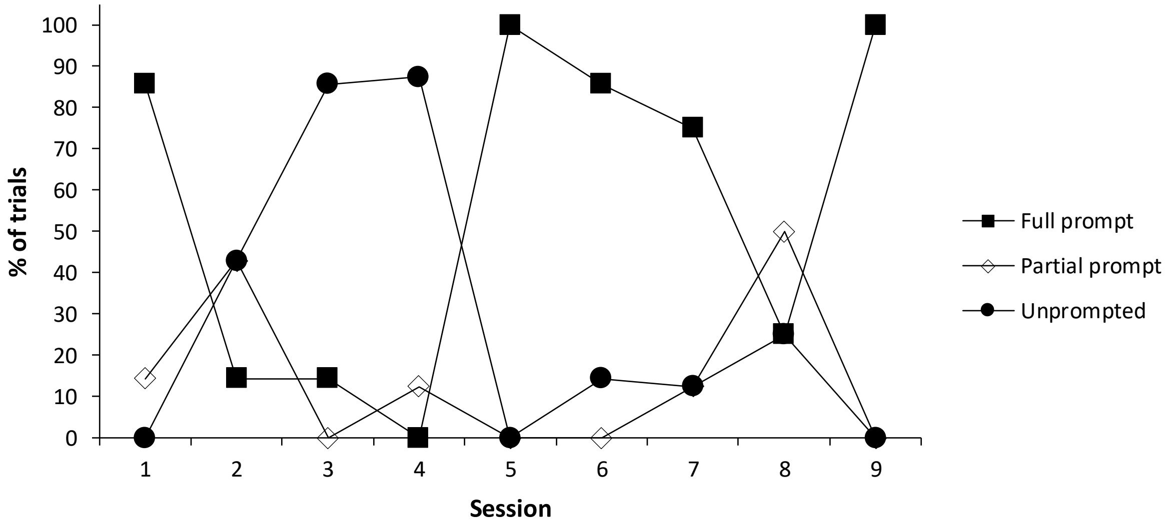
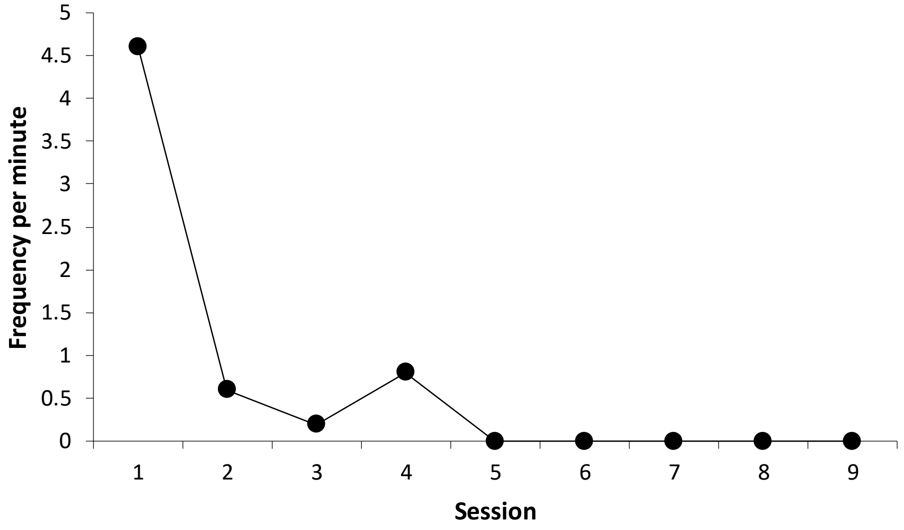


Figure 23

Frequency Per Minute of Challenging Behaviour During Communication Training Sessions for Donna



Fidelity. Figure 24 displays fidelity data for Donna's mother's implementation of procedures for each session type per appointment. As noted above, these data are graphed as the percentage of 10-second intervals correct per session type per appointment meaning that in Figure 24 appointment five is represented twice as it involved two types of session. Fidelity was above 80% on average for all appointments (mean = 89.79, range = 84.62-96.61).

Figure 24

Fidelity of Family Carer Implemented Procedures for Donna

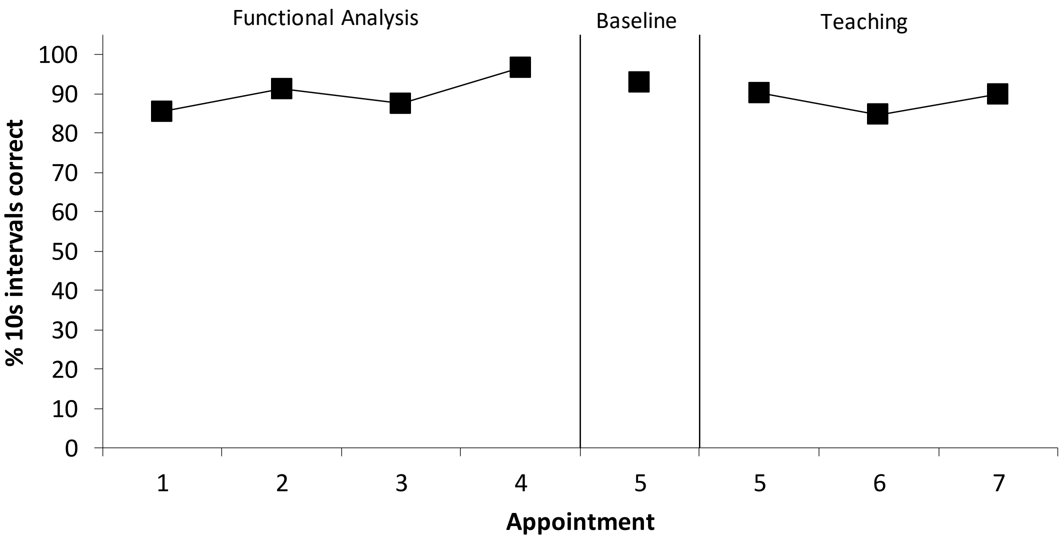


Table 11 displays the breakdown of fidelity data for Donna’s mother. In line with the pattern for other participants, Donna’s mother achieved above 80% average fidelity for all session types with the exception of the demand condition of the EFA in which she achieved 69% fidelity on average (range = 61.11-81).

Table 11

Breakdown of Fidelity Data per Session Type for Donna

Session type	No. of sessions	Mean % of 10s intervals correct	Range % of 10s intervals correct
EFA overall	15	87.06	61.11-100
Play condition	4	99.15	96.61-100
Demand condition	4	69	61.11-81
Tangible condition	4	83.33	66.67-100
Attention condition	3[a]	100	-
Baseline	3	94.81	90.32-100
Teaching	9	89.75	82.22-100

Note. [a] Only three attention sessions were conducted for Donna as described above.

Interim Discussion – Donna. The completed FA for Donna provided clear results and allowed the development of an FCT intervention. As with other participants, Donna’s mother was trained in the assessments and implemented these with high fidelity, supporting the feasibility of the training procedures. However, the communication training sessions for Donna were not successful within the timeframe of the study despite initial promising results in the first session. Several factors may have influenced this. Firstly, the setting for the sessions was changed after the EFA on the request of Donna’s mother. Donna had become resistant to entering the clinic setting in the final EFA appointment and Donna’s mother reported that this was often a typical pattern for Donna in that she would engage in something on a few occasions but would then become noncompliant with all activities. Donna's mother felt that changing the location of the sessions to her home would be more successful. However, given that this represented a significant change from the context in which the EFA had been conducted it is possible that this influenced the effectiveness of the teaching procedures. This conclusion is not well supported with the data, as CB was still observed in the baseline and teaching sessions, however over time it is possible that this influenced outcomes. Furthermore, the pattern previously described for Donna was also observed during the teaching sessions in that although she initially engaged well with the sessions, over time she become resistant to this which manifested as satiation with reinforcers that would usually be very highly preferred (e.g., the iPad), and requests to go to school instead. It also appeared that the required change to her routine as a result of the sessions (i.e., the delay in going to school) was particularly problematic and influenced Donna's willingness to engage in the sessions. Donna's mother felt that it would not be possible to overcome this in the current study and therefore requested that she be withdrawn.

It is possible that alternative procedures may have been more effective for Donna. For example, sessions conducted in more natural contexts which do not necessitate a change to routine, and shorter sessions (rather than blocks of sessions) may have ameliorated issues relating to lack of engagement in sessions and distress due to a disrupted routine. Anecdotally this conclusion is supported as Donna's mother reported that she had used DRA in other less contrived settings (e.g., during dinner times) which had been more successful. However, the study's ethical approval did not allow for procedures to be conducted in this way and Donna's mother had asked for her withdrawal from the study, therefore she was withdrawn at this point as described above.

Questionnaire Measures

Table 12 below displays questionnaire scores for all participants. Given that participants were withdrawn at different points in the study, these results are difficult to robustly interpret (as discussed below) but provide an indication of change in outcomes targeted by the study.

Family Carer Measures

Across the course of the study participants' total scores and subscale scores on the PTC (Sanders, M. R. & Woolley, 2001; Sanders, M. R. & Woolley, 2005) increased on average and participants' individual scores increased in all cases, with the exception of Gary's PTC setting score which decreased slightly. This suggests that after the study participants felt more confident in undertaking various activities with their child. It is possible that this was a result of the training provided which may have changed family carers' perceptions of their child's behaviour more generally by providing an overview of the functional nature of challenging behaviour. This conclusion is partially supported by the corresponding decrease in management difficulty as rated on the CBC (Harris et al., 1994), although it is difficult to definitively draw this conclusion without additional data. However, for all participants (with the exception of Donna), total and subscale scores on the FQOLS (Hoffman et al., 2006; Park et al., 2003) decreased during the course of the study suggesting reduced family quality of life after completion of the study. The reasons for this finding are unclear. However, in comparison to the PTC data, the FQOLS covers a wider range of areas and this finding may therefore reflect outcomes less likely to change as part of the support provided during the study (e.g., economic stability, emotional and service support).

Although participants were withdrawn before completion of the final stage of the intervention, they rated the study procedures highly on the TARF-R (Reimers & Wacker, 1988), suggesting they were satisfied with the study procedures and training. Anecdotally participants commented that they had found the training useful and would continue to use the procedures in future. Donna's mother also reported that she had used the procedures in other settings and with other target behaviours (e.g., at the dinner table when Donna typically displayed aggression) which had proven successful in reducing instances of aggression and increasing Donna's use of communication in this setting. Taken together, these results suggest a potential improvement in family carer quality of life although as noted above this is not reflected in FQOLS scores.

Child Measures

Scores on the CBC (Harris et al., 1994) decreased on average between pre and post data collection suggesting that children displayed fewer, less frequent, and less severe behaviours at the point of withdrawal from the study. It is important to note however that this likely reflects maturation (rather than an effect of the study) due to all participants being withdrawn before completion of the final intervention sessions. Participants’ scores on Section G of the FAI (O'Neill et al., 2014) increased slightly across time points, suggesting the development of more advanced communication methods for all participants. However, this is again likely to represent maturation (particularly given the young age of the children and their continued engagement in schooling) rather than an effect of the study.

Table 12

Pre and Post Questionnaire Scores for all Participants

		Billy[a]		**Millie[a]**		**Gary[b]**		**Jack[b]**		**Donna[b]**		**Mean (SD)**	
	Measure	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**
PTC	**Total Score (%)**	**167**	**-**	**110**	**-**	**115**	**128**	**122**	**135**	**137**	**197**	**130.20**	**153.33**
		(69.58)		**(45.83)**		**(47.91)**	**(53.33)**	**(50.83)**	**(56.25)**	**(57.08)**	**(82.08)**	**(22.95)**	**(37.98)**
	Setting (%)	94	-	85	-	78	75	70	71	64	101	78.20	82.33
		(67.14)		(60.71)		(55.71)	(53.57)	(50)	(50.71)	(45.71)	(72.14)	(11.88)	(16.29)
	Behavioural (%)	73	-	25	-	37	53	52	64	73	96	52	71
		(73)		(25)		(37)	(53)	(52)	(64)	(73)	(96)	(21.42)	(22.34)
FQOLS	**Total Score (%)**	**88**	**-**	**122**	**-**	**98**	**65**	**100**	**94**	**101**	**108**	**101.80**	**89**
		(70.40)		**(97.60)**		**(78.40)**	**(52)**	**(80)**	**(75.20)**	**(80.80)**	**(86.40)**	**(12.42)**	**(21.93)**
	Family interaction (%)	20	-	29	-	25	15	28	24	26	30	25.00	23
		(66.66)		(96.67)		(83.33)	(50)	(93.33)	(80)	(86.66)	(100)	(3.51)	(7.55)
	Parenting (%)	20	-	29	-	21	18	26	25	24	26	24.00	23
		(66.66)		(96.67)		(70)	(60)	(86.66)	(83.33)	(80)	(86.66)	(3.67)	(4.36)

		Billy[a]		Millie[a]		Gary[b]		Jack[b]		Donna[b]		Mean (SD)	
	Measure	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**
	Emotional wellbeing (%)	10 (50)	-	19 (95)	-	16 (80)	6 (30)	5 (25)	7 (35)	8 (40)	9 (45)	11.60 (5.77)	7.33 (1.53)
	Physical / material wellbeing (%)	21 (84)	-	25 (100)	-	18 (72)	15 (60)	25 (100)	25 (100)	25 (100)	25 (100)	22.80 (3.19)	21.67 (5.77)
	Disability related support (%)	17 (85)	-	20 (100)	-	18 (90)	11 (55)	16 (80)	13 (65)	18 (90)	18 (90)	17.80 (1.48)	14 (3.61)
CBC	**No. of behaviours**	9	-	11	-	10	9	15	10	16	10	11.67 (2.97)	9 (1.50)
	Mean frequency[c]	3.55	-	4.18	-	4.60	3.66	4.30	3	4.43	3.40	4.22 (0.40)	3.35 (0.33)

		Billy[a]		**Millie**[a]		**Gary**[b]		**Jack**[b]		**Donna**[b]		**Mean (SD)**	
	Measure	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**
	Mean management difficulty[c]	1.22	-	2.63	-	3	2.77	3.20	1.60	3	2.30	2.61 (0.80)	2.22 (0.59)
	Mean severity[c]	1.50	-	2.09	-	3	2.66	2.07	1.86	2.85	1.20	2.30 (0.62)	1.90 (0.73)
FAI (G)	**Mean highest score across function**[d]	15.25	-	15.00	-	13	14.38	18	19	14.88	14.88	15.23 (1.79)	16.08 (2.53)
TARF-R	**Total Score (%)**	**-**		**-**		**121 (86.42)**		**129 (92.14)**		**119 (85)**		**123 (5.29)**	

Note. **PTC** = Parenting Task Checklist, **FQOLS** = Family Quality of Life Scale, **CCB** = Challenging Behaviour Checklist, **FAI (G)** = FAI Section G **TARF-R** = Treatment Acceptability Rating Form-Revised. [a] Post measures & TARF-R unavailable. [b] Post measures & TARF-R completed at withdrawal point (i.e., after teaching trials for Gary & Donna, after baseline attempts for Jack). [c] Out of a maximum of 5. [d] Out of a maximum of 18.

General Discussion

This study aimed to examine the feasibility of a range of factors relating to the use of FBIs in the UK and training family carers in these procedures. Results suggest that it was feasible to train a small number of family carers to implement FA procedures with acceptable fidelity, design an FCT intervention in conjunction with these family carers, and train them to complete initial intervention sessions. However, feasibility questions relating to recruitment and retention were not completely met. There are several possible explanations for the low recruitment levels in this study. Firstly, the study procedures were extensive and likely to be unfamiliar to families given the lack of behavioural provision in the UK, which may have limited willingness to take part. As a result of the complexity of the study, the information sheet was also extensive (see Appendix J) and may have been a barrier to participation for some. The study itself involved several procedures over a six-month period, which may have been too high a response cost for families. It is therefore possible that these factors inhibited involvement for some families. Secondly, recruitment efforts were, in most cases, reliant on support from other professionals and the researcher was unable to contact potential participants directly. Whilst this was necessary due to ethical considerations and the composition of services in the UK, it may have presented a barrier to participation for some families who had no prior experience with the researcher. Although efforts were made to ensure potential participants could easily contact the researcher to ask questions, this still required effort on the part of the participant and therefore may have prevented some potential participants from enrolling. In addition, whilst repeated contact was made with professionals involved in supporting recruitment, recruitment was reliant on professionals identifying potential participants who met inclusion criteria and sending these individuals information packs and follow up letters. Given professional workloads it is possible that information was not circulated as frequently or as extensively as intended.

These difficulties are consistent with research suggesting that indirect methods of recruitment such as email, telephone or post are not the most effective for recruitment of families of children with IDD (Adams et al., 2017). However, the most effective method identified by Adams et al. (2017) (i.e., face to face recruitment) was not feasible for this study given that eligible participants who display CB are unlikely to attend clinics (which are often not CB specific) in high enough numbers to justify researcher presence in waiting rooms, and the extensive time commitment required. Finally, it is possible that the procedures being part of a research project and conducted by a researcher from a University rather than a clinician was a barrier for some families. Had such support been provided in routine clinical settings it is possible that this would have been more acceptable to families although there is no known research examining this. As noted above, much of the research concerning these behavioural approaches is conducted in the USA within hospital or clinic services, where it may be easier to encourage participation. As a result, it can be concluded that whilst it was feasible to recruit a small number of participants to this type of research, recruitment for studies such as this may require extensive efforts. Furthermore, the methods utilised in this study were not as effective as anticipated therefore alternative methods should be investigated.

Whilst feasibility was not fully confirmed for all questions, these findings are promising and provide emergent evidence for the effectiveness of training family carers and the importance of involving family carers in all procedures. This supports research from the USA suggesting that training family carers in FA techniques is an effective approach (e.g., Derby et al., 1997; Fettig et al., 2015; Harding, Wacker, Berg, Lee et al., 2009; Marcus, Swanson et al., 2001; Wacker et al., 2005) and mirrors findings relating to the use of similar training techniques for EFAs with a range of stakeholders (e.g., teachers, Moore et al., 2002; care staff, Phillips et al., 2001). Furthermore, this may suggest that these FA and training procedures translate well into a UK context utilising both home and clinic settings. This is an important finding as available input from professionals in the UK is often limited, and training family carers in FA procedures may ensure that less professional time is used at the assessment stage, allowing time to be reserved for intervention procedures. However, the current study did not test the feasibility of family carers implementing procedures without researcher coaching during sessions, therefore the fidelity with which family carers may have implemented procedures independently is unknown. Furthermore, whilst it was possible to complete a FA for each participant in this study and achieve differentiated outcomes, some of the assessment procedures were found to be more successful than others. Specifically, family carers implemented the EFAs with acceptable average fidelity. However, observation procedures were successful for only 20% of participants, and with some limitations (e.g., the duration and context of videos for Donna). In order to keep study procedures brief in line with the study aims, only one observation session lasting 30 minutes was planned for each participant and it may therefore have been difficult to capture the target behaviours on video during such a limited timeframe. Furthermore, family carers often recorded only the target behaviours (i.e., not the context prior to the behaviours) and terminated recording before a full 30 minutes had elapsed (i.e., limiting analyses of consequences), suggesting some inconsistencies in their understanding of the purpose of the observation procedures. This reflects potential limitations in the scope of the family carer training package utilised during the study and the procedures selected for the observation. Despite these difficulties, differentiated outcomes were obtained for nearly all participants after the full FA process, with one or more functions identified in each case, enabling the design of an FCT based intervention.

Whilst the assessment procedures were completed successfully for nearly all participants, the communication training procedures were unsuccessful for all participants and none of the participants progressed to the final FCT intervention phase. This finding was somewhat unexpected given evidence from the USA of the utility of training family carers in FCT procedures (e.g., Derby et al., 1997; Fettig et al., 2015; Harding, Wacker, Berg, Lee et al., 2009; Marcus, Swanson et al., 2001; Moes & Frea, 2002; Robertson et al., 2013; Wacker et al., 2005). However, data relating to teaching the communication response is rarely reported in FCT literature and it is therefore possible that the difficulties encountered in this study (which were all at the communication training stage) were unrelated to family carers' ability to implement FCT intervention procedures, but were instead related to difficulties in training families to teach or strengthen mands within the context of FCT.

However, the data suggests that family carers did implement communication training procedures with acceptable fidelity, and therefore a number of other general and individual factors may account for the lack of success in the communication training procedures. Individual factors are discussed for each participant above and include issues identifying reinforcers or reinforcer satiation (Billy, Gary, Donna), restricted or repetitive behaviours (Billy, Donna), and prompt fading difficulties (Billy, Gary). These difficulties are rarely reported in the literature but are likely to be common difficulties encountered in clinical settings. It is possible that pragmatic issues such as word limits within journal articles prevent researchers from reporting such difficulties. Alternatively, it is possible that, as in this study, these difficulties often result in intervention approaches being ineffective and that publication bias (as demonstrated in ABA research, e.g., Sham & Smith, 2014; Tincani & Travers, 2019) subsequently prevents the publication of these interventions. Nevertheless, the lack of discussion of these issues in the literature is problematic and represents an area for further research. In addition, several broader factors relating to the study itself may also have accounted for this finding or exacerbated the individual factors identified. Firstly, due to the context of the study as research it was necessary to obtain extensive ethical approval which therefore resulted in procedures being fixed and, in some cases, not responsive to participant need. Where procedures such as this are undertaken within clinical contexts it is often possible to modify procedures more extensively which may have been beneficial to the participants in this study (e.g., conducting longer baseline sessions for Jack, implementing shorter teaching sessions for Gary, integrating teaching sessions into naturalistic contexts for Donna) and can ensure that procedures are individualised. However, in this study the procedures needed to be detailed from the outset and were not able to be substantially modified without seeking further approvals from the ethics committee which can often take weeks or months to be granted. It is not known to what extent interventions reported in the literature are modified for individual participants and it is unclear whether similar issues are encountered by other researchers where ethical approval procedures may differ (e.g., in the USA). Where possible the research team attempted to pre-empt potential difficulties based on their knowledge and experience of completing clinical work with families, in order to build flexibility into the ethics committee application. However, the extent of flexibility able to be incorporated was limited and it was also difficult to anticipate the level and type of flexibility needed since these details are rarely reported in the literature as noted above. Had a greater level of flexibility been possible, it is likely that the communication training phase would have been successful for at least some of the participants included in this study.

Secondly, scheduling of appointments proved difficult for all participants and contributed to one participant's withdrawal from the study. In some cases, this was due to natural circumstances (e.g., illness, family holidays) but in other cases related to extenuating circumstances experienced by the family which required the researcher to pause the research study and protect the family's emotional wellbeing rather than prioritising experimental need. The presence of extenuating circumstances within this study supports arguments in Chapter One about the importance of considering these factors in clinical support given that many families of children with IDD often experience such difficulties. These difficulties are also likely to be experienced in clinical practice but may be less problematic within this context as additional catch up or booster sessions could be arranged given the greater flexibility in procedures. Whilst it may have been possible to require more regular appointments with families during the study, it is possible that this would have resulted in some families feeling the need to withdraw from the study and this was not felt appropriate given the extensive difficulties in recruiting participants as described above. The research context itself may have contributed to lack of regular engagement with families if the work was perceived to be more flexible and less official than clinical appointments. Whilst the researcher held a research contract with the local NHS trust they would not have been perceived as a clinician or part of the clinical team. Again, these difficulties are not routinely reported in the literature and were therefore difficult to anticipate.

These scheduling difficulties often meant that large gaps were needed between appointments, exacerbating the possibility of participant maturation influencing outcomes which was particularly evident for Billy and Jack. Anecdotally, participants in this study did report that the topography and / or perceived function of their child's behaviour had changed over the course of the study. Given this finding, further research is needed to consider whether CB topography and function remains stable in young children, or changes based on key variables (e.g., at key transitions such as entering school, key developmental periods etc.). A more extensive training programme involving teachers and other family carers may have overcome these limitations by enabling work to continue outside of sessions with the researcher and therefore facilitating more regular sessions. However, this was outside the scope of this study and represents an area for future research. Despite these difficulties, it was possible during the study to design an FCT intervention for each participant and to complete family carer training procedures relating to this. This provides some suggestion of the feasibility of implementing the training procedures although it is not possible to conclude that families would achieve high fidelity when implementing the final intervention procedures as it was not possible to test this in situ.

Taken together, the results of this study support the emergent feasibility of: training families in FA techniques; completing EFAs within defined timescales and achieving differentiated outcomes; designing an FBI in conjunction with family carers; and completing training for families in intervention procedures. These procedures were also rated highly by participants on the TARF-R (Reimers & Wacker, 1988) despite the relative lack of success at the intervention stage, suggesting that the training and assessment techniques were acceptable to families. In particular, items on the TARF-R focusing on the time required for the approaches were also rated highly, suggesting that participants felt the time required was proportionate to potential outcomes. It should be noted, however, that whilst participants found the time required acceptable and the study procedures were completed within anticipated timeframes, the time required for the researcher was typically far greater than the appointments themselves. It is estimated that around five hours of preparation (e.g., preparing individualised materials, data collection sheets) and follow up work (e.g., collecting data from video recordings on fidelity, synthesising assessment results, collaborating with other professionals in the design of the intervention) was required for each hour of participant contact, suggesting that professional time may be impacted negatively by the indirect work required when training families in FA and intervention techniques. Further research is needed to examine professional time requirements when training family carers in procedures within clinical contexts, as compared to clinician led work. Some of these time burdens could be limited in clinical practice and related to the nature of the study as research (e.g., extensive family carer fidelity data coding) although most are still likely to be needed in clinical contexts (e.g., preparing individualised materials, synthesising assessment results).

Limitations and Directions for Future Research

Whilst this study achieved promising results in relation to the feasibility of training families (particularly for FA procedures), some limitations should be considered when interpreting results. Firstly, none of the EFAs included alone conditions due to the lack of evidence of an automatic reinforcement function for any participant during the descriptive FA. As a result, it is not possible to completely eliminate the potential that some participants' behaviour may have been at least partly maintained by automatic reinforcement. This is less likely for Billy, Jack and Gary for whom the targeted response class was aggression which is known to be less likely to be maintained by automatic reinforcement (Beavers et al., 2013; Emerson & Bromley, 1995), but may have been the case for Donna who displayed self-injury. Secondly, the EFAs utilised single function conditions, rather than synthesised conditions as in recent research (Hanley et al., 2014; Jessel et al., 2016; Jessel et al., 2018; Jessel et al., 2019; Slaton et al., 2017), which is an important consideration given that all participants' behaviour was found to be multiply controlled. It is therefore possible that, had individualised synthesised contingencies been utilised combining potential sources of reinforcement for each participant, clearer outcomes would have been achieved, resulting in the design of more successful communication training and intervention procedures. Research on synthesised conditions is currently emerging and little is known about the relative clinical utility of synthesised contingencies when compared with single function analyses. To date, only one study (Slaton et al.,

2017) has compared interventions based on these analysis formats, finding equal or increased intervention effectiveness for interventions based on synthesised contingencies rather than single function analyses. However, other researchers (Fisher et al., 2016) have questioned the validity of synthesised analyses and argue that information gained from synthesised analyses has limited additional clinical utility over standard EFAs. The relative lack of and conflicting research in this area precludes definitive conclusions and further research is therefore needed.

Thirdly, some general limitations were found in the family carer training procedures as outlined above (e.g., misunderstandings about observation procedures, poorer fidelity in demand conditions of the EFA compared to other condition types), and future research could usefully target those areas found to result in low fidelity in this study. Furthermore, the training itself was not fully competency based since it was not continued to a predetermined accuracy criterion and was limited in scope and duration by the aims of the study. It is therefore possible that some of the clinical issues encountered (e.g., issues with prompt fading) may have been ameliorated using more extensive training procedures. It has been argued that both intervention fidelity (i.e., implementing the intervention procedures as intended) and implementation fidelity (i.e., implementing the training as intended) are equally important in influencing family carer and child outcomes (see, for discussion, Barton & Fettig, 2013), suggesting that these variables are likely to be important considerations for studies such as this which aim to train families to implement defined procedures (i.e., FAs and FBIs) in order to influence child outcomes (i.e., identification of function, CB, targeted mands). Implementation fidelity was not measured during this study and it is unknown whether the training was implemented as intended and therefore whether difficulties are related to factors relating to the training itself, or factors relating to the procedures or individual family skills. This reflects a limitation of the research relating to family carer fidelity more generally which rarely reports implementation fidelity (Barton & Fettig, 2013), but nevertheless represents an area where further research is needed.

Fourthly, as noted above there were a number of issues highlighted with IOA data collection (see Table 7). In many cases these issues were a result of the use of videos for data collection by IOA observers (whereas data were often collected in real-time by the main observer), or to instances in which there were few occurrences of the variable of interest, meaning that a small number of disagreements had a large impact on the overall IOA percentage. In addition, due to the complexities of data collection it was not possible to collect IOA data across at least 30% of sessions for all variables and participants, meaning that there is less IOA data available for this study than is usually expected. This represents a limitation and should be considered when interpreting results since the reliability of data collection cannot be confirmed. Nevertheless, this study was a small-scale feasibility study and this limitation therefore suggests that future trials using this methodology should have a clearer focus on IOA and aim to overcome the issues identified here.

Finally, whilst extensive collaboration with family carers was evident throughout, other stakeholders (e.g., clinicians) were involved in only a limited way (e.g., distributing information packs) and this represents a key limitation for the study. It is possible that some of the difficulties encountered throughout this study may have been overcome had it been possible to build greater collaboration with relevant stakeholders into the project, given suggestions that user involvement is likely to improve outcomes in clinical research (e.g., Medical Research Council, 2006). For example, greater involvement of clinicians both for recruitment and implementation of procedures may have ameliorated issues relating to recruitment and participant drop out. This may also have enabled some of the practical challenges encountered throughout the research to be anticipated from the outset and greater flexibility to therefore be built into procedures to overcome issues relating to the rigidity of procedures. Future research in this area should aim to implement the Medical Research Council’s (2006) guidelines on the development and evaluation of complex interventions and ensure greater collaboration with all relevant stakeholders across all stages of the project.

Conclusion

Whilst this study provides evidence of the emergent feasibility of training family carers in FA and FBI approaches as outlined above, it also highlights the practical difficulties of translating research findings into practice, particularly where research findings are largely from a different context and relate to clinical work with participants. Research literature rarely reports details relating to the clinical aspects of the procedures (e.g., family carer support, individual factors for each participant which require modified approaches) and this study highlights the importance of detailing these aspects where possible to enable other researchers and clinicians to more effectively anticipate and plan for these issues. However, even where it is possible to plan for such issues it may still be difficult to build enough flexibility into routine ethical approval procedures for research to enable truly individualised work to take place and this represents a significant difficulty in conducting clinically focused research in the UK. These and other issues relating to translating research evidence to practice are discussed further in Chapter Seven as they represent key themes identified across the thesis.

The results of this study demonstrated that family carers were able to successfully implement FA procedures and rated these procedures and associated training procedures as acceptable. Chapter Five therefore replicates and extends the training procedures relating specifically to the FA to identify whether such training can effectively be delivered via telehealth technology (i.e., videoconferencing) whilst maintaining positive outcomes in relation to high family carer fidelity and differentiated assessment outcomes.

Chapter Five

Study Two - Training Family Carers in Functional Assessment via Telehealth for Young Children with Intellectual / Developmental Disabilities who Display Challenging Behaviour: A Feasibility Study

Chapter Overview

This chapter presents the results of a second study focusing on the feasibility of training family carers to implement functional assessments (FAs) with their child with intellectual / developmental disabilities (IDD) via telehealth. Study one focused on the feasibility of training family carers in FAs and functional communication training (FCT). Several elements were completed successfully, demonstrating the emergent feasibility of the procedures. However, despite it being feasible to train families in both the assessments and the intervention procedures, the effectiveness of the interventions themselves was limited for a number of reasons (see Chapter Four for discussion). In contrast, the FA procedures were more successful and were able to identify functions for the child's behaviour in all cases where families were trained.

The current study therefore focuses on the FA procedures only and extends analysis of feasibility to delivering training and coaching in these procedures via telehealth. Telehealth methodologies (e.g., videoconferencing) may be a useful way to increase the reach of professional support for families, and in Chapter Three were found to have good outcomes for family carers and their children when utilised for a range of procedures including FAs. However, none of the studies identified in Chapter Three were conducted in the UK and it is therefore not known how well this methodology would fit within the support systems and culture of the UK. This chapter therefore presents the results of a study which aimed to address this gap and examine the feasibility of the use of telehealth in the UK with a small number of family carers. Furthermore, this study extends the procedures of study one by incorporating additional fidelity measures relating to both training delivery and implementation of procedures by trainees to examine the feasibility of collecting this type of data, and assess the possible influence of fidelity on outcomes. In addition, success criteria were attached to the feasibility questions for this study since preliminary feasibility was confirmed in study one.

Introduction

As noted in earlier chapters, training family carers in behavioural techniques for their child with IDD is a particularly important focus of work within the UK. This is important both within the current economic climate, in which professional time and resources are limited, and within the service and support structure of the UK which emphasises stakeholder involvement and empowerment. There are numerous successful examples of training family carers in behavioural techniques within the literature (e.g., Lafasakis & Sturmey, 2007; Laski et al., 1988; Matson, M. L. et al., 2009; McConachie & Diggle, 2007; Seiverling et al., 2012), and the use of natural intervention agents is demonstrated to be more effective than support provided by professionals (e.g., Carr et al., 1999), as well as supporting generalisation by enabling transfer to natural reinforcement contingencies (Stokes & Baer, 1977). In addition, there are often further benefits to family carers who receive training in behavioural approaches such as increased knowledge, confidence, improved family interactions, and reduced stress (e.g., Feldman & Werner, 2002; Koegel, R. L. et al., 1996; McConachie & Diggle, 2007).

Whilst these approaches often have clear benefits for families and their children, they present practical challenges such as the distance between families and professionals. This means that support is often dependent on the location of professionals, and families who live in more rural areas or in areas without professionals with behavioural expertise are often unable to receive behavioural support for their child. In recent years, technological advances have been used to modify family carer training approaches and overcome some of these practical difficulties. Telehealth has been defined as “the use of telecommunications and information technology to provide access to health [or behavioral health] assessment, diagnosis, intervention, consultation, supervision, education, and information across distance" (Nickelson, 1998, p. 527), and may involve a range of technologies from sophisticated videoconferencing systems, to basic telephone and email support. Chapter Three reviewed literature focusing on the use of telehealth to train stakeholders in behavioural techniques, demonstrating positive outcomes for the individuals trained and those whom they support. For family carers specifically, telehealth has been used to provide training in a range of techniques such as experimental functional analyses (EFAs: e.g., Lindgren et al., 2016; Machalicek et al., 2016; Suess et al., 2014; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013), behavioural teaching approaches (e.g., Fisher et al., 2014), intervention approaches for challenging behaviour (CB: e.g., Lindgren et al., 2016; Machalicek et al., 2016; Suess et al., 2014; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013), and intervention systems such as the Early Start Denver Model (e.g., Vismara et al., 2013; Vismara et al., 2018; Vismara et al., 2012). The majority of examples within the literature focus on the use of telehealth for family carers of children with IDD who display CB, and telehealth methodology may be particularly beneficial for this group of family carers. Specifically, this group of family carers often experience additional difficulties such as elevated stress compared to those whose children do not display CB (Floyd & Gallagher, 1997; Hastings, 2003; Herring et al., 2006), and social isolation leading to difficulties taking their child out of the house and attending appointments (Griffith & Hastings, 2014). As a result, telehealth has the potential to enable support to be provided directly within the family home for these family carers, removing the need for travel to appointments, and potentially reducing stress and burden associated with receiving support for their child's behaviour. Furthermore, research suggests that assessment and intervention for CB is often more successful in natural settings with natural intervention agents as this allows for easier identification of the contingencies maintaining CB in the natural environment (Carr et al., 1999; English & Anderson, 2004; Huete & Kurtz, 2010; Lang et al., 2008; Ringdahl & Sellers, 2000). As telehealth approaches necessitate the involvement of stakeholders to conduct assessments and implement interventions, they may offer a way to maximise the effectiveness of support for CB whilst minimising difficulties associated with accessing such support for family carers.

In addition, research evidence demonstrates positive outcomes for family carers and their children where telehealth approaches have been used to support CB assessment and intervention (see Chapter Three). For example, Wacker and colleagues conducted a series of studies (Suess et al., 2014; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) in which they trained 32 family carers to implement EFAs and deliver FCT to their child with IDD (aged 2-7 years). They were able to successfully identify social functions for most children's behaviour and demonstrate large reductions in CB following family carer implementation of FCT. Family carers also evidenced good levels of fidelity across procedures. Similarly, Machalicek et al. (2016) trained three family carers via telehealth to conduct EFAs and deliver a range of interventions for CB (e.g., differential reinforcement of alternative behaviour, FCT, antecedent strategies) with their children with IDD (aged 8-16 years). They demonstrated differentiated EFA results and reductions in CB for all children. Furthermore, when compared to support provided in person, telehealth support relating to CB has been found to have comparable outcomes at a reduced cost (e.g., Lindgren et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013), suggesting key advantages to this methodology both for family carers and professionals / organisations.

As noted above however, there are no known examples within the literature of the use of telehealth to train family carers in FA approaches in the UK. The use of telehealth in the UK may be particularly important given its paucity of professionals with expertise in behavioural support, and culture which values stakeholder involvement and training (see earlier chapters for discussion). As a result, study two utilised telehealth methodology to train family carers to implement FAs with their child, and aimed to examine the feasibility of the use of telehealth methodology for this purpose in the UK. This study extends procedures that were demonstrated as feasible, with successful outcomes, for training in-person in study one. For this reason, study two focused solely on FA procedures, as utilised in study one, rather than intervention approaches for which some elements did not achieve anticipated outcomes in study one (see Chapter Four). In place of training for prescribed intervention procedures, participants in the current study were instead supported to develop a behaviour support plan (BSP) for their child at the end of the study. The development of a more general BSP as opposed to the use of a prescribed intervention approach is also likely to be beneficial to family carers since the BSP can be more clearly tailored to the needs of their child, their family circumstances, and can focus on approaches that more closely align with their values (i.e., it is likely to have better contextual fit and social validity). The current study aimed to answer the following feasibility questions:

1. Is it feasible to recruit at least three families to take part in FA procedures conducted via telehealth methodology, rather than in-person?
2. Is it feasible to identify a second individual for each family to act as a Family Carer Assistant (FCA: see below) during the study?
3. Is it feasible to retain all three families and FCAs to take part in all elements of the study when procedures are conducted via telehealth methodology, rather than in-person?
4. Is it feasible to collect behavioural data (i.e., across all data types [see below] for each session relating to child CB and fidelity) via telehealth either during sessions or from video recordings following sessions?
5. Is it feasible to complete all elements of training in FA procedures for family carers via telehealth methodology, with an acceptable level of fidelity (i.e., >80% accuracy overall for each participant)?
6. Can family carers implement latency based EFA procedures with an acceptable level of fidelity (i.e., >80% accuracy overall for each participant) when support is provided solely via telehealth rather than in person?

7. Is it feasible to collect additional questionnaire data (e.g., relating to child behaviour, family quality of life) via telehealth with all participants both prior to and following any training or assessment procedures?
8. Are technical difficulties experienced in the use of technology for the study, and if so, is it feasible to resolve these with minimal impact on study procedures (i.e., any difficulties resolved in a way that enables the session to be continued rather than abandoned for more than 80% of affected sessions)?
9. Are training and assessment procedures considered socially valid by family carers when implemented via telehealth (i.e., scores of above 80% on the Treatment Acceptability Rating Form – Revised [TARF-R, Reimers & Wacker, 1988] – see below)?

Methodology

Many of the procedures used in this study are similar or identical to those used in study one, therefore references to study one are made where appropriate and differences in procedure between the studies are highlighted where relevant.

Participants

Participant Inclusion Criteria

Child participants were required to be under 16 years of age with an identified IDD. The expanded age range in comparison to study one was utilised to ease recruitment efforts following the difficulties experienced in study one. Given that there were no prescribed intervention procedures and the BSP could be highly individualised in this study, criteria relating to medical conditions or communication ability were not included for study two, and participants could be in receipt of support relating to the child's behaviour as the study focused on assessment within a brief timeframe rather than intervention. Participants who were fully deaf and blind were excluded as in study one due to the increased complexity involved in supporting this population. Criteria for inclusion of family carers were identical to study one.

Participant Recruitment

Participants for this study were recruited via advertisements (see Appendix O) circulated on social media. Initial recruitment plans involved collaborating with professionals working for a charitable organisation in Northern Ireland so that these professionals could also act as FCAs (see below). However, the charity found it difficult to recruit families through these methods and were severely restricted in their efforts due to long breaks in the service over school holidays. As a result, advertisements were also circulated via social media (Facebook, Twitter) and the required number of family carers made contact following advertisements, meaning that recruitment via the charitable organisation was no longer needed. A recruitment target of three families was set to match the number trained in study one. However, due to participant drop out (see Results) only two participants took part in the study.

Participant Characteristics

As noted above, two families took part in the study and are described below. All names used below are pseudonyms to protect participant confidentiality.

Jason was 13 years old with a diagnosis of Autism Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD). He used full sentences to communicate, had good motor skills and was able to write. He attended a mainstream school and lived at home with his mother, father, and brother. He was also taking medication for anxiety, ADHD and sleep difficulties which remained constant throughout the study. Jason displayed a number of behaviours of concern reported at the outset of the study including aggressive behaviours (pulling other people’s hair, scratching face / eyes, slapping, kicking, throwing objects at another person, punching another person in the genitals), destructive behaviours (banging items on a hard surface, pulling the television off of the wall) and potentially self-injurious behaviours (attempting to climb out of windows). Jason’s parents chose to focus on the aggressive behaviours during the study. Jason's mother, *June* (aged 45 years) was trained in all procedures during the study and his father, *Peter* (aged 46 years), supported as the FCA (see below).

Arthur was nine years old with a diagnosis of ASC. He was able to speak in full sentences, although he had previously experienced a speech delay and stutter, had good motor skills, and was able to write. During the study he attended a mainstream school and lived at home with his mother, father, and sister. His mother reported a number of behaviours of concern including aggressive behaviours (digging his nails / chin into another person, hitting, kicking, hair pulling, squeezing another person, scratching, pinching, choking), destructive behaviours (slamming doors, shaking door handles, throwing items) and self-injurious behaviours (gouging his skin with objects, picking around his nail beds or picking at wounds, self-biting). His mother chose to focus on the aggressive behaviours during the study. Arthur's mother, *Anne* (aged 39 years), was trained in all procedures during the study. Anne was not able to identify someone to act as the FCA during the study and so was trained without the use of an FCA (discussed further below).

Data Collection

Behavioural Data

As with study one, the primary outcome measures for this study related to observed CB and family carer / researcher implementation fidelity, therefore behavioural observation data were collected for these outcomes.

Response Definitions. As in study one, target behaviour definitions were individualised for each participant and a specific response class (aggression, self-injury, property destruction) was selected for each child in consultation with their family carer (see Table 13 below). Both family carers chose to focus on aggression which included any behaviour that could cause physical injury to another person.

Table 13

Targeted Challenging Behaviour Response Class and Individual Topographies for Each Participant

Participant	***Challenging behaviour response class:* Individual topographies**
Jason	*Aggression*: pulling other people's hair (usually directed towards his mother), scratching another person's face using both hands (directed at the person's eyes), slapping another person with an open hand, kicking another person's leg, throwing objects at another person, punching another person in the genitals (usually directed towards his brother)
Arthur	*Aggression*: digging his nails in another person's hand, digging his chin into another person's neck, hitting, kicking, hair pulling, squeezing another person's hand, scratching, pinching, squeezing others, choking others (usually directed towards his sister)

Response Measurement. As in study one, latency to target behaviour (from the start of the condition) was collected during the EFA using a stopwatch. No other behavioural observation data were recorded for child participants. Both family carer and researcher fidelity data were collected as described below.

Procedural Fidelity. Data relating to family carer fidelity of implementation for the EFA were collected in the same way as described for study one. In study two, researcher fidelity was also examined for implementation of both the training sessions and in-session coaching. The task analysis used during training sessions was expanded further for study two (see Appendix P) and task analysis elements were scored as either 'implemented' or 'not implemented'. A percentage of steps implemented was then calculated for each training session. During in-session coaching, data were collected on accurate correction of family carer errors of omission (i.e., not completing a step of the condition) or commission (i.e., completing a step out of sequence or adding a new step). Error and error correction definitions for each EFA condition type can be seen in Appendix Q. Errors were further subcategorised as *critical errors* that were likely to influence EFA outcomes due to modifying the motivating operation (MO) in place relating to the condition, or *non-critical errors* which were not likely to affect analysis outcomes as they were not likely to alter the MO. As the EFA conducted during this study utilised a latency analysis methodology (see below) any errors focusing on responses to target behaviour were deemed non-critical since the MO would not need to be reinstated in a condition.

Error corrections were required for critical errors of any type with a greater than 10 second inter-response time (IRT) from a previous error. This IRT criterion was set to minimise rapid error correction if a high number of errors occurred which would risk damaging rapport and family carer confidence when implementing procedures. Non-critical errors were not required to be corrected during in-session coaching and could be corrected through feedback at the end of the condition or end of the appointment. In addition to accurate error correction, specific descriptive praise (i.e., describing what had been done well) was required at least once for each play, attention or tangible condition (as in some instances only one opportunity for descriptive praise would be available during these conditions), and at least every three demand trials within each demand condition. Non-descriptive praise (e.g., “excellent”, “well done”) was required at least once per minute in each condition to support family carer confidence. The inclusion of these praise criteria served to ensure that social-positive reinforcement was delivered to family carers at a high frequency both contingently and noncontingently to maintain accurate performance and support their confidence in undertaking procedures.

As trainer fidelity is rarely reported in the literature (see Chapter Three) and methods are often not detailed, these coaching criteria were set with reference to the research team’s clinical experience as well as experience of providing in-session coaching for study one. These criteria were piloted using video footage of a session from study one and no modifications were needed to criteria following this. Data were collected on the number of opportunities of corrections, descriptive praise and non-descriptive praise completed accurately for each condition. Percentage of opportunities correct was then calculated for each variable and graphed per appointment.

Interobserver Agreement. It was not possible to collect Interobserver agreement (IOA) data for this study for two main reasons. Firstly, as previously described only one participant completed all procedures meaning that IOA data would be based on a very low number of sessions and would therefore be susceptible to biases or errors in data collection. Secondly, as discussed in Chapter Four, several difficulties were encountered in collecting IOA data when using the procedures detailed here and these difficulties required a range of strategies, including additional resources, to resolve. As there were no additional resources available for this study and the study focused solely on the feasibility of utilising procedures from study one via telehealth, IOA data were not collected as part of the procedure. Whilst this was justified given these reasons and context, a lack of IOA data is acknowledged to represent a limitation to the study and is discussed further below.

Questionnaire Data

Questionnaire measures were identical to study one with the exception that the Parenting Task Checklist (Sanders, M. R. & Woolley, 2001) was not used and section G (relating to communication) of the Functional Assessment Interview (FAI: O'Neill et al., 2014) was not repeated as these measures were not expected to change given that the study focused on evaluating FA procedures only. An additional measure (five-minute speech sample [FMSS] – see below) was included to assess family carer's attitudes and understanding about their child's behaviour. Family carers completed the Beach Centre Family Quality of Life Scale (FQOLS: Hoffman et al., 2006; Park et al., 2003) and FMSS in the first and last appointments (i.e., prior to any training and after completion of the FA). The FAI (modified in the same way as described for study one) was completed in full in the first appointment with section A repeated in the last appointment, and the TARF-R (Reimers & Wacker, 1988, modified for this study in the same way as in study one) was also completed in the final session. As with study one, the Functional Assessment Observation Form (FAOF, O'Neill et al., 2014) was completed during the structured observation to support the FA.

Five-Minute Speech Sample. In order to assess family carer's perceptions and understanding of their child's behaviour, they were asked an open-ended question (i.e., "Why do you think your child displays challenging behaviour" – see Appendix T) and given a five-minute period to talk openly on this topic without any interruption, comment or feedback from the researcher. This measure was selected given the lack of consensus in the literature of the most appropriate ways to measure CB knowledge and perceptions for family carers, and the need to keep assessment measures brief. Participants were not required to speak constantly, and the recording was terminated if participants indicated that they had no more to say.

The FMSS was completed prior to any training and again following the FA. The first sample also supported the FA by providing initial details about the situations evoking behaviour and its potential function. Recordings were then transcribed and scored according to predetermined criteria devised for the purposes of this study (see Appendix T). Specifically, statements relating to explanations of the causes for the child's behaviour (i.e., behavioural function [further specified by reinforcement type], emotional cause, diagnostic / biological cause, environmental cause, cognitive cause, unable to predict / no cause) and their ability to manage the behaviour (i.e., positive, negative) were counted. Individual scores were converted to a frequency per minute by dividing the score by the number of minutes family carers spoke for, and scores were then compared between the two FMSSs.

Data Analysis

As with study one, all procedures were assessed in relation to feasibility questions as outlined above. Behavioural data were additionally analysed as follows. Latency data during the EFA were graphed and visually analysed to identify the condition type associated with the shortest average latency to behaviour, indicating a functional relation. Researcher and family carer fidelity data were graphed per appointment as described for study one and visually analysed to assess changes in fidelity across study procedures, or common areas of low fidelity. Questionnaire data were analysed by examining change in mean score pre-post training for all family carers and the FMSS was analysed by examining change in score per minute across the individual categories pre-post training. Inferential statistics were not used due to low participant numbers.

Setting and Materials

Family carer and child participants were located an average of 207 miles ('remote sites') from the researcher's University in Canterbury ('host site'). Family carers did not meet the researcher in-person during the study. All sessions took place in the family carer's home with the researcher joining via videoconferencing either from the host site or their own home. Materials used during the sessions were the same as those described for study one and varied by EFA condition type. All necessary materials for the EFA were already available to family carers in their homes. All training materials needed by family carers (i.e., the manual [see below], response prompt cards) were sent by the researcher in the post. At the host site, either a desktop computer with external webcam and integrated microphone, or laptop computer with integrated webcam and microphone was used for videoconferencing, along with headphones to improve sound volume.

At the remote sites, a laptop with integrated webcam and microphone was used by one family alongside headphones, and an iPad with integrated webcam and microphone was used by the other family alongside headphones. Family carers used their own equipment but would have been provided with a webcam with integrated microphone if this were required. One family was initially provided with a webcam, but this was not compatible with their laptop and they therefore used the iPad as described above. Zoom software (www.zoom.us) was used for videoconferencing sessions and enabled recording of sessions for later fidelity data collection. WeTransfer Plus (www.wetransfer.com) software would have been utilised in order to transfer video files of the observations during the descriptive FA in between appointments to enable data collection. However, neither of the families were able to obtain video footage of the behaviour as described below and WeTransfer was therefore not needed during the study.

Procedure

Participants who expressed interest in the study were sent an information sheet (see Appendix R) and consent form electronically and asked to return these via email. Following this, an initial meeting was scheduled to discuss the study and complete descriptive FA measures.

Functional Assessment

As in study one, the FA consisted of the modified FAI (O'Neill et al., 2014) completed with the family carer, an observation conducted by the family carer using the FAOF (O'Neill et al., 2014), and a latency based EFA (Thomason-Sassi et al., 2011). All FA procedures were identical to study one with the exception that training was provided via telehealth methodology as described below. All appointments were video recorded by the researcher using Zoom videoconferencing software.

Development of Behaviour Support Plan

After completion of the FA, the researcher worked with family carers to devise strategies to include in a multi-element BSP based on assessment results and the model of Positive Behavioural Support (PBS) proposed by LaVigna and Willis (2005). These strategies included positive programming (i.e., skills teaching, such as communication or independence skills), ecological manipulations (i.e., environmental adaptations, such as reducing noise / light, noncontingent reinforcement), focussed support strategies (e.g., differential reinforcement, extinction), and reactive strategies (i.e., those aimed at maintaining safety if CB occurs). This process was overseen by the researcher's academic and clinical supervisors. The effectiveness and implementation of the BSP were not evaluated as part of the study as the focus was on FA procedures and feasibility of providing training for these via telehealth methodology. However, the inclusion of a BSP was felt important, primarily to ensure that families benefited from their involvement in the study given the extensity and complexity of procedures, and secondarily to support recruitment efforts.

Family Carer Training Via Telehealth

Procedures for family carer training were identical to study one, with the exception that all training was provided via telehealth (i.e., videoconferencing) and an additional individual (the FCA) was present to support family carers during the training and EFA sessions. The use of an FCA has been reported in the literature (see Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) as a way to provide practical support to family carers during behavioural procedures and the FCA can also pass messages between the researcher and family carer. As noted above, an FCA was available for only one family and therefore the second family were trained without additional support from an FCA. The implications of this are described in the Results and General Discussion below. The FCA role was to provide logistical support during training and EFA sessions (e.g., with setting up the room, providing necessary materials, connecting videoconferencing calls to the researcher, relaying messages to / from the researcher, supporting the management of child behaviour if needed, acting as a child confederate during role plays in the training sessions etc.). The FCA did not provide direct training or coaching to family carers as this was provided by the researcher, and they did not receive separate training. Instead, they attended all training sessions with family carers to provide support as described above, and to facilitate a collaborative model between family carers and professionals rather than an expert led model. This differs from Wacker and colleagues (Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) in which a more expert driven model was utilised and FCAs were independent professionals who received separate training. Such a model was felt to be less consistent with practice in the UK in which a more social model predominates as highlighted previously, and therefore less likely to be acceptable to families or clinicians involved in supporting families (though this assumption requires empirical validation). The FCA was present at all sessions which the researcher attended via videoconferencing. The manual provided to family carers during training was modified from study one to include information about the FCA role and the development of the BSP rather than the FCT procedures (see Appendix S).

Ethical Considerations

Ethical approval was obtained from the Tizard Centre (University of Kent) ethical review committee. Given the similarity to procedures in study one, many of the ethical considerations were the same (i.e., safety criteria and reactive plans were utilised). However, given the use of telehealth, additional considerations were required in relation to security of data both during sessions conducted via videoconferencing and during transfer using WeTransfer Plus (if needed). Videoconferencing software was chosen which utilises encryption to protect against the risk of unauthorised access during appointments (Zoom, 2019). Separate WeTransfer Plus accounts were arranged for each family during the study to ensure that families could only access their own data. In addition, WeTransfer is a secure platform in that it encrypts data during transfer and storage (Navid, 2018). As a further safeguard, family carers / FCAs were asked to ensure that personal information was not sent via WeTransfer (i.e., file names did not include participant details) and to notify the researcher when data had been uploaded to ensure that the researcher was able to download and remove it as soon as possible.

Results

As in study one, results will firstly be considered in relation to the study feasibility questions followed by the presentation of individualised results for each participant.

Feasibility Questions

Is it Feasible to Recruit at Least Three Families to Take Part in FA Procedures Conducted Via Telehealth Methodology, Rather Than In-Person?

Recruitment for this study was comparatively easier than recruitment for study one. In less than one month, fourteen family carers had contacted the researcher (with the majority of these contacting the researcher within 24 hours of the advertisement being circulated). It is unclear why recruitment efforts were easier for this study though possible explanations are suggested in the General Discussion below. Despite considerable initial interest in the study, only three families were eventually enrolled (see below for further discussion relating to participant retention). However, this met the initial recruitment target and therefore evidences feasibility of recruitment for this study.

Is it Feasible to Identify a Second Individual for Each Family to Act as an FCA During the Study?

For each family carer enrolled into the study, efforts were made to identify an individual to act as an FCA during the study procedures as described above. June was able to identify an FCA relatively easily as her husband also expressed an interest in taking part in the study. However, this was more difficult for Anne as her husband was not willing to take part in the study alongside Anne. She was also not able to identify anyone else known to the family who could commit to being present during all procedures. Efforts were made to identify a more formal FCA (e.g., someone who was routinely employed in a role which involved supporting family carers), however the research team did not have links with any organisations located close to Anne in the UK and it was therefore not possible to identify an external FCA. As a result, Anne completed study procedures without an FCA. The feasibility criterion is therefore not met for involvement of FCAs. This suggests that identification of an FCA for some families may be straightforward but that this may be more challenging for other families based on individual circumstances. This is discussed further in the General Discussion below.

Is it Feasible to Retain All Three Families and FCAs to Take Part in All Elements of the Study When Procedures are Conducted Via Telehealth Methodology, Rather Than In-Person?

Whilst recruitment efforts were highly successful for this study, enrolment of families who had initially made contact was comparably more difficult for this study than for study one. Of the initial 14 who contacted the researcher, five did not respond to follow up contact, two subsequently withdrew their interest (one due to being unwilling to use telehealth methodology, and the other did not provide a reason), and four were not eligible to take part (three who were awaiting assessments for ASC, and one who did not meet criteria relating to behavioural topography). This resulted in three families progressing through to the study. However, one of these subsequently did not respond to follow up and was withdrawn before any study procedures could be completed. Whilst the reason for this lack of contact after enrolment is unclear, it is possible that this was due to the use of videoconferencing as the family carer had initially expressed interest in the study if it were possible to complete procedures in-person. As a result, two family carers took part in the study. This is slightly lower than the initial recruitment target of three families. However, it was not possible to recruit additional families within the timeframe remaining for the study. The lack of contact from one family after enrolment suggests that efforts to retain families when undertaking this type of support may be difficult under some circumstances. However, the other two families both progressed through to study procedures. As noted below, one family was subsequently withdrawn due to the child being unwilling to continue which also influenced the retention rate of the study. As a result, one family completed all study procedures and was retained throughout the study, resulting in a final retention rate of 33.33% which does not meet feasibility criteria relating to participant retention. This suggests that it may be feasible to retain families for study procedures in some circumstances, but that difficulties are likely for other families which may be exacerbated by the use of telehealth methodology. The implications of this finding are discussed further in the General Discussion below.

Is it Feasible to Collect Behavioural Data (i.e., Across all Data Types for Each Session Relating to Child CB and Fidelity) Via Telehealth Either During Sessions or From Video Recordings Following Sessions?

For both families behavioural data relating to child CB and family carer fidelity were collected by the researcher. Some of this data (i.e., latency to CB) were collected during sessions and subsequently verified from videos of sessions. However, family carer fidelity data were not collected during sessions and were instead collected from video recordings of the sessions as in study one. This was due to the complexity of collecting such data and the need for the researcher to focus on coaching and supporting the family carer during implementation of procedures. Whilst this approach was generally successful, in a small number of instances the video quality impacted collection of this data (e.g., due to camera angle, technical failure of the recording). Similarly, researcher fidelity for in-session coaching was collected from video recordings. As these data were reliant on family carer fidelity data as described above, this data collection was therefore subject to the same difficulties. As a result, the feasibility of collecting behavioural data in this study was only partially supported since it was not possible to collect some types of data for a small number of sessions, and data collection was reliant on the quality of video recording during sessions. The implications of this finding are discussed further in the General Discussion below.

Is it Feasible to Complete all Elements of Training in FA Procedures for Family Carers Via Telehealth Methodology, with an Acceptable Level of Fidelity (i.e., >80% Accuracy Overall for Each Participant)?

As noted above, training consisted of two main elements in this study: standalone training sessions focusing on the rationale and implementation of procedures, and in session coaching during implementation of procedures. As in study one, the standalone training sessions were conducted as planned with high levels of researcher fidelity (100% across all sessions) suggesting that this element of the training was feasible to complete via telehealth. However, the in-session coaching elements were more difficult to implement in some instances.

For Anne, no difficulties were encountered in implementing these procedures as planned given that the researcher could coach her directly through headphones. When supporting Anne during sessions, the researcher's fidelity averaged 80% across all variables (range = 62.50-100%) and therefore met feasibility criteria, although there was some variability for specific session types or variables (see Table 15). However, difficulties were encountered with in-session coaching for June as messages were relayed by the FCA during sessions and it was not possible for the researcher to coach June directly. This meant that researcher coaching was mediated by the FCA who did not always pass on messages as planned. As a result, it was not possible to collect in-session coaching fidelity data for June given these influences on the implementation of coaching, and it is unclear to what extent June's fidelity was impacted by variable in-session coaching. As a result, the feasibility of implementing these training procedures via telehealth was only partially supported since it was not possible to collect researcher fidelity data for both participants and evidence greater than 80% accuracy overall. Further discussion of the implications of this finding is provided below.

Can Family Carers Implement Latency Based EFA Procedures with an Acceptable Level of Fidelity (i.e., >80% Accuracy Overall for Each Participant) When Support is Provided Solely Via Telehealth Rather Than in Person?

Both families were able to implement latency based EFA procedures with an acceptable level of fidelity (i.e., average fidelity > 80%), therefore meeting feasibility criteria relating to family carer fidelity. June completed the analysis with an average fidelity of 83.10% (range = 30.80-100%) whilst Anne completed sessions with an average fidelity of 94.17% (range = 83.33-100%). However, Anne's fidelity data were based on only one implementation of each condition type and therefore it is not known whether this would have continued across all sessions of an EFA. As in study one, fidelity across different session types varied and June implemented some sessions with considerably lower fidelity (i.e., 30.80% for one tangible session), and with lower fidelity for demand sessions overall (mean for demand sessions = 75.12%, range for demand sessions = 65.40-87.50%). This reflected difficulties experienced by June in implementing some conditions and may have been exacerbated by the use of telehealth and the difficulties in providing coaching / support directly to June as discussed above. Taken together, overall family carer fidelity evidenced in this study met feasibility criteria (i.e., greater than 80% accuracy overall) and suggests that it was feasible for family carers to implement EFA procedures when supported solely via telehealth. However, additional coaching / support may be required in relation to particular condition types as discussed below.

Is it Feasible to Collect Additional Questionnaire Data (e.g., Relating to Child Behaviour, Family Quality of Life) Via Telehealth with all Participants Both Prior to and Following any Training or Assessment Procedures?

As detailed below, both families completed all questionnaire measures both pre training and at withdrawal / post training, therefore meeting feasibility criteria relating to questionnaire data collection. Questionnaires were completed via videoconferencing and the FMSS was recorded for later analysis. Neither family experienced difficulty completing the questionnaires, therefore suggesting that questionnaire completion via videoconferencing for this study was feasible and that families were willing to complete questionnaires, even where the study did not provide the outcomes anticipated by families (see Individual Participant Results below for discussion).

Are Technical Difficulties Experienced in the Use of Technology for the Study, and if so, is it Feasible to Resolve These with Minimal Impact on Study Procedures (i.e., Any Difficulties Resolved in a Way that Enables the Session to be Continued Rather Than Abandoned for More Than 80% of Affected Sessions)?

Few technical difficulties were encountered during the study and where technological difficulties were experienced these were resolved quickly and easily with no sessions abandoned as a result of technical difficulties. Feasibility criteria relating to resolution of technical difficulties was therefore met. Technical difficulties usually related to sound or video quality at either the host or remote sites. There was initially an intermittent problem with the sound volume on Zoom which related to a setting on the host site software. However, this was quickly resolved for subsequent sessions. For Jason's family, the quality of the remote site video or sound (as viewed at the host site) was impaired temporarily in some sessions but in these instances these difficulties did not affect the session itself and quality was not so severely impaired as to hinder procedures or data collection. For Arthur's family, the sound quality on the remote site computer was impaired in one instance at the start of the appointment before procedures were implemented. However, this problem was quickly resolved through troubleshooting potential solutions for the remote site equipment and did not impact on the appointment. In general, any technical difficulties were easily resolved through troubleshooting and did not significantly interfere with study procedures as noted above.

Extensive support for technology use was not needed during this study. Families were provided instructions relating to the use of WeTransfer and support was provided by the researcher (who had basic knowledge of the technology used) for any issues that arose during sessions. Taken together, these findings suggest that few technological difficulties were encountered in this study, even where existing technology (rather than specific equipment provided by the study) was used, and that any technological difficulties were easily resolved. Some difficulties were encountered with the practical usage (rather than performance) of the technology as described below, however these issues were not due to technical difficulties. The implications relating to the use of technology and practical difficulties encountered are discussed further in the General Discussion below.

Are Training and Assessment Procedures Considered Socially Valid by Family Carers When Implemented Via Telehealth (i.e., Scores of Above 80% on the Treatment Acceptability Rating Form – Revised [TARF-R])?

Both families rated the study procedures highly on the TARF-R (Reimers & Wacker, 1988) and results of this questionnaire can be seen in Table 16. This is significant given that neither assessment identified clear results for participants (see below) and Anne decided to withdraw from the study. However, feasibility criteria relating to the TARF-R score were not met as scores were not greater than 80%, which suggests that social validity as assessed by the TARF-R could be improved. Despite this, participants' qualitative responses highlighted that they felt there were benefits to having taken part (June & Peter: "flexible, accessible, easy to do", "we've learnt he can do this", "given a little bit of hope that he can change"; Anne: "helped to think differently about the behaviour") although June and Peter also mentioned that they thought Jason found the procedures stressful and they did not like the FMSS. Anne noted that she felt the method would work for other families but not for Arthur. This provides preliminary evidence that the procedures were considered acceptable by families when support was provided via telehealth which further supports results in study one relating to the acceptability of the same procedures when support was provided in-person.

Individual Participant Results

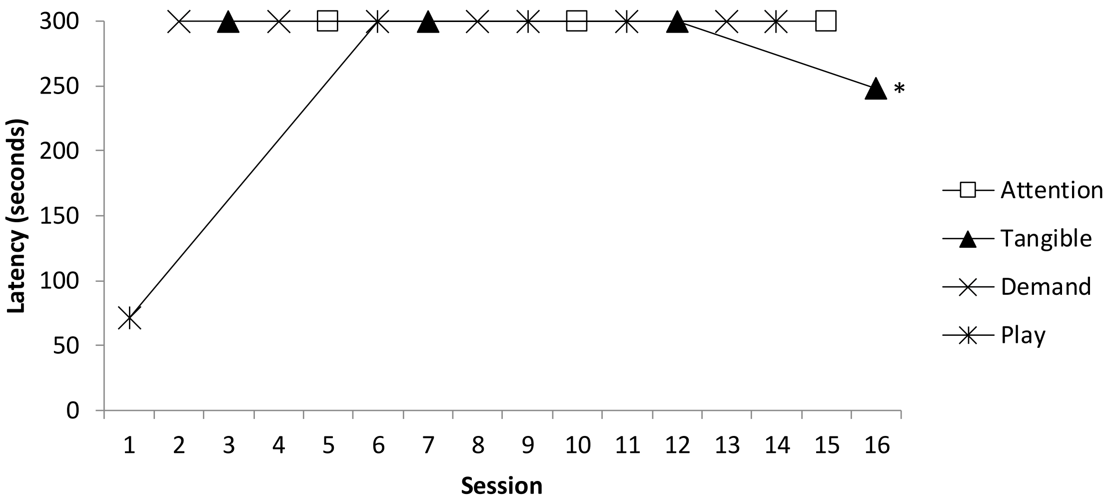
Jason

Descriptive Functional Assessment. The FAI (O'Neill et al., 2014) was completed with June and Peter and identified potential tangible and escape functions for Jason's behaviour. In addition, the FAI revealed that Jason displayed a specific topography of aggressive behaviour (slapping a person's head) in response to an auditory stimulus (someone sniffing) which appeared to be a respondent, rather than operant, behaviour due to its short latency from the stimulus, brief duration, and lack of consistent consequence. This behaviour may therefore have been a side effect of stimulus and sensory sensitivity rather than an operant behaviour. As Jason's family did not view this behaviour as problematic in comparison to other aggressive behaviours, further investigations to confirm this assumption were not made and the study procedures were instead focused on the tangible and escape functions identified for Jason's other aggressive behaviours. Structured observations were attempted with the FAOF (O'Neill et al., 2014) but were unsuccessful due to difficulty with capturing the behaviour on video. However, given that the FAI had identified clear potential functions the latency based EFA was conducted.

Experimental Functional Analysis. The results of Jason's EFA can be seen in Figure 25 below.

Figure 25

Results of Jason's Experimental Functional Analysis



*Non-targeted aggressive behaviour directed towards the FCA, rather than family carer (see below).

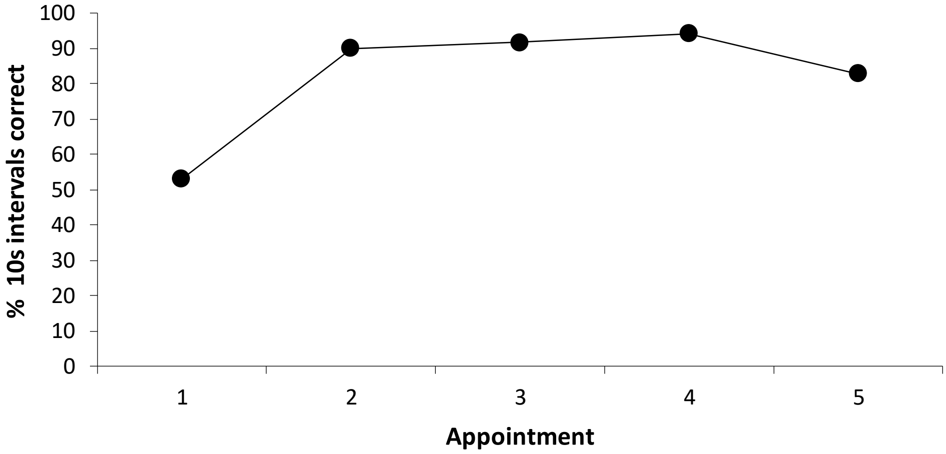
An alone condition was not conducted for Jason as there was no suggestion from the FAI of an automatic reinforcement function for his behaviour. A procedural error resulted in only three attention conditions being conducted for Jason's analysis and five play sessions. However, the target behaviours were not observed in any of the attention conditions therefore it was felt unnecessary to implement another attention condition after the analysis was finished.

As can be seen in Figure 25 Jason's EFA was undifferentiated due to a lack of target behaviours in most sessions. The only target behaviours observed during the analysis occurred exclusively in the first appointment, except for session 16 (tangible) in which a non-targeted aggressive behaviour occurred towards the FCA. In this session, biting was observed towards the FCA but this was not a previously identified behaviour for Jason, and it is unclear whether this behaviour was a recently emerged topography of aggression, or a playful behaviour. Jason's parents did not report that biting was problematic at home prior to the analysis. In addition, target behaviours observed during sessions were typically individual topographies of behaviour (e.g., kicking) and did not represent the typical pattern of behaviours described by June and Peter which involved an escalating behavioural chain. The implications of this are discussed below.

Family Carer Fidelity. The fidelity with which June implemented the EFA sessions per appointment can be seen in Figure 26 below. June implemented the procedures with an average fidelity of 81.23% per appointment but with some variability between appointments (range = 47.13-94.12%).

Figure 26

Percentage of 10s Intervals Implemented Accurately per Appointment for June



A breakdown of June's fidelity per session type can be seen in Table 14 below. June implemented the EFA with acceptable overall fidelity across sessions (mean = 83.10%, range = 30.80-100%) but with a high degree of variability. Specifically, fidelity was lower during tangible (mean = 68.60%, range = 30.80-100%) and demand (mean = 75.12%, range = 65.40-87.50%) sessions. This result is discussed further below.

Table 14

Fidelity Data for June per Experimental Functional Analysis Session Type

	No. of sessions	Mean	Range
EFA overall	16	83.10[a]	30.80-100
Tangible	3[b]	68.60	30.80-87.50

Attention	3[c]	86.02	77.42-93.55
Play	5[c]	96.43	88.80-100
Demand	4	75.12	65.40-87.50

Note. [a] This total differs from the total average fidelity cited above as the average here was calculated using individual session rather than aggregated appointment data. [b] Data included for only 3 tangible sessions due to a technical failure with the video. [c] As noted above, due to a procedural error only three attention conditions were included in the analysis and five play sessions.

Researcher Fidelity. The researcher implemented all coaching sessions as intended (i.e., implementing 100% of task analysis steps required for each of the two coaching sessions). However, due to modifications that were necessary for EFA sessions (i.e., the use of headphones for the FCA meaning that June was unable to hear the researcher's instructions) it was not possible to collect data on researcher implementation of in-session coaching as it was not possible to coach June directly. Although messages were passed to the FCA as planned, these often were not repeated to June or were modified by the FCA meaning that any data relating to the researcher's coaching would be invalid as this was confounded by the FCA's communication of messages from the researcher. Feedback was instead provided between sessions relating to June's implementation of procedures as described above. The implications of this finding are discussed further below.

Interim Discussion - Jason. The full FA procedures were completed with Jason's family. However, similar to participants in study one, the observation was unsuccessful due to difficulties in capturing the target behaviours on video. Furthermore, the results of Jason's EFA were undifferentiated and several explanations for this are possible. Firstly, the sessions themselves may not have adequately isolated contingencies and stimuli that usually evoked Jason's behaviour. It was necessary to complete sessions in the family lounge which was an area not often used by Jason and it is therefore possible that the relevant contingencies / stimuli were not present in this setting. This assumption is supported by the fact that the few target behaviours observed did not typically reflect

Jason's behaviour as described by his family carers. As the study focused on the feasibility of the training procedures, it was not possible within the scope or ethical approval of the study to significantly modify procedures. However, literature does suggest that idiosyncratic variables may in some instances maintain behaviours (e.g., Camp et al., 2000; Carr et al., 1997; Hausman et al., 2009; Schlichenmeyer et al., 2013) and that modifications may be required to FA procedures to better identify these variables (e.g., Roscoe et al., 2015). It is therefore possible that, had modifications and further assessment been conducted, differentiated results may have been obtained for Jason.

Furthermore, Jason's level of awareness and cognitive ability may have negatively contributed to the EFA outcomes as he quickly understood the session types and their procedures. This may have meant that any MO relating to his behaviour was weakened as he was aware that the session lasted only a brief period. An EFA conducted in more naturalistic routines utilising a trial-based format rather than block appointments (e.g., Austin et al., 2015; Lambert, J. M. et al., 2012) may have been more appropriate for Jason. In addition to these difficulties, the use of telehealth technology presented some issues during the EFA. Specifically, in the first appointment Jason was very aware of the equipment and the researcher's presence, as well as the fact that his older brother was not required to be present. This resulted in him leaving the room and refusing to engage in the sessions. For subsequent appointments, it was necessary to modify procedures to ensure his brother was present, and to make the researcher's presence less salient by turning the host site video off and using headphones for the FCA who then passed messages from the researcher to family carer. This invariably impacted fidelity as messages were not consistently delivered, and calls into question the utility of the praise elements of the in-session coaching protocol which were often not passed on by the FCA. For this reason, it was not possible to collect data on researcher fidelity for in-session coaching as described above. Wireless headphones used by the family carer may have overcome this difficulty but were unavailable and are unlikely to have been successful given Jason's level of awareness. It is therefore possible that these issues may have contributed to fidelity errors made by the family carer. June implemented the procedures with acceptable overall fidelity but comparatively poorer fidelity for tangible and demand sessions. This mirrors fidelity issues experienced in study one in relation to demand conditions and highlights an area in which further initial training may be needed. However, fidelity issues relating to the tangible conditions were unexpected given high levels of fidelity for these sessions found in study one, though it is possible that the telehealth methodology impacted this more subtly as described below.

Finally, the use of a family member as the FCA presented both advantages and challenges. Peter was able to engage in the FAI and provide additional information in the initial assessments, which was a useful addition to the procedures. Furthermore, because he was well known to June he was able to provide personal support and encouragement both during and in between the EFA sessions, and as he was also one of Jason's family carers he is also likely to have benefited from attending training sessions alongside June. However, his presence also altered Jason's behaviour at times, as Jason attempted to interact with him, and Peter also influenced the conditions on occasion by providing instructions to Jason or interacting with him. It is possible that these difficulties would have been reduced by using an FCA who was not as well known to the child, although this would likely have affected the sessions in other ways (e.g., through additional observer effects on Jason's behaviour).

Arthur

Descriptive Functional Assessment. The FAI (O'Neill et al., 2014) was completed with Anne and identified potential escape and tangible functions for Arthur's aggressive behaviours. Observations were attempted using the FAOF (O'Neill et al., 2014). However, these were unsuccessful due to difficulty in capturing the behaviour on video, therefore the latency based EFA was attempted based on the FAI results.

Experimental Functional Analysis. A latency based EFA was attempted with Arthur, conducted by his mother. However, in the first appointment Arthur became very distressed as he was aware of the researcher's presence. Due to the lack of an FCA, it had been necessary to turn the laptop towards Arthur and his mother to capture video, therefore Arthur was aware of the use of the videoconferencing software. He terminated the appointment by ending the videoconferencing call and was not willing to re-engage with the researcher at subsequent appointments, therefore it was necessary to withdraw the family from the study at this point. During this initial appointment, four EFA sessions were completed (i.e., one of each session type) and no target behaviours were observed during these sessions.

Family Carer Fidelity. Anne completed the EFA sessions in appointment one with an average of 94.17% fidelity (range = 83.33-100). Fidelity for each session type was over 80% with 100% fidelity in play and tangible sessions, and 83.33% and 86.67% fidelity for demand and attention sessions respectively. However, caution must be exercised when interpreting these results as they relate to only one implementation of each condition in the same appointment.

Researcher Fidelity. The researcher conducted 100% of training session steps for both coaching sessions accurately. Training relating to the implementation of the EFA was modified due to the lack of an FCA such that the role plays were shortened and focused on verbal recall of procedures rather than implementation. The implications of these modifications are unknown, though do not appear to have influenced June's fidelity during the actual EFA given the high rates of fidelity found.

Fidelity data for the researcher's implementation of in-session coaching procedures can be found in Table 15 below. On average, the researcher implemented in-session coaching procedures with 80% fidelity across all measures (range = 62.50-100%), but variable fidelity between measures with non-descriptive praise achieving the highest average fidelity across sessions (100%), followed by error correction (average = 75%, range = 50-100%) and descriptive praise (average = 62.50%, range = 0-100%). The descriptive praise elements were implemented with the lowest fidelity overall and suggest an area where further improvements could be made in coaching procedures. However, it is important to note that these data represent only one implementation of each EFA condition type and are therefore limited in scope. As a result, it is unclear whether lower fidelity was related specifically to one condition type and these results should be interpreted with caution.

Table 15

Researcher Fidelity of In-Session Coaching Procedures for Anne

	Error Correction	Descriptive Praise	Non-Descriptive Praise
All sessions	75%	62.50%	100%
Tangible	N/A[a]	0%	100%
Demand	100%	50%	100%
Play	N/A[a]	100%	100%
Attention	50%	100%	100%

Note. [a] No family carer fidelity errors made during these sessions.

Interim Discussion - Arthur. In contrast to Jason, it was not possible to complete all FA procedures with Arthur and one of the possible explanations for this relates to the telehealth methodology. The study protocol required that family carers inform the researcher about their child's cognitive ability and determine whether to undertake assent procedures based on their perceptions of their child's ability, since the researcher had no opportunity to meet the child prior to the study commencing. Anne felt at the beginning of the study that Arthur would not be able to understand the study procedures and provide assent, therefore the researcher did not meet Arthur until the first appointment. This was exacerbated by the lack of video footage of Arthur from the observational component of the FA as described above. As a result, the researcher was unaware of the likelihood that Arthur would be responsive to the researcher's presence and influence on his mother's behaviour. As noted above, Anne did not have an FCA and it was therefore necessary to have the laptop facing Arthur and his mother, and for Anne to use headphones to listen to instructions from the researcher. This made the videoconferencing equipment and researcher's presence highly salient and increased Arthur's distress about the procedures as he had no opportunity to meet the researcher and become comfortable in their presence. This may have been reduced by using an external webcam, though the use of headphones and an obvious camera would still have been salient variables. Attempts were made to meet with Arthur after this first appointment to discuss the study with him and enable him to get to know the researcher. However, he declined these meetings, and this was therefore taken as him indicating that he did not wish to take part in the study. He was therefore withdrawn from the study as described above. Anne reported at the withdrawal appointment that she felt the study procedures would have been effective for Arthur had they not been conducted via telehealth, suggesting a key consideration for the feasibility of using these procedures with families. The lack of an FCA exacerbated these issues as it was not possible to modify the procedures (as was also needed for Jason) to reduce the saliency of the researcher's presence. In addition, other difficulties were encountered in the EFA appointment with Arthur that may have been ameliorated with the use of an FCA, such as Arthur leaving the room, difficulties moving the equipment around the room when activities changed location, and the ability for Arthur to turn the videoconferencing equipment off. This may suggest the importance of having an FCA available during this type of support. Finally, the family were also experiencing a high level of stress during the study as they were seeking an ASC diagnostic assessment for their daughter. It is possible that this influenced Anne's ability to engage with the study and her willingness to support Arthur to become more comfortable with the study procedures. Arthur's behaviour was also reported to be less frequent and severe at the withdrawal appointment (see questionnaire measure below) suggesting that Anne's motivation to access such support may have reduced.

Questionnaire Measures

Questionnaire scores for both families at pre and post / withdrawal data points can be seen in Table 16 below. Given the low sample size it is difficult to draw firm conclusions based on these measures alone, but they provide an indication of change in outcomes targeted by the study for individual participants.

Family Carer Measures. For both participants, FQOLS (Hoffman et al., 2006; Park et al., 2003) total score and all subscale scores (with the exception of emotional wellbeing for Jason's family and physical / material wellbeing for Arthur's family) decreased slightly between pre and post / withdrawal data points. This likely reflects changes occurring outside of the study for both families. Anecdotally, Jason's family reported that his CB was occurring more frequently and was more intense, resulting in exclusions at school and difficulties with support provided at school, as well as difficulties in managing his behaviour at home. These circumstances likely influenced scores in particular subscales of the FQOLS (e.g., disability related support, parenting) though are unlikely to account for decreases in all areas. For Arthur's family, as noted above the family were seeking an ASC diagnostic assessment for their daughter and a diagnosis had been given at the time of the withdrawal meeting. This is likely to have been exerting stress on the family and therefore may have influenced FQOLS scores, particularly in relation to emotional wellbeing, family interaction, and parenting subscales. It is important to note, however, that it was possible to complete study procedures and provide support to families even within the context of these additional difficulties which is a significant finding and is further discussed below. In addition to these difficulties, it is also important to note that the study focused on assessment only and did not train families in intervention or support techniques. Whilst Jason's family received a BSP, this was presented at the same time as post data collection and therefore would not have been expected to influence scores on the FQOLS. This represents a limitation of the use of the FQOLS for this study, given that outcomes are unlikely to change significantly as a result of the study alone.

Data from the FMSS suggests different conclusions for each family. For Jason's family, June identified environmental causes (e.g., "if things don't work"; 1 comment per minute) for Jason's behaviour at the pre assessment data point, with some references to cognitive (e.g., "he doesn't have the capacity of reasoning"; 0.60 comments per minute) and emotional causes (e.g., "frustration"; 0.20 comments per minute), and no mention of operant behavioural function. She also suggested that it was difficult to identify a cause / trigger for Jason's behaviour (0.40 comments per minute) and made exclusively negative comments about her ability to manage his behaviour (0.40 comments per minute). At the post assessment data point, June mentioned a higher frequency of emotional and environmental causes (0.73 comments per minute) and more instances of being unable to identify a cause / trigger (0.73 comments per minute). She mentioned relatively less cognitive causes (0.24 per minute) but still made only negative comments about her ability to manage his behaviour (0.73 comments per minute). As noted above, Jason's behaviour had reportedly become more frequent and severe which is likely to account for these changes.

At the pre assessment data point, Anne identified diagnostic / biological causes for Arthur's behaviour (e.g., "because he has autism"; 1.20 comments per minute), as well as emotional (e.g., "he has very low self-esteem"; 0.80 comments per minute) and environmental (e.g., "the way we parent him"; 0.40 comments per minute) causes. She mentioned being unable to identify a cause / trigger for his behaviour (0.60 comments per minute) and exclusively negative comments about her ability to manage his behaviour (0.20 comments per minute). In contrast, at the withdrawal point Anne identified two operant functions for Arthur's behaviour (i.e., tangible, escape; 1.05 comments per minute), and similarly high rates of emotional (1.05 comments per minute), diagnostic / biological (1.58 comments per minute), or environmental causes (1.05 comments per minute). She did not mention being unable to identify a trigger / cause and made equal numbers of positive (0.53 comments per minute) and negative (0.53 comments per minute) statements about her ability to manage his behaviour. As a result, there was some suggestion that June felt more confident about her ability to manage Arthur's behaviour and was using a functional understanding to interpret instances of his behaviour. Although the full FA was not completed for Arthur, Anne did take part in all of the training sessions relating to this and it is therefore possible that the knowledge gained during these sessions influenced her understanding of his behaviour.

Child Measures. Scores on the Challenging Behaviour Checklist (CBC, completed as part of the FAI: Harris et al., 1994) differed for each family. Unsurprisingly for Jason, the number of behavioural topographies identified increased between pre and post data points, although all other variables (i.e., frequency, management difficulty, severity) decreased. This was somewhat unexpected given anecdotal reports that his behaviour had become both more severe and frequent. However, the measure does not allow for rating of a cluster of behaviours and this may have influenced results. As noted above, Jason did not often display individual topographies of behaviour in isolation and was instead described to experience a 'meltdown' which encompassed several different behaviours. The CBC may therefore not have been adequately assessing this cluster of behaviours when asking about individual topographies. For Arthur, all variables on the CBC decreased between pre and withdrawal data points suggesting that his CB had decreased in number of topographies displayed, frequency, management difficulty and severity. However, it is unlikely that this finding can be attributed to the study since Arthur was withdrawn prior to completing the EFA and did not receive a BSP.

Table 16

Questionnaire Measures for Both Participants at Pre and Post / Withdrawal Data Points

		Jason		Arthur		Mean (SD)	
		Pre	Post	Pre	Withdrawal[a]	Pre	Post / Withdrawal
FQOLS	**Total score (%)**	**82.50 (66)**	**78 (62.40)**	**102 (81.60)**	**93 (74.40)**	**92.25 (13.79)**	**85.50 (10.61)**
	Family interaction (%)	21 (70)	19 (63.33)	27 (90)	22 (73.33)	24 (4.24)	20.50 (2.12)
	Parenting (%)	19.50 (65)	19 (63.33)	25 (83.33)	24 (80)	22.25 (3.89)	21.50 (3.54)
	Emotional wellbeing (%)	9 (45)	11 (55)	17 (85)	11 (55)	13 (5.66)	11 (0)
	Physical / material wellbeing (%)	23 (92)	21 (84)	22 (88)	25 (100)	22.50 (0.71)	23 (2.83)
	Disability related support (%)	10 (50)	8 (40)	11 (55)	11 (55)	10.50 (0.71)	9.50 (2.12)
CBC	**Number of behaviours**	**10**	**13**	**14**	**7**	**12 (2.83)**	**10 (4.24)**
	Mean frequency[b]	3.90	3.23	3.43	2.71	3.66 (0.33)	2.97 (0.37)
	Mean management difficulty[b]	3.40	3.15	2.77	2.17	3.08 (0.45)	2.66 (0.70)

		Jason		Arthur		Mean (SD)	
		Pre	Post	Pre	Withdrawal^{a}	Pre	Post / Withdrawal
	Mean severity^{b}	2.44	1.55	2.91	2.50	2.68 (0.33)	2.02 (0.67)
FMSS	**Behavioural function per minute**	**0**	**0**	**0**	**1.05**	**-**	**-**
	Behavioural function types	-	-	-	Tangible, escape	-	-
	Emotional cause per minute	0.20	0.73	0.80	1.05	0.50 (0.42)	0.89 (0.23)
	Diagnostic / biological cause per minute	0	0	1.20	1.58	-	-
	Environmental cause per minute	1	0.73	0.40	1.05	0.70 (0.42)	0.89 (0.23)
	Cognitive cause per minute	0.60	0.24	0	0	-	-
	Unable to predict / no cause per minute	0.40	0.73	0.60	0	0.40 (0.60)	-
	Positive statements about managing behaviour per minute	0	0	0	0.53	-	-

		Jason		Arthur		Mean (SD)	
		Pre	Post	Pre	Withdrawal[a]	Pre	Post / Withdrawal
	Negative statements about managing behaviour per minute	0.40	0.73	0.20	0.53	0.30 (0.14)	0.63 (0.14)
TARF-R	**Total score (%)**	**-**	**101 (72.14)**	**-**	**90 (64.30)**	**-**	**95.50 (7.78)**

Note. [a] Questionnaires completed at withdrawal point as Arthur was withdrawn before completion of all procedures. [b] Out of a total of five.

General Discussion

This study aimed to examine the feasibility of a range of factors relating to training family carers in FA procedures via telehealth. The procedures themselves had demonstrated emergent feasibility when support was provided in-person in study one, therefore study two focused on their implementation when support was provided solely via telehealth. The feasibility questions posed by the study were partially confirmed by the results. Firstly, it was found to be feasible to recruit families to take part in the study and there was initially significant interest in the study. It is unclear why greater interest was shown in this study than study one, although there are at least four possible explanations for this. Firstly, the advertisement for this study was more engaging which may have resulted in more family carers attending to it on social media and subsequently contacting the researcher. Secondly, this study involved a more general intervention approach (i.e., a BSP as opposed to a communication intervention) which some families may have felt was more applicable to their child, and lower response effort since family carer training focused only on the assessment procedures rather than a full intervention. These factors may have contributed to families feeling that the study was both more applicable to their child and less disruptive to the family routine, therefore increasing their interest in taking part. Thirdly, delivery of procedures via telehealth as opposed to in-person may have been preferable to some families since this does not necessitate travel to appointments, or visits to the family home by a researcher. Finally, the inclusion criteria and study location were expanded and may have enabled family carers from a larger geographical area or whose children had more diverse needs and characteristics to express interest.

However, despite high initial interest, retention of these families was difficult and of the three families eventually enrolled into the study only one was retained throughout all procedures, resulting in feasibility criterion relating to participant retention being unmet. Whilst this suggests that there may be particular issues relating to the retention of families for this type of research, it is also likely that this finding is not unique to this study or the use of telehealth, as retention is a common issue for research studies across a range of fields (e.g., Ely & Coleman, 2007; Prinz et al., 2001; Spoth & Redmond, 1994; Young & Dombrowski, 1990). Retention issues were less pronounced in study one, however this may be due to the different recruitment methods used as participants were mainly recruited via contact with professionals who they already knew in study one, and in-person recruitment has been demonstrated to be a more successful strategy when recruiting family carers of children with IDD (Adams et al., 2017). This strategy was attempted in the current study with the charitable organisation in Northern Ireland but proved difficult as described above, therefore recruitment relied on advertisements. It is possible that, with additional time and resources, further family carers could have been identified to take part in the study and retained throughout all procedures, however this assumption requires validation in a larger scale study.

Additional procedures may also have facilitated retention such as the provision of videoconferencing equipment for use by families during the study, or the option to complete procedures in-person if preferred. As noted in earlier chapters, the option to receive support in-person may be important for some families and it is unlikely that telehealth will be appropriate in all circumstances (see Chapter Three), however given the focus of this study on examining feasibility specifically relating to telehealth it was not possible to offer this option. Further research could explore whether retention is comparatively easier where families can also opt to receive support in-person, and this would also provide a useful indication of the uptake of telehealth by families. Furthermore, provision of equipment for use by families may be useful although none of the families who made contact or took part in this study indicated that this was a barrier to their participation. Nevertheless, it is possible that some families may not have appropriate equipment and would have benefited from the use of this throughout the study. Issues were also encountered in this study with child willingness to take part (which resulted in one family being withdrawn from the study), as the researcher relied on family carers judging whether their child would be able to understand the study procedures and provide assent for these which was not always a successful strategy as highlighted above. It may therefore be important in future studies conducted via telehealth to ensure that the researcher has an opportunity to confirm whether child assent is needed by meeting with or observing the child prior to the first appointment. Additionally, it may be important to routinely build in additional sessions to enable the child to habituate to the presence of the technology and researcher prior to the beginning of the study. This was not needed in study one as procedures were completed in-person and rapport building was ongoing throughout sessions as the researcher was able to interact with the child and play with them between conditions (to provide a clear break between conditions), supporting the child to habituate to the researcher's presence. This approach was not possible for the current study and therefore additional specific sessions may be useful as noted above.

The feasibility of identifying an FCA was only partially supported as one family experienced difficulty with this and this contributed to issues that resulted in their subsequent withdrawal. Initial plans for the study involved providing an option for an FCA to be provided by a charitable organisation which routinely supports family carers in Northern Ireland however as noted above this approach was unsuccessful and the researcher had to rely on connections they or the wider research team had with organisations around the country near to family carers who were taking part in the study. Unfortunately, this meant that for Anne there was no option of an external FCA being provided and although some of the study procedures were subsequently completed with Anne in spite of this, the lack of a FCA did present difficulties in the study as described above. Wacker and colleagues (Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013) utilised external FCAs when training family carers in FA and intervention with promising results, suggesting that this option is likely to be feasible. However, the FCAs' role in these instances was different to their role in this study in that they were trained separately to families and FCAs offered coaching and procedural support to families. It is therefore unknown whether the model adopted in this study (whereby FCAs were involved mainly in logistic and moral support but received training alongside the family carer) would be impacted by the use of an external FCA. This could usefully be explored in future research.

Secondly, the collection of relevant data was found to demonstrate emergent feasibility throughout the study. Both behavioural and questionnaire data were successfully completed as intended and enabled the analysis of results as described above. This supports findings in other studies conducted via telehealth in this field (e.g., Barkaia et al., 2017; Fischer, Dart, Radley et al., 2016; Fisher et al., 2014; Wainer & Ingersoll, 2015) in which behavioural and questionnaire data have also been completed via telehealth. Some difficulties were encountered where it was not possible to collect data during appointments in which the researcher's attention was directed to coaching family carers as described above. However, these difficulties were also encountered in study one suggesting that they are not unique to the use of telehealth. In some instances other researchers (e.g., Barretto et al., 2006; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013; Wainer & Ingersoll, 2015) have used additional individuals to collect data though it is often unclear whether this involved the presence of a second individual during sessions, or data collection from video recordings as utilised in this study. The presence of another individual during sessions may result in additional observer effects for family carers and child participants and was therefore avoided for this study. An alternative option would be to train FCAs to take data during the sessions although this would likely impact the FCA's ability to carry out other elements of their role (e.g., relaying messages to the family carer, supporting with child behaviour during sessions). It is also unlikely that this would resolve all of the issues relating to data collection as multiple types of data were collected per session meaning that it is likely that some data collection would still need to take place from video footage after the sessions. Despite these issues, data collection was impacted by technological issues for very few sessions only and this therefore represents a relatively minor influence on the data for this study. The use of a minimum specification of technology (e.g., as detailed in Lee et al., 2015) may ameliorate some of these difficulties but would present alternative issues in necessitating the provision of acceptable equipment to family carers. It is therefore necessary to balance the difficulties of data collection with the availability of equipment.

Thirdly, conducting the procedures solely via telehealth also demonstrated emergent feasibility. Training procedures were generally implemented as intended, with 100% fidelity for standalone training sessions. However, in-session coaching proved more difficult for one family in which the FCA mediated messages between the researcher and the family carer. As a result, the feasibility criterion relating to researcher fidelity was met for only one participant. The implications of this on family carer fidelity or their confidence in completing procedures are unknown and require further investigation in future studies. Procedures relating to in-session coaching evident in the literature vary with some researchers / clinicians coaching families directly (e.g., Machalicek et al., 2009a; Machalicek et al., 2009b; Machalicek et al., 2010; Suess et al., 2014), whilst others also train FCAs to coach families (e.g., Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). It is therefore unclear which method is most appropriate and as research in this area develops this will be an important question to address. Furthermore, fidelity of in-session coaching components was variable for some EFA sessions and some specific variables. As there are no examples of criteria for in-session coaching fidelity in the literature these criteria were devised according to the clinical experience of the researcher and their supervisors. Although these were piloted with video recorded sessions from study one, it is possible that these procedures were not set sensitively with reference to the telehealth context and therefore need to be modified. More extensive piloting of these criteria would be useful. Alternatively, it is possible that researcher in-session coaching fidelity interacts with family carer fidelity and may covary with family carer fidelity. For example, Anne implemented the demand condition with lower overall fidelity than other conditions, indicating that a greater number of error corrections were required by the researcher. This may therefore have impacted on fidelity for the descriptive praise element of the in-session coaching criteria which was lower during the demand session. However, it is not possible to fully examine this hypothesis given that full family carer fidelity and researcher in-session coaching fidelity data are available for only four EFA sessions across the study.

Family carer fidelity was generally high, evidencing acceptable average fidelity across sessions for both families and meeting the feasibility criterion relating to this. This is a particularly significant outcome given difficulties identified in the literature relating to reaching criterion fidelity for telehealth-based training interventions (see Chapter Three). Similarly to study one, fidelity varied by session type with demand sessions being associated with comparatively lower fidelity. This indicates an area for more focused training / in-session coaching, and suggests that training procedures could usefully be expanded. June also achieved lower fidelity for tangible sessions which anecdotally she found particularly difficult. She reported that she disliked these sessions and found it uncomfortable to keep removing an item from her son. Discussions were held with June and Peter about the rationale for these procedures and the importance of withholding the tangible rather than relinquishing and re-removing it during the session, and fidelity for subsequent tangible sessions did improve. However, although not possible to substantiate with data at this stage, anecdotally it was more difficult to support June in relation to these sessions via videoconferencing than when similar difficulties had been encountered with other families in study one where support was provided in-person. Specifically, the researcher was unable to provide visual feedback and encouragement (e.g., smiles, nods, reassurance) during the sessions as June was unable to see the researcher, and messages of support were only intermittently relayed by the FCA. As a result, June may not have felt as well supported and coached during sessions and this may have resulted in her feeling less able to continue with procedures if these were experienced as difficult, and subsequently making fidelity errors. This suggests that, whilst it may be feasible for families to implement procedures via telehealth, the support provided by the researcher during sessions may be impacted by the use of telehealth. This has not been reported in the literature and therefore requires further examination via qualitative studies focusing on family carer and professional perceptions of this type of support which may help to highlight issues such as these and suggest potential solutions.

In addition to the emergent feasibility of implementing procedures, the procedures themselves were reported to be acceptable to families who took part in the study, with high scores on the TARF-R (Reimers & Wacker, 1988), though not meeting the feasibility criterion as outlined above. This is similar to results found in study one and is particularly significant for this study given that outcomes were not as anticipated for either family carer, and participants may therefore have felt greater dissatisfaction with procedures. Some of the measures were rated less favourably (i.e., the FMSS) and Anne noted that she felt the telehealth methodology was inappropriate for Arthur. June and Peter also noted that they felt the procedures were difficult and distressing for Jason but felt that this was proportionate to outcomes. A level of discomfort during EFA procedures for children is expected given that the procedures are designed to test contingencies maintaining their CB. However, it is important for researchers to monitor this and devise clear criteria for terminating a session based on the child's wellbeing as was used for this study and study one. Despite this, the procedures were rated highly by families and this is an encouraging finding for future research in this area utilising telehealth. Social validity was retrospectively examined in this study (i.e., after participants had experienced the procedures) and therefore it is not known how family carers perceive the use of telehealth for behavioural procedures prior to taking part in this type of study; this has also not been examined in the literature to date (see Chapter Three). Further research examining prospective social validity is therefore needed and is the aim of study three (Chapter Six).

Finally, few technological difficulties were encountered and any difficulties that were encountered were easily resolved as highlighted above, meeting the feasibility criterion relating to this. This therefore suggests that it may be feasible to conduct procedures via telehealth with technology readily available to families. However, it is important to note that some family carers might not have access to appropriate technology and therefore researchers / clinicians may need to be prepared to provide equipment where needed as has been done in other studies (e.g., Knowles et al., 2017; Lee et al., 2015; Suess et al., 2014). In addition, whilst not needed for this study, it is possible that some families may require additional support relating to the use of technology if they are less confident or fluent in this as highlighted by Lee et al. (2015). The practical usage of technology posed some problems in this study (e.g., the salience of the technology and the researcher's presence) and it is unclear whether a minimum technological configuration is required for telehealth support. Other studies have varied in the technology used from highly sophisticated videoconferencing systems which can be remotely controlled (e.g., Barretto et al., 2006; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013) and basic technology similar to the current study (e.g., Barkaia et al., 2017; Benson et al., 2018). It will be necessary for researchers / clinicians to balance practical implications of technology with the costs and availability of more advanced types of technology, and further consideration of this issue is needed in future research to detail different equipment configurations and ways to minimise practical difficulties relating to the use of technology. Future research should also aim to examine the full range of telehealth technologies that might be utilised by families. As technology develops it is likely that the equipment required for telehealth will be more readily available, and families may be able to select from a range of possible options ranging from low intensity (e.g., smartphones with headphones) to high intensity (e.g., a dedicated videoconferencing centre). It will therefore be important to ascertain the effectiveness of the full range of technology options, in order to offer a complete menu of options to families and enable them to select the options that fit best with their circumstances.

Furthermore, as noted in earlier chapters, the availability of technology and feasibility of conducting these procedures via telehealth should not be taken as an indication of its appropriateness in every context, as there may be some instances in which telehealth support is inappropriate (e.g., where very severe CB is displayed, where family carers have significant emotional support needs or experience difficulties with engaging with support due to personal characteristics / circumstances). It is, however, encouraging that even within the context of challenging circumstances experienced by families in this study (e.g., difficulties relating to their child's schooling as discussed above), study procedures were able to be completed and the researcher was able to support families effectively alongside these circumstances. This suggests that, whilst external difficulties may impact on support provided via telehealth and undoubtedly need to be considered and sensitively handled, it may be possible to provide telehealth support even within the context of such difficulties (although this will not be the case in all instances, as evident from the impact of challenging circumstances experienced by participants in study one). Nevertheless, the appropriateness of telehealth for behavioural support has not yet been examined as noted in Chapter Three and will be an important direction for future research in order to avoid use of telehealth as simply a way to reduce costs or increase ease for professionals.

Limitations and Directions for Future Research

The results of this study provide promising preliminary evidence of the feasibility of various elements relating to the use of telehealth for behavioural support in the UK. Future studies should aim to examine these elements on a larger scale given the low number of families included here and consider factors highlighted above as requiring further investigation. However, results of this study should be interpreted with caution due to methodological limitations. Specifically, the study included a very small number of participants, only one of whom completed all study procedures. Whilst it is not uncommon for feasibility studies to utilise small participant groups, this does represent a limitation which restricts the generalisability of the results. Consequently, it is unclear whether results from these two participants are representative of outcomes that would be achieved with a larger pool of participants. Further demonstrations of the feasibility of the use of telehealth in the UK with a larger number of participants, in differing contexts, and utilising different equipment and procedures are needed. In addition to this, due to low participant numbers and difficulties encountered in study one it was not possible to collect IOA data for this study. Whilst IOA data for study one demonstrated good levels of agreement for some participants / variables (though with considerable variability as discussed in Chapter Four), utilising the same data collection procedures as this study, the lack of such data for this study nevertheless represents a limitation in relation to the reliability of the data presented here. Further investigations of how to improve the ease with which IOA data can be collected in similar studies are needed as outlined in Chapter Four.

Furthermore, the current study focused only on the feasibility of procedures and therefore did not examine effectiveness in detail. As result, whilst the emergent feasibility of implementing FA procedures by training family carers via telehealth is supported by the study, it is unclear whether the assessments were able to reliably identify behavioural function and whether it is possible to use this information to develop effective interventions. This is a particularly important consideration given that Jason's EFA result was undifferentiated. Although undifferentiated analysis outcomes are not uncommon (Hagopian et al., 2013) and successful interventions have been developed for children with IDD following undifferentiated outcomes (see Chapter Two), it is unclear whether this would have been possible for Jason in the current study. Similarly, although Jason's family carers were provided with a BSP, they received no training in the implementation of the strategies contained within the BSP and therefore the effectiveness of these strategies in reducing CB is unknown. Nevertheless, examination of effectiveness was not the aim of the current study and this therefore remains an area for future research.

In addition, whilst each of the feasibility questions was at least partially confirmed by the results, some issues arose relating to the procedures which represent limitations in the conclusions that can be drawn. Specifically, similarly to study one it was not possible to complete a FA observation for either participant in this study. Whilst this was also found in study one, the decision was made to attempt the procedure since this study aimed to examine the feasibility of the study one procedures when delivered via telehealth. Future research should aim to identify more effective procedures for completing an observation within these contexts which may involve a) the researcher or another individual conducting some live (rather than video recorded) observations on numerous occasions, b) asking family carers to complete observations at prescribed times, on multiple occasions, or for longer periods of time, or c) building in additional procedures to enable child participants to habituate to the use of a video camera to record their behaviour.

The lack of FA observation data in the current study represents a limitation in three main ways. Firstly, it is unclear whether the EFA procedures were sensitive to each child's behaviour since this had not been previously observed. As discussed above for Jason, it is possible that idiosyncratic variables maintained some participants' behaviour and had an observation been completed before the EFA it may have been possible to identify these and incorporate these into the procedures. Secondly, it is unclear whether behavioural definitions were correct since these were based on discussions with family carers only. Whilst family carers were asked to review the definitions and indicate whether they were consistent with their child's behaviour, the behaviour itself was not observed prior to the analysis and it is therefore possible that the definitions were not correct and / or complete. This is most clearly seen in Jason's data, since a new behavioural topography (biting) emerged during the analysis which had not been reported prior to this but may have been observed during a FA observation and allowed for refinement of the definitions. Thirdly, the issues relating to child awareness of the researcher's presence and use of technology may have been pre-empted had an observation been possible to complete prior to the analysis. This would then have allowed the researcher to ensure that the child participants were consulted about their involvement and assent procedures followed, which may have reduced the likelihood of Arthur being withdrawn from the study. However, as noted in Chapter Four, many of the practical issues encountered in both study one and two may have been overcome had greater collaboration with a range of stakeholders been built into procedures across both studies, in line with the Medical Research Council's (2006) guidelines on the development and evaluation of complex interventions. Future research should evaluate the approaches utilised throughout this thesis with greater reference to these guidelines in order to maximise effectiveness.

Finally, as discussed above, some issues arose relating to the family carer / researcher fidelity data and data collection procedures. Issues relating to data collection were also found in study one and related to the need to collect these data from video recordings of sessions, rather than during sessions. As discussed above, the solution to this issue is not straightforward and requires further examination in future research. Issues also arose in relation to the fidelity data itself. Some EFA sessions were associated with lower family carer fidelity which suggests that the initial training provided to family carers and / or in-session coaching may not have been effective in preventing fidelity errors. Whilst family carer fidelity has also been shown to vary in the literature (see Chapter Three) future research could usefully examine the variables influencing this and aim to improve training or coaching procedures to overcome issues relating to fidelity. In addition, in-session coaching fidelity data were difficult to collect and subject to similar issues as family carer fidelity data collection, as well as co-varying with family carer fidelity. As noted above, there were no examples in the literature to inform these procedures and therefore the procedures used in this study require further refinement. As these data are more routinely collected and clinical experience of supporting family carers via telehealth in the UK increases it is also likely that in-session coaching fidelity will improve. Taken together, these fidelity issues call into question conclusions that can be drawn about the outcomes of the assessments conducted, or the effectiveness of family carer training. Despite this, as noted above, examination of effectiveness was not the main aim of this study and therefore these limitations will be important considerations for future studies focusing on the effectiveness of these procedures on a larger scale.

Conclusion

The results of this study provide initial evidence of the emergent feasibility of the use of telehealth procedures for training family carers in FA procedures in the UK. As noted above, the UK context is significant given the minimal availability of professionals able to provide behavioural support. The use of telehealth procedures may therefore enable more family carers to access support regardless of their location in the UK. This was clear in the current study as participants were located an average of 207 miles from the researcher. Whilst a number of areas remain for future research to explore as discussed above, this study provides the first demonstration of the use of these techniques in a UK context and is therefore unique, providing significant preliminary evidence of the feasibility of utilising this type of support within the UK. However, whilst the emergent feasibility of implementing these procedures was demonstrated in the current study, the results provide only limited information about family carer perceptions of the use of telehealth and social validity was only assessed retrospectively. Furthermore, it is not known whether clinicians based in the UK would be willing and able to integrate telehealth into their practice. As a result, whilst it may be feasible to implement these procedures within the UK, the extent to which they are likely to be used and acceptable to both family carers and professionals is unknown. These are important areas of consideration as the feasibility of procedures may not be a sufficient condition for their uptake. The final empirical study in this thesis (Chapter Six) therefore aims to examine these issues in more detail.

Chapter Six

Family Carer and Professional Perceptions of the Use of Telehealth for Behavioural Support for People with Intellectual / Developmental Disabilities in the UK: A Delphi Consultation

Chapter Overview

This chapter presents the results of a Delphi consultation examining the perceptions of professionals and family carers of people with intellectual / developmental disabilities (IDD) about the use of telehealth for behavioural support services. Whilst the potential effectiveness of telehealth for this purpose has been established in the literature (see Chapter Three) and through initial demonstrations as part of this thesis (see Chapter Five), the social validity of the approach has not yet been extensively examined. Social validity is not only a hallmark of applied behaviour analysis (ABA) interventions (Baer et al., 1987) but in this context is also likely to be an important determinant of the uptake of telehealth. A greater understanding of the factors influencing stakeholder perceptions of support provided via telehealth will allow service providers to maximise the advantages of the approach for clients, as well as minimise any disadvantages / barriers to ensure that telehealth support is widely accessible. This is also likely to provide information about the most appropriate uses and methods of telehealth when supporting family carers of people with IDD. This chapter therefore aims to identify the most influential factors related to professional and family carer likelihood of using telehealth, and present solutions to any disadvantages / barriers identified.

Introduction

As noted in earlier chapters, sophisticated use of technology is widespread in modern society with numerous innovative applications to healthcare, education, and social care. For example, smart house technologies are providing automated support / monitoring for people in care homes and new assistive technologies are launched regularly; iPads and educational applications are common in schools to support student learning and engagement; and healthcare professionals are utilising a range of new technologies for monitoring health and supporting patients, including videoconferencing for healthcare appointments, smartphone applications to monitor health outcomes for patients, and portable technology for accessing and updating patient records. The application of technology to such health and support services has been termed 'telehealth' and is defined as "the use of telecommunications and information technology to provide access to health [or behavioural health] assessment, diagnosis, intervention, consultation, supervision, education, and information across distance" (Nickelson, 1998, p. 527). As outlined in earlier chapters, a wide range of benefits relating to the use of telehealth have been cited in the literature, including increased access to populations that may be harder to reach (e.g., due to rural areas or poor service support), reduced travel time, and lower overall service costs (e.g., Hilty et al., 2002; Lindgren et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013).

The use of telehealth is now widespread in many fields including, for example, health assessment, diagnosis, intervention, and professional collaboration (e.g., Edison et al., 2008; Fatehi et al., 2014; Turkstra et al., 2012), speech and language therapy (e.g., Grogan-Johnson et al., 2011), parent training (e.g., Reese et al., 2015), and mental health support (e.g., Klein et al., 2010). Whilst traditionally the use of telehealth in behavioural services has been less common, a number of recent examples have emerged in the literature which report positive outcomes (see Chapter Three), suggesting that its use is increasing in this field. Where evaluated, behavioural support provided via telehealth has been reported to be acceptable to family carers, teachers, and therapists who access it (e.g., Fisher et al., 2014; Gibson et al., 2010; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013). However, there are no known studies prospectively (i.e., before the use of telehealth) or hypothetically (i.e., where there is no prospect of receiving support via telehealth) evaluating family carer and professional perceptions of the use of telehealth for providing behavioural support, with only retrospective attempts at assessing the social validity of an intervention that has already been delivered via telehealth. This means that it is not known whether family carers view telehealth as an acceptable way to receive behavioural services prior to these services being provided, whether they perceive any barriers in relation to accessing such support, or whether they perceive any advantages to receiving support via telehealth rather than in-person. Information is similarly lacking about professionals' views of providing behavioural support services via telehealth, and any issues or barriers they perceive in doing this.

A more hypothetical evaluation of social validity (i.e., in the absence of any prospect of behavioural support being provided via telehealth) relating to the use of telehealth in this field is likely to highlight factors that are able to improve uptake of telehealth support, as well as identify some of the factors influencing the appropriateness of telehealth for specific client groups or specific intervention areas. This is important given evidence from other fields that participant uptake of telehealth is generally low with high levels of refusal (Choi et al., 2013; Gorst et al., 2014; Sanders, C. et al., 2012; Subramanian et al., 2004), as well as within the context of the specific service structure in the UK, in which behavioural expertise is scarce making it difficult for clients to access behavioural support in-person. Whilst no such hypothetical evaluation has been conducted to date in the field of ABA, evidence from other fields focusing on a range of telehealth approaches (e.g., the use of videoconferencing, telephone support, remote assessments, transmission and remote review of health data) suggests a number of potential factors are likely to influence both client and professional uptake of telehealth. For clients, these include the technology requirements, preference for in-person support, concerns about the client-professional relationship, or perceptions about the type and quality of support provided via telehealth (e.g., Gorst et al., 2014; Sanders, C. et al., 2012; Swinton et al., 2009). Professionals may similarly be concerned about the client-professional relationship or the technological requirements of telehealth, as well as recognising key benefits to telehealth in relation to supporting access for patients and maximising use of resources (Brewster et al., 2014; Collier et al., 2016; Taylor et al., 2015). Clinician acceptance in particular has been highlighted as the most important factor influencing the use and success of telehealth within a service (Wade et al., 2014). However, whilst this evidence provides some insight into such factors, the application of telehealth to behavioural support is unique in that this most often involves a consultation model in which a mediator (e.g., a family carer) is trained to provide support to a client (e.g., their relative), rather than the clinician directly supporting the client as in many other telehealth applications (see Chapter Three for further discussion). As a result, whilst there are likely to be overlaps with evidence from other fields where support is provided directly to the targeted client, some of the issues (e.g., concerns about the influence on participants' level of independence, self-care or identity: Sanders, C. et al., 2012) are likely to have only limited generalisability to behavioural support provided via telehealth. As a result, a more detailed examination of factors influencing family carer and professional perceptions of the use of telehealth specifically for behavioural support is warranted to identify any unique advantages or disadvantages / barriers highlighted by stakeholders in this field.

The current study therefore aims to examine family carer and professional perceptions of the use of telehealth for behavioural support where there is no prospect of participants receiving support via telehealth (i.e., a hypothetical evaluation of social validity). The study utilises a Delphi panel method (Adler & Ziglio, 1996; Linstone & Turoff, 1975) to generate consensus amongst professionals (panel one) and family carers (panel two) about the most important factors influencing uptake and adoption of telehealth methodology for behavioural support, including any advantages and barriers they perceive in relation to the use of telehealth. The Delphi method has been used in similar ways to understand important features of service design and uptake for people with IDD and their supporters (e.g., Hempe et al., 2015). This method also has a number of advantages over other methodologies in that it enables expert consensus through a series of rounds in which participants are asked to comment on or evaluate a particular topic, without issues relating to group dynamics or perceived hierarchies influencing participants' responses. Furthermore, it avoids the necessity of a large group of individuals meeting in-person at a specific time for focus groups (which may be particularly difficult for family carer participants), and allows participants to engage confidentially at a time and location that is convenient to them. The specific research questions that this study seeks to answer are:

1. What are the potential advantages perceived by family carers and professionals to the use of telehealth to provide behavioural support?
2. What are the potential disadvantages or barriers perceived by family carers and professionals to the use of telehealth to provide behavioural support?
3. How might any disadvantages / barriers to the use of telehealth in this field be overcome?

Methodology

Participants

Participant Inclusion Criteria

Two parallel panels were formed for this Delphi consultation with a recruitment aim of 10-15 participants per panel. Whilst no consensus exists regarding an optimum number of participants per panel in Delphi studies, Atkins et al. (2005) cite panel sizes of between 10 and 100 members and research suggests that panel sizes of 10-15 individuals are sufficient to obtain stable results (Ziglio, 1996). Furthermore, a number of studies in the field of IDD have used panels of ten to twenty individuals (e.g., Hempe et al., 2015; Petry et al., 2007; Tuffrey-Wijne et al., 2016) suggesting that this panel size is both realistic and sufficient for a Delphi consultation in this field. The recruitment aim for this study was therefore set in line with this, and in acknowledgement of the difficulties of recruiting participants in this field as discussed in earlier chapters.

The first panel consisted of professionals from any background (e.g., behaviour analysts, learning disability nurses, clinical psychologists) with experience of providing support to relatives of people with IDD (of any age) about their relative's behaviour. The second panel consisted of family carers (e.g., parents, adult siblings, grandparents) of people with IDD (of any age) who had previously received support from a professional in relation to their relative's behaviour. All participants were required to be over 18 years of age. Inclusion criteria were kept deliberately broad to ensure as wide a range of experiences as possible in each panel and to minimise difficulties with recruitment. Furthermore, the inclusion of family carers of people with IDD of any age (i.e., rather than specifically children with IDD) was in order to ensure ease of recruitment, and to enable families to draw on a potentially longer and more varied history of receiving support for their relative's behaviour when commenting on methods for receiving this support.

Participant Recruitment

Participant recruitment occurred by circulating advertisements (see Appendix U) on the Tizard Centre's social media platforms, via charitable organisations supporting family carers, and through networks for professionals working with people with IDD. All participants were recruited through these methods. Recruitment for the professional panel was not problematic and the final professional panel consisted of eleven professionals (see below). However, recruitment for the family carer panel was more difficult. The advertisement was subsequently redesigned specifically for the family carer panel (see Appendix V), however in spite of this and having circulated advertisements multiple times, the recruitment target for family carers was not met after one year of recruitment efforts. As a result, the final family carer panel consisted of six family carers (see below). Whilst this was a smaller than anticipated panel of family carers, as noted above there is currently no consensus on the minimum panel size needed in Delphi studies with panel sizes known to vary, and some studies having utilised fewer than 10 panel members (see Akins et al., 2005). Furthermore, given the lack of research on family carer perceptions of telehealth for behavioural support this study is exploratory in nature. The smaller panel size for family carers was therefore felt to be acceptable with results likely to still provide important initial data about family carers perceptions of the use of telehealth for behavioural support. Further discussion on this point is provided in the Discussion below.

Participant Characteristics

As noted above, two panels were formed for this Delphi consultation.

Panel One: Professionals. Panel one consisted of eleven professionals who had experience of supporting family carers of people with IDD in relation to their relative's behaviour. One professional did not complete questionnaires in rounds two to four, resulting in ten professionals who completed all rounds. Given that this participant completed only the first round, which was used to generate items for inclusion in subsequent rounds for consensus building, their drop out did not influence consensus data in rounds two to four. The characteristics of participants in panel one can be seen in Table 17 below.

Table 17

Participant Characteristics for Panel One (Professionals)

Characteristic	Category	No. of panel members (%)
Gender	Male	2 (18.2%)
	Female	9 (81.8%)
Age	26-35 years	6 (54.5%)
	36-45 years	2 (18.2%)
	46-55 years	3 (27.3%)
Professional background[a]	Behaviour analyst	7 (63.6%)
	Speech and language therapist	2 (18.2%)
	Learning disability nurse	1 (9.1%)
	Teacher / educational staff	2 (18.2%)
	Support worker	1 (9.1%)

Characteristic	Category	No. of panel members (%)
Years' experience supporting family carers	1-5 years	3 (27.3%)
	6-10 years	4 (36.4%)
	More than 10 years	4 (36.4%)

Note. [a] Participants could select more than one answer for this question, therefore totals do not equal 100%.

Panel one represented professionals working with people with IDD of all ages and with a variety of needs including: intellectual disability (ID: mild – profound); autism spectrum conditions (ASC); Down syndrome; global developmental delay; acquired brain injury. Professionals offered support to family carers in a variety of settings including clinic based (e.g., NHS sites), community based (e.g., care services, schools), or the family carer's home. The support provided by professionals included advice, signposting / written information, training, therapy, advocacy, or reassurance. This support was provided in meetings (in-person), in writing, via videoconferencing, via email, over the telephone, using text messaging or other messaging platform, using social media, or using online forums / chatrooms. Approximately half of the panel (*n*=6, 54.5%) reported having used telehealth methodology in their professional practice (e.g., videoconferencing, telephone consultations with families / clients, text message prompting, email etc.) and the remainder of the panel had not used telehealth before.

Panel Two: Family Carers. Panel two consisted of six family carers of people with IDD. Variable numbers of family carers completed questionnaires for each round (as discussed below) therefore demographic details are available only for those family carers who completed questionnaires in which demographic questions were asked (i.e., rounds one and two). Available demographic information about family carer participants can be seen in Table 18 below.

Table 18

Available Demographics of Participants in Panel Two (Family Carers)

Characteristic	Category	No. of panel members (%)[a]
Gender	Male	0 (0%)
	Female	5 (83.3%)
Age	36-45 years	2 (33.3%)
	46-55 years	3 (50%)
Relationship to person with IDD	Parent	5 (83.3%)

Note. [a] Demographic information was only available for family carers who completed questionnaires in rounds one and two, therefore the number of participants selecting each category is presented alongside the percentage of the total panel (i.e., including those who did not complete demographic questions) that this represents.

Panel two represented family carers of individuals with IDD aged 6-18 years (where this information was available, *n*=4, 66.6%) with a variety of needs including severe / profound ID, ASC, language disorder, attention deficit hyperactivity disorder, and physical conditions affecting the joints. Panel members had last received support about their relative’s behaviour between 0-5 years ago (where this information was available, *n*=4, 66.6%) and this support involved advice, information / signposting, or support through clinical services. This support had been provided in-person at meetings, in writing, via email or over the telephone by clinical psychologists, speech and language therapists, occupational therapists, teachers / educational staff, general practitioners (GPs), or direct payments personal assistants. Three family carers (50%) reported having received support for their relative’s behaviour via telehealth (e.g., via email).

Procedure

Individuals who were interested in taking part in the study were required to contact the researcher using details provided on the advertisement. They were then provided with an information sheet (see Appendix W) and consent form and asked to return this via email to the researcher. After all participants were recruited for a panel, the round one questionnaire (see below) was sent to all participants in the panel. For each round, participants were given two weeks to complete the questionnaire and were sent three reminders (10 days after the start of the round, at the end of the round, and one week later). One week after the final reminder, all responses were analysed as described below. The questionnaire for the next round was then produced and sent to participants along with feedback about the results from the previous round. Feedback included qualitative descriptions of responses to any open-ended questions, as well as quantitative information about the group median for items, and the number of items that had reached consensus, had nearly reached consensus, or were removed from the item pool. After the final round four questionnaire, participants were provided with feedback about the results of round four and an overview of the panel's results across all rounds. Feedback about results from both panels was provided to all participants at the end of the study.

Ethical Considerations

Ethical approval for the study was obtained from the Tizard Centre (University of Kent) ethical review committee on the 13th of April 2017. Participants provided informed consent to their participation in the research electronically (via email) after having received information sheets (see Appendix W) from the researcher and had the opportunity to ask any questions they had. Furthermore, in line with convention in Delphi studies, participant's responses were kept anonymous using a unique participant code across rounds which was generated by participants themselves. This code was used to enable participants to select their unique questionnaire link from a table provided to all participants for round three. A unique questionnaire was required for each participant for round three as this round required the researcher to provide individual feedback to participants about their previous score for specific items. The use of a participant code ensured that although the researcher knew who was taking part in the study they could not match participants to their individual questionnaire responses, and they only knew whether participants had taken part in a specific round if the participant disclosed this information to them. Furthermore, participants were not provided with any information about other members of the panel beyond basic demographic details collected as part of round one.

Data Collection

Data collection varied across rounds (see below) and involved questionnaires using mainly open-ended qualitative questions (rounds one and four), and Likert scale responses (rounds two to four), with some closed ended categorical questions used to gather data about participant demographics (round one for both panels, and round two for panel two) and identify participants' most influential advantages / disadvantages (round four). Questionnaires for both panels in each round were similar with the exception that panel one (professionals) was asked questions about their willingness to use telehealth to provide support to family carers about their relative's behaviour, and panel two (family carers) was asked about their willingness to receive support about their relative's behaviour via telehealth. Questionnaires for all rounds were prepared and distributed using Google Forms software, which enabled participants to complete questionnaires at a time and location convenient to them.

Round One

The round one questionnaire for both panels (see Appendix X and Appendix Y) consisted of questions about the participant's characteristics, their past use and willingness to use telehealth methodology, and a series of open-ended questions about the advantages and disadvantages / barriers to the use of telehealth for the participant themselves and others (e.g., other professionals / family carers, the family carer / their relative). At the beginning of round one, panel members were provided with Nickelson's (1998) definition of telehealth (as stated above) and asked to think of telehealth in line with this definition throughout the study. Qualitative responses from round one were used to extract a list of advantages and disadvantages / barriers related to the use of telehealth highlighted by panel members in order to form the basis of the panel's round two questionnaire (see Analysis for further detail).

Round Two

The round two questionnaire (see Appendix Z and Appendix AA) consisted of the advantages and disadvantages / barriers identified as part of round one. Participants were asked to rate items according to how influential the item was to their likelihood of being willing to use telehealth either to provide support to family carers about their relative's behaviour (panel one), or to receive support about their relative's behaviour (panel two). Items were rated on a five-point Likert scale (1 – not influential to 5 – extremely influential) and participants were also given the option of selecting 'not specific' if they felt that the item was not specific to the use of telehealth, or '?' if they felt that the item was unclear and required clarification. If more than one participant rated an item as requiring clarification the item would have been modified for round three (this never occurred during the study), and any item rated by more than one panel member as 'not specific' would be removed from the item pool (this occurred for one item in round two for panel two). This ensured that the majority of panel members felt items extracted from round one were clear and relevant to the use of telehealth, therefore removing the influence of the researcher in deciding which items were relevant or clear enough from round one. Participants were additionally asked to identify any additional advantages and disadvantages / barriers that had not been listed as part of round two.

Round Three

The round three questionnaire (see Appendix BB and Appendix CC) involved presenting any new items identified by panel members in round two for rating as described above, as well as re-presenting items that had almost reached consensus in round two (see below for criteria used to determine items to be re-presented). Participants were provided with information about the group median for items that were re-presented, and their own previous score, and asked to use this information to reconsider their score for the item. They were advised that they could choose to either change their score or leave the score the same for each item. This was designed to identify whether consensus could be reached on these items after participants had been provided with further information about the group's rating of the item.

Round Four

The final questionnaire (see Appendix DD and Appendix EE) for each panel involved presenting the list of advantages that had reached consensus as being influential and asking panel members to select the five most influential to their own likelihood of using telehealth. They were then asked to select the top two most influential from these five. This was designed to give an indication of the items felt to be most important by participants in each panel. In addition, they were presented with a series of open-ended question about the disadvantages / barriers that had reached consensus as being influential and asked to suggest potential solutions to these. Disadvantages / barriers were grouped thematically to reduce the number of open-ended questions and maximise the likelihood that participants would respond fully to each question.

Analysis

Given the range of question types included across the different rounds, analysis procedures varied. Open-ended questions were analysed by synthesising responses and identifying themes in panel members' responses, using similar methodology to Thematic Analysis (Braun & Clarke, 2006) by reading and rereading transcripts to identify codes then grouping codes into themes, in order to identify items for use in subsequent rounds (round one) or solutions to disadvantages / barriers identified by panel members (round four). For questions using Likert scales, a group median score was calculated for each item. In addition, the frequency of panel members selecting each Likert scale score was recorded to identify whether consensus was reached or nearly reached on the item.

Consensus was defined in line with other Delphi studies (see Diamond et al., 2014 for review) as at least 80% of panel members indicating that the item was influential (i.e., a score of four or five). Where greater than 60% of panel members rated the item as influential (i.e., a score of four or five) and less than 30% indicated that it was not influential (i.e., a score of one or two), the item was identified as having nearly reached consensus and was re-presented in round three as described above. Items where responses were highly varied (i.e., more than 30% of panel members indicated that the item was not influential) were removed from the item pool as it was determined that consensus was unlikely to be reached on these items. Additionally, items where consensus was reached that the item was not influential were also removed from the item pool, as the focus of the study related to items that were influential to participants' likelihood of using telehealth. For the purposes of analysis, where a participant indicated that the item was not specific to telehealth this was converted to a score of one, as it suggested that this item would not be influential to their use of telehealth specifically. If a participant indicated that an item needed clarification their score for that item was removed from analysis and not used in consensus calculations. Closed ended categorical questions were analysed by examining the frequency and percentage of respondents selecting each category.

Results

Panel One (Professionals)

As noted above, panel one included eleven participants, ten of whom completed all rounds and one of whom only completed round one.

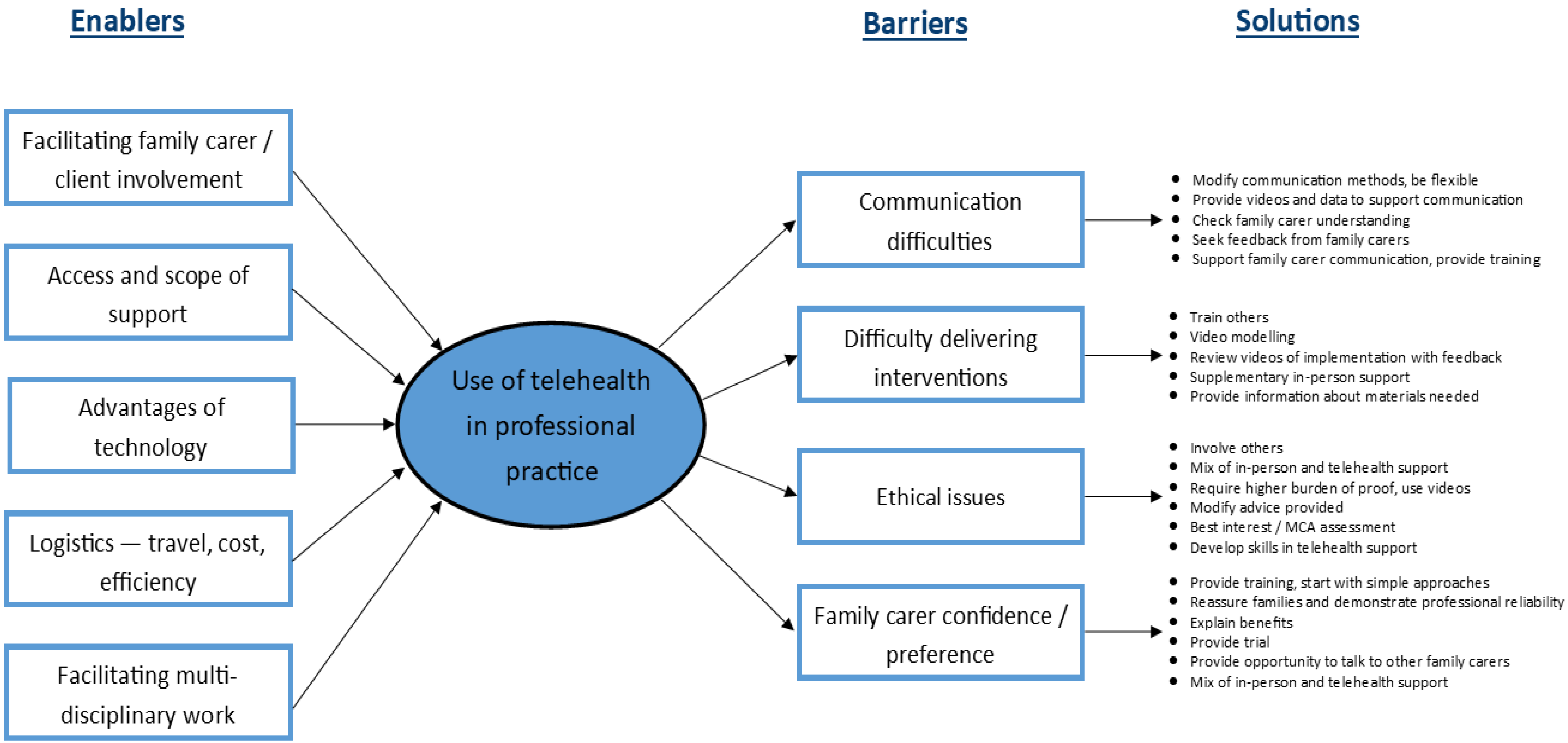
Enablers and Barriers Model

The results from all rounds for panel one were synthesised into a model of the most influential categories of enablers (i.e., advantages that had reached consensus) and barriers to the use of telehealth for professionals working with family carers and providing support in relation to their relative's behaviour. It was not possible to combine results from both panels into one model as panels identified a different number of items within each category and approached this from a different perspective (as discussed in General Discussion below). The full model for panel one, with key solutions identified by panel members for the barriers, can be seen in Figure 27 below. Further discussion of each area of the model and individual results for each round are provided below.

As can be seen in Figure 27, panel one identified more enablers than barriers to the use of telehealth in their professional work, and were able to generate a number of solutions to barriers identified. Enablers perceived by panel one focused on the advantages of the use of telehealth for the individuals supported (e.g., access to support, facilitating their involvement) and to panel members' work more generally in relation to logistics, multidisciplinary work or useful features of the technology (e.g., the use of video). However, panel one also had some reservations about the use of telehealth (specifically about ethical issues, family carer preferences, issues related to communication via technology and intervention delivery via technology) although these reservations were not perceived to be insurmountable and a range of solutions were identified for each barrier. Solutions identified were relatively simple and likely to be within the control of individual practitioners (e.g., consideration of communication methods, additional support for specific areas of work, supplemental in-person support). Overall, panel one seemed to perceive the use of telehealth positively with a range of advantages and felt that any barriers could be resolved through sensitive consideration of work conducted via telehealth. As noted above, a more detailed discussion of results for panel one follows.

Figure 27

Model of Enablers and Barriers (with Solutions) for Panel One



Round One

Ten panel members (90.9%) indicated that they would be willing to use telehealth in order to provide support to family carers about their relative's behaviour, and only one (9.1%) indicated that they would not be willing to use telehealth for this purpose. Participants were asked to provide information about why they would be willing or unwilling to use telehealth and answers to these open-ended questions were analysed alongside answers to subsequent open-ended questions (as described above) in order to identify advantages and disadvantages / barriers to the use of telehealth. Where participants indicated that they would be willing to use telehealth, they were also asked to indicate which methods they would be willing to use. The most common methods identified were videoconferencing, email and telephone, with some panel members also willing to use text messaging, social media, or online forums.

Answers to open-ended questions were combined and synthesised as described above. Four main themes emerged with associated subthemes (see Table 19 below), and for each subtheme, responses were grouped into advantages or disadvantages / barriers to the use of telehealth relevant to that subtheme. The results of this exercise can be seen in Table 19 below.

Table 19

Themes and Subthemes Identified in Round One Responses for Panel One and Specific Comments Made by Participants

Main theme	**Subtheme**	**Category**	**No. of panel members (%)**	**Specific comments**
Direct work	Assessment	Advantages	3 (27%)	Streamlined assessment process Minimised cost Assessment facilitated through the use of videos
		Disadvantages / barriers	7 (64%)	Telehealth inappropriate in early stages of consultation Some information may be missed due to inability to observe in some contexts or families not knowing what to report Some professionals (e.g., GPs) may need to meet client in-person
	Intervention	Advantages	4 (36%)	Ability to monitor procedural fidelity and ensure consistency across all individuals involved in delivering intervention Easier to plan intervention when stakeholders are in the same place as the intervention will be delivered, due to availability of resources

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
		Disadvantages / barriers	4 (36%)	Some techniques would be difficult / impossible to model via telehealth ABA therapists would be unable to work via telehealth Families may feel that support provided via telehealth is lower quality than that provided in-person
	Monitoring / review	Advantages	3 (27%)	Ability to record sessions, create permanent products, and share these with stakeholders Ability to adapt plans in real time using screen share
	Training	Advantages	2 (18%)	Ability to train a range of individuals at the same time, minimising cost, and increasing flexibility in training timing or location Ability to provide training to families before full behaviour support plan (BSP) is developed, enabling them to support their relative during a crisis in the interim

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
Logistics	Cost	Advantages	9 (82%)	Minimised costs for professionals and families due to reduced travel time, less use of clinic space / room hire costs, reduced financial impact of missed appointments
		Disadvantages / barriers	1 (9%)	Increased costs for families relating to accessing equipment for telehealth
	Location	Advantages	7 (64%)	Ability to provide support via any location, allowing several individuals to join sessions without being in the same place
				Reduced barriers relating to accessing support for families who may struggle to attend in-person appointments due to caring or other commitments, illness, mobility problems or anxiety
				Families may feel more comfortable receiving support in their own home and better able to discuss sensitive or emotive topics
				Ability for professionals to work from home

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
		Disadvantages / barriers	3 (27%)	Need for a quiet space for sessions Family carers may be less able to protect time for appointments if at home due to caring responsibilities or interruptions
	Speed of contact	Advantages	6 (55%)	Support could be provided more quickly Family carers could access support via email or telephone rather than waiting for in-person appointments Professionals could collect information from family carers / clients in a timelier manner Family carers could access advice quickly during a crisis, enabling de-escalation of the situation, and could clarify things more quickly via telehealth
		Disadvantages / barriers	1 (9%)	Emails can be easily ignored

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
	Technology	Advantages	7 (64%)	Emails are quick and flexible, allowing family carers / clients to send these at a time most convenient to them Ability to record sessions and share recordings Ability to share screens would be useful when modifying BSPs
		Disadvantages / barriers	9 (82%)	Possibility of technical difficulties Issues relating to accessing technology for community teams and family carers Some individuals may be less comfortable with the use of technology Potential difficulties for family carers who do not speak English, and the difficulty of providing interpreters when using telehealth

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
	Time / scheduling	Advantages	11 (100%)	Telehealth could save professionals time in relation to reduced travel time, enabling more appointments to be offered and more flexible appointment timing Family carers could save time in relation to reduced travel time and reduced time needed overall for support, making it easier to schedule appointments around other commitments Increased flexibility in appointment scheduling would enable multiple individuals to attend sessions or training when time for traveling to the meeting location is removed
		Disadvantages / barriers	1 (9%)	May be more difficult for family carers to protect time for appointments

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
	Travel	Advantages	11 (100%)	Reduced travel for professionals, family carers and others involved in the client's support would enable the involvement of those who live further away and facilitate involvement of a wider range of people
Interpersonal	Communication	Advantages	2 (18%)	Barriers to communication could be removed as family carers may feel more able to discuss sensitive / emotive topics via telehealth A more considered response could be sent to queries if using email or text messaging
		Disadvantages / barriers	8 (73%)	Easy to misinterpret information due to it being in written format without additional context, having less visual feedback to check understanding, or due to limitations in the camera resulting in the professional appearing disinterested when writing notes

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
				Increased barriers in communication as a result of telehealth for clients who find communication difficult, or family carers if they need to make a strong point about something in relation to their relative's support
	Lack of in-person contact	Disadvantages / barriers	5 (46%)	Need to meet clients in-person Potential for important information to be missed if client is not met in-person Work can sometimes change after having met the client which might not occur if contact is only via telehealth Some individuals might prefer in-person meetings Some professionals (e.g., GPs) might need to meet clients in-person
	Emotional implications	Advantages	3 (27%)	Benefit to family carers who experience anxiety, or individuals who find large meetings intimidating or overwhelming; telehealth could reduce this and enable

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
				individual to feel more comfortable by allowing them to be in a more comfortable location and communicate via technology
	Rapport / relationship	Advantages	1 (9%)	Rapport might improve due to flexibility in use of technology enabling family carers to avoid frequent cancellations
		Disadvantages / barriers	5 (46%)	Concern about impact on developing rapport and a positive relationship with family carers / clients via telehealth Concerns about implications for family carers trust in and relationships with the professional
Wider context	Access	Advantages	2 (18%)	More individuals could access service (e.g., those who would have been unable to due to distance or inability to leave home) Enables professionals to support clients from around the world

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
	Choice / preference	Advantages	4 (36%)	Could support family carer / client preference about how they would like to receive support and communicate with professionals, and about what information they would like Telehealth is convenient for family carers and could be used as required
		Disadvantages / barriers	4 (36%)	Individuals may prefer to meet in-person
	Ethics	Disadvantages / barriers	5 (46%)	Concerns about data protection, confidentiality and security (and whether family carers would have encrypted devices or secure email accounts) Greater potential for mistakes or incorrect advice to be given due to the potential of missing wider environmental variables / important information and the risk of receiving incorrect descriptions of behaviour Suggestion that professional is 'ever available' when using telehealth with implications for professional boundaries

Main theme	Subtheme	Category	No. of panel members (%)	Specific comments
	Group collaboration	Advantages	9 (82%)	Group work could be facilitated as telehealth removes the need for attendees to be in the same location; facilitates a more collaborative approach and involvement of more people (including translators) Supervision for professionals could be facilitated as supervisors could more easily sit in on sessions and information can be shared more widely Easier to arrange multi-disciplinary meetings enabling access to a wider professional network Family carers may be able to more easily access group and peer support
		Disadvantages / barriers	1 (9%)	Would not be appropriate to use telehealth for all team meetings

Based on panel members' responses in round one, a pool of 47 advantages and 37 disadvantages / barriers were identified (see Table 20 below) and presented to panel members in round two.

Rounds Two and Three

In rounds two and three, panel members rated the pool of advantages and disadvantages / barriers according to how influential each item was in relation to their likelihood of using telehealth to provide support to family carers about their relative's behaviour. In round two, the initial 84 items were presented with 19 (including 15 advantages and four disadvantages / barriers, see Table 20 below) initially reaching consensus as influential. Of the remaining 68 items, 16 (10 advantages, six disadvantages / barriers) met criteria to be re-presented and 42 were removed from the item pool due to highly variable responses across participants. An additional three items (two advantages and one disadvantage / barrier) were also identified to be presented in round three, resulting in 19 items (12 advantages, seven disadvantages / barriers) that were presented in round three. None of the round two items were rated as not specific to telehealth. Only two items were rated as requiring clarification by one panel member each, therefore suggesting that most panel members felt they understood all of the items.

Following round three, consensus was reached on 11 advantages and six disadvantages / barriers. The remaining two items did not reach consensus and were removed from the item pool. Eleven items were rated by panel members as not specific to telehealth, meaning that their scores were converted to one for these items as described above. Only three items were rated as unclear by one panel member each, suggesting that most panel members felt they understood all of the items.

In a total, 36 items (26 advantages and 10 disadvantages / barriers) reached consensus as being influential to panel members' likelihood of using telehealth to provide support to family carers about their relative's behaviour across either round two or three. Table 20 below provides an overview of the items achieving consensus in each round and the group median for each item when it reached consensus.

Table 20

Items Reaching Consensus (in Round Two or Three) as Influential for Panel One

	Item	**% rating as influential (round two)**	**% rating as influential (round three)**	**Group median^a**
Advantages	The possibility of using video observations	90%	-	4.5
	Ability to train families in support methods before the full behaviour plan development	80%	-	4
	Minimised / removed travel costs for you as a professional	80%	-	4.5
	Minimised / removed travel costs for family carers	80%	-	4.5
	Ability for family carers to join sessions from their own home	80%	-	4
	Ability for others to be in situ (e.g. in the service setting) with all necessary resources during sessions	80%	-	4
	Ability to offer appointments more quickly	80%	-	4
	Ability to offer more appointments overall	80%	-	5

Item	% rating as influential (round two)	% rating as influential (round three)	Group median[a]
Increased ability to gather information from family carers without waiting for in-person clinic appointment	90%	-	4.5
Increased ability to monitor procedural fidelity via video recordings	80%	-	4
Flexibility for family carers in relation to fitting appointments around their other commitments	90%	-	5
Reduced travel for you as a professional	80%	-	5
Reduced travel for family carers and others involved in the client's support	80%	-	5
Increased access to support for family carers who cannot travel, live far away, or cannot leave home	90%	-	5
Ability to involve more people in the client's support	90%	-	4
Increased ability to record sessions	50%	80%	4
Ability to share recordings of sessions	50%	80%	4

	Item	% rating as influential (round two)	% rating as influential (round three)	Group median[a]
	Ability for family carers to contact professionals quickly using email	70%	90%	4
	Ability to share emails and other permanent products with others	60%	80%	4
	Ability to arrange multi-disciplinary meetings more easily	50%	80%	4
	Reduced waiting times for support	60%	80%	4
	Increased time to deal with administration tasks	60%	80%	4
	Increased choice for family carers about what information they are given and how	60%	80%	4
	Increased convenience for family carers	50%	90%	4
	Ability for family carers to access group or peer support	50%	80%	4
	Clients / families have a known point of contact to develop rapport with	-	80%	4
Disadvantages	Difficulty with modelling specific intervention strategies via telehealth	80%	-	5

Item	% rating as influential (round two)	% rating as influential (round three)	Group median[a]
Difficulty with delivering specific intervention strategies via telehealth, e.g. ABA therapy	90%	-	5
Family carer preference for meeting in-person	90%	-	4.5
Ethical issue of offering support / advice without seeing situation in-person	80%	-	5
Potential for mistakes to be made in assessment / advice given	50%	80%	4
Lack of confidence using technology for family carers	60%	80%	4
Possibility of misinterpreting communication e.g. via email	60%	90%	4
Difficulty for family carers to get point across via technology	50%	80%	4
Difficulty related to checking misunderstandings	50%	90%	4.5
Difficulty in understanding family carer's reactions to suggestions	50%	90%	4

Note. A dash (-) indicates that the item was not presented in the particular round either because it was a new item identified during round two and therefore only presented in round three, or because consensus had already been reached in round two. [a] Group median presented for the round in which consensus was reached for the item.

Round Four

In round four, panel members were asked to select the top five most influential advantages (from the 26 that had reached consensus in earlier rounds) to their likelihood of using telehealth, and then to further select their top two advantages from these five. The items selected most frequently as one of panel members' top five most influential were 'increased convenience for family carers' (*n*=6) and 'reduced waiting times for support' (*n*=6). The item selected most frequently as one of panel members' top two most influential was 'increased access to support for family carers who cannot travel, live far away, or cannot leave home' (*n*=3). Full results for this stage of round four can be seen in Table 21 below.

Table 21

Advantages Selected by Panel Members in Panel One as Their Top Five or Top Two Most Influential

Item	**Frequency - top five**	**Frequency - top two**
Increased convenience for family carers	6	2
Reduced waiting times for support	6	2
Ability to offer appointments more quickly	3	-
Increased ability to gather information from family carers without waiting for in-person clinic appointment	3	1
Flexibility for family carers in relation to fitting appointments around their other commitments	3	1
Increased access to support for family carers who cannot travel, live far away, or cannot leave home	3	3
Increased ability to record sessions	2	-
Ability to share emails and other permanent products with others	2	1

Item	Frequency - top five	Frequency - top two
Ability to arrange multi-disciplinary meetings more easily	2	2
The possibility of using video observations	2	2
Minimised / reduced travel costs for you as a professional	2	1
Minimised / reduced travel costs for family carers	2	-
Ability for family carers to join sessions from their own home	2	-
Ability to offer more appointments overall	2	2
Increased ability to monitor procedural fidelity via video recordings	2	1
Ability to share recordings of sessions	1	-
Ability for family carers to contact professionals quickly using email	1	1
Increased choice for family carers about what information they are given and how	1	-
Clients / families have a known point of contact to develop rapport with	1	-
Ability to train families in support methods before the full behaviour plan development	1	-
Reduced travel for you as a professional	1	-
Reduced travel for family carers and others involved in the client’s support	1	-
Ability to involve more people in the client’s support	1	1

In addition, panel members were asked to suggest potential solutions to the disadvantages / barriers that had reached consensus as being influential in earlier rounds. The ten disadvantages / barriers were grouped thematically as described above.

Disadvantages / Barriers Relating to Ethical Issues. This category included the following items: ‘potential for mistakes to be made in assessment / advice given’; ‘ethical issue of offering support / advice without seeing situation in person’. The most common solutions mentioned by panel members to overcome these disadvantages / barriers related to involving others. This could mean involving professionals who are skilled in providing support via telehealth, involving others who know the client to gather more detailed information, or involving a second person to complete observations / assessments. Panel members also suggested that using a mix of in-person and telehealth-based support might be useful here and the importance of making sure that families were made aware that in-person meetings might also be required.

The use of video observations was also reported as a potential solution, however panel members stated that they might require a higher burden of proof before making conclusions from assessments or providing advice when using telehealth. They suggested requiring additional video observations to take place in multiple settings, requiring more detailed information from multiple individuals who support the client, or requiring additional observations / assessments completed by a second observer. Two panel members mentioned that they would modify the way advice is provided by giving a more detailed rationale so that others could understand any assumptions they had made, or ensuring that advice was provided with caveats as they do with in-person support. One panel member felt that it would be the professional’s responsibility to learn how best to use these approaches and become familiar / confident with this, and another felt that a best interests and mental capacity assessment would be useful.

Three panel members felt that these disadvantages / barriers might not be an issue when using telehealth in practice, and two did not have suggestions for ways to overcome these barriers.

Disadvantages / Barriers Relating to Practice Issues. The items in this category included: ‘difficulty with modelling specific intervention strategies via telehealth’; ‘difficulty with delivering specific intervention strategies via telehealth, e.g. ABA therapy’. Panel members mentioned training others in techniques as solutions to these practice-based barriers, with training either provided by the professional themselves or via a more general ABA course. The use of videos to train family carers, observe practice and provide feedback were the most common solutions highlighted. Some panel members highlighted the possibility of providing video modelling either pre-recorded or by using a second individual to role-play with the professional, as well as having a video library or catalogue available to the family carer which modelled common approaches. Panel members felt that family carers could also provide videos of themselves implementing techniques, which the professional could then provide feedback on, or could role-play in situ with another individual, and some panel members mentioned that Behavioural Skills Training (see Miltenberger, 2008) could be utilised here. Two panel members mentioned the possibility of providing supplementary support in-person, either as a last resort (if other approaches to provide training were unsuccessful), or as the initial meeting to train families. One panel member mentioned the importance of providing information to family carers about materials needed ahead of meetings to ensure that these were available, and one panel member did not have any suggestions for how to overcome these disadvantages / barriers.

Disadvantages / Barriers Relating to Communication Issues. This category included the following items: ‘possibility of misinterpreting communication e.g. via email’; ‘difficulty related to checking misunderstandings’; ‘difficulty in understanding family carer's reactions to suggestions’; ‘difficulty for family carers to get point across via technology’. When considering these disadvantages / barriers, panel members most often suggested modifying communication to ensure it is understandable, explaining things via audio or video recording rather than in writing only, accompanying email with additional evidence (e.g. videos, data), and ensuring that they are flexible in their language use and provide opportunities for clarification. Panel members also suggested explicit methods to check any potential misunderstandings such as follow up meetings / phone calls, asking follow up questions, or observing family carers implementing techniques as a way to check their understanding. Many panel members felt that encouraging feedback from families would be helpful, either through questionnaires and feedback forms or more informal feedback opportunities. Panel members also felt that supporting family carer communication was important by providing opportunities for them to communicate in multiple ways, providing training or support and discussing difficulties relating to the use of technology, encouraging the use of emoticons, and facilitating open and honest communication.

Two panel members felt that these disadvantages / barriers were unlikely to cause difficulties when using telehealth in practice or felt it was the professional's responsibility to utilise their skills in communication. Two panel members did not have suggestions for overcoming these barriers / disadvantages.

Lack of Confidence Using Technology for Family Carers. Panel members suggested a range of ways to provide training to families to increase their confidence in using technology. This included creating accessible guides in multiple languages, structuring training using task analyses, running general information and practice events, providing general IT support, using fake or dummy technology for training, or signposting family carers to other support services and training. Some panel members also felt that professionals could support families by reassuring them, demonstrating reliability over technology, and using simple approaches when families first begin using technology. One panel member thought this disadvantage / barrier was unlikely to be an issue in practice as families are used to using Skype / Facebook and one panel member did not have suggestions for ways to overcome this disadvantage / barrier.

Family Carer Preference for Meeting In-Person. Two panel members stated that family carer preferences should be respected, therefore suggesting that this disadvantage / barrier should not be overcome. Other panel members suggested ways to increase the likelihood that family carers would use telehealth including explaining the benefits of using telehealth both for the family carer and their relative, providing a trial for family carers, or providing opportunities for them to talk to other family carers who have had a good experience using telehealth. The most common solutions focused on providing a mix of in-person and telehealth-based support, with in-person methods suggested for initial meetings, being alternated with telehealth meetings, or used more flexibly as needed. Some panel members suggested scheduling regular reviews in-person (e.g., every one to three months), or gradually reducing in-person meetings as families become more comfortable with telehealth. One panel member suggested that if, after a trial, family carers were still resistant to using telehealth and it was detrimental for others then alternative providers could be suggested. One panel member had no suggestions for overcoming this barrier.

Panel Two (Family Carers)

As noted above, panel two consisted of six family carers of people with IDD. Variable numbers of family carers completed each round as reported below.

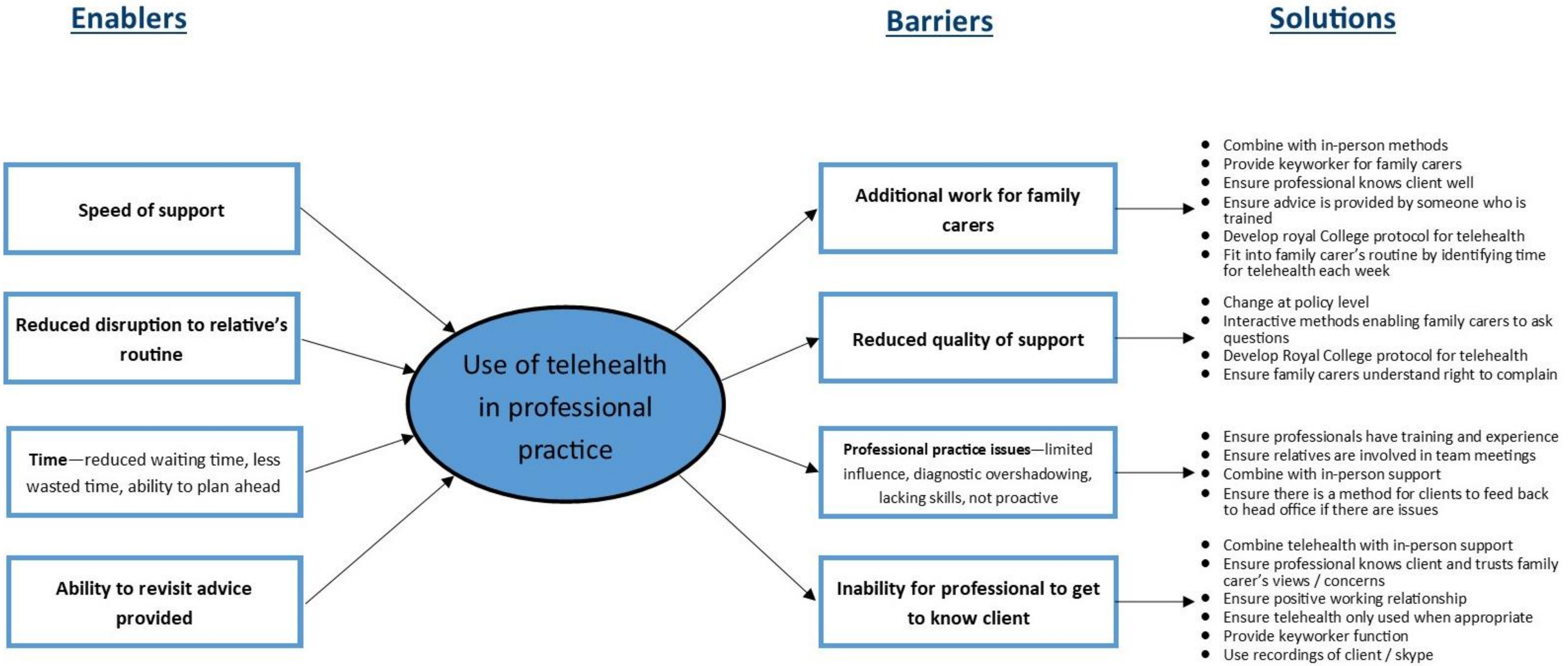
Enablers and Barriers Model

The results from all rounds for panel two were synthesised into a model of the most influential categories of enablers (i.e., advantages that had reached consensus) and barriers to family carers' likelihood of using telehealth to receive support for their relatives' behaviour. The overall model of enablers and barriers (with solutions) for panel two can be seen in Figure 28 below with further discussion of results for each round below. In contrast to panel one, panel two identified a similar number of enablers and barriers to the use of telehealth to provide behavioural support for their relative.

Enablers generally focused on logistics of support with panel members highlighting advantages for the speed of support provided, time related to receiving support, and the ability to revisit advice provided, as well highlighting reduced disruption for their relative through the use of telehealth. Barriers focused on broader areas, including concerns about the investment required by family carers when support is not provided in-person, the quality of support compared to that provided in-person, and professional issues such as poor practice or difficulties getting to know the panel member's relative. Whilst panel two identified a range of solutions for the barriers identified (e.g., additional training for professionals, supplemental in-person or professional support for family carers), many of these would require a co-ordinated organisational or national effort and are therefore likely to be out of the control of individual practitioners (e.g., the development of national guidelines for telehealth practice). Overall, panel two appeared to perceive the use of telehealth positively with some advantages identified but had greater concerns about support provided in this way than panel one. As noted above, a more detailed discussion of these results follows.

Figure 28

Model of Enablers and Barriers (with Solutions) for Panel Two



Round One

Four family carers completed round one. All the panel members indicated that they would be willing to receive support about their relative's behaviour via telehealth. The most common telehealth methods panel members were willing to use were email or telephone, with some also indicating that they would be willing to use videoconferencing, text messaging, social media or online forums / chatrooms. Panel members were asked open-ended questions about their views of the use of telehealth and the possible advantages / disadvantages of this for themselves, their relatives, and others. Two main themes and 17 subthemes emerged in panel members' answers, and for each subtheme responses were grouped into advantages or disadvantages / barriers. The outcomes of this exercise can be seen in Table 22 below.

Table 22

Themes and Subthemes Identified as Part of Round One by Panel Two Participants and Specific Comments Made by Participants

Theme	Subtheme	Category	No. of Panel members (%)[a]	Specific comments
Logistics	Access	Advantages	1 (25%)	Access might be facilitated for those who find social interaction difficult (e.g., those with ASC)
		Disadvantages / barriers	1 (25%)	Access for some individuals would be difficult if they don't have access to the internet
	Location	Advantages	2 (50%)	Ability to access support at home would be useful for family carer and relative (as relative could choose whether to join / leave discussion, and would feel more comfortable)
		Disadvantages / barriers	2 (50%)	Accessing support at home might be more difficult for relative as they would not associate home with support from professionals

Theme	Subtheme	Category	No. of Panel members (%)[a]	Specific comments
				Finding time and a quiet location for appointments at home might be difficult
	Records	Advantages	1 (25%)	Email would produce permanent record which would be useful for case files and complaints
				Use of telehealth would enable family carer to revisit advice provided
	Speed of support	Advantages	2 (50%)	Support could be provided more quickly, reducing referral times enabling issues to be dealt with as they arise, rather than having to wait for in-person appointments
	Time / scheduling	Advantages	3 (75%)	Scheduling appointments would be easier and would minimise disruption to relative’s routine
				Reduced time wasted due to unhelpful appointments

Theme	Subtheme	Category	No. of Panel members (%)[a]	Specific comments
				Greater flexibility to fit support around other commitments
		Disadvantages / barriers	2 (50%)	Timing of appointments might still be difficult when appointments are provided at home, and scheduling might not be convenient
	Travel	Advantages	1 (25%)	Would need to travel less and would not need to find parking for appointments
	Family burden	Disadvantages / barriers	1 (25%)	Co-ordinating support via telehealth would require greater oversight and management from families which would be difficult for some families who are often already tired
	Security	Disadvantages / barriers	1 (25%)	Concern about data security and potential for information to be shared inappropriately

Theme	Subtheme	Category	No. of Panel members (%)[a]	Specific comments
	Technology	Disadvantages / barriers	3 (75%)	Lack of access to technology for some families Issues understanding the technology used Reluctance of professionals to use technology as this would mean committing things to writing
Support provided	Communication	Advantages	2 (50%)	Communication would be easier via telehealth, particularly for people with ASC or for relatives who might find it easier to communicate with people in their own home
		Disadvantages / barriers	3 (75%)	Potential misunderstandings Missed social signals Poor responses provided by professionals via telehealth

Theme	Subtheme	Category	No. of Panel members (%)[a]	Specific comments
	Emotional implications	Advantages	1 (25%)	Support would be provided in a more relaxed environment and would enable relative to be more comfortable
	Quality of support	Disadvantages / barriers	2 (50%)	Support via telehealth may be poorer quality due to inability for professionals to meet relative or directly observe them, resulting in less in-depth or well-informed advice Potential for poorer support and responses provided by professionals via telehealth (e.g., more generic or inappropriate guidance rather than individualised support)
	Relationship	Disadvantages / barriers	1 (25%)	Professionals might not get to know relative as well via telehealth and may have low expectations which would impact on the support they provide

Theme	Subtheme	Category	No. of Panel members (%)[a]	Specific comments
				Professionals might not see relative often enough to notice small changes / issues
	Professional skill	Disadvantages / barriers	1 (25%)	Professionals might not have the right skills to provide support via telehealth if they are not proactive
	Professional scope	Disadvantages / barriers	1 (25%)	Professionals might not be able to influence others who are involved in the relative's support, or might not be able to effect change more generally when working via telehealth
	Relative's engagement	Disadvantages / barriers	2 (50%)	Relative might not engage with support provided via telehealth, either due to this being at home (and not traditionally associated with professional support) or due to willingness / ability to engage with support more generally

Theme	Subtheme	Category	No. of Panel members (%)[a]	Specific comments
	Lack of in-person contact	Disadvantages / barriers	2 (50%)	It is important for professionals to meet clients in-person A mix of in-person and telehealth support would be needed

Note. [a] Refers to percentage of participants who contributed to round one (*n*=4) rather than the percentage of the total panel (*n*=6).

Based on panel members' responses in round one, 36 items (15 advantages, 21 disadvantages / barriers; see Table 23) were extracted for rating in round two.

Rounds Two and Three

Five family carers took part in round two, and three took part in round three. Two participants who had taken part in round two did not complete the round three questionnaire. In these instances, participants' round two responses were used to calculate consensus for round three items where possible (i.e., for items that appeared in both round two and round three).

In rounds two and three panel members were presented with items identified as part of earlier rounds and asked to rate how influential the item was to their likelihood of accessing support for their relative's behaviour via telehealth. In round two, consensus was reached on 16 items (five advantages, 11 disadvantages / barriers) indicating that the panel agreed that these items were influential to their likelihood of accessing support for their relative's behaviour via telehealth. Three items nearly reached consensus (one advantage, two disadvantages / barriers) and were re-presented in round two. The remaining 17 items (seven advantages, nine disadvantages / barriers) did not reach consensus and were removed from the item pool. Nine items were rated as 'not specific' and participants' scores were therefore converted to a one as described above. One of these items was rated by two panel members as 'not specific' and was therefore removed from the item pool. Two items were rated by only one panel member each as requiring clarification, suggesting that most panel members understood the items. Ten additional items (six advantages, four disadvantages / barriers; see Table 23) were also identified by panel members as part of round two, resulting in 13 items presented in round three. Of these 13, six items (three advantages, three disadvantages / barriers) reached consensus in round three. Two items were rated as requiring clarification by one panel member each, suggesting that most panel members understood the items in round three.

Across both rounds, 22 items (eight advantages, 14 disadvantages / barriers) reached consensus as being influential to panel members' likelihood of accessing support for their relative's behaviour via telehealth. Table 23 below provides an overview of the items achieving consensus in each round and the group median for each item when it reached consensus.

Table 23

Items Reaching Consensus in Either Round Two or Three for Panel Two

	Item	**% rating as influential (round two)**[a]	**% rating as influential (round three)**[a]	**Group median**[b]
Advantage	Increased ability to revisit any advice that was provided	80%	-	4
	Ability for support to be provided more quickly as issues arise	80%	-	5
	Ability to arrange appointments more easily	80%	-	4
	Reduced disruption to your relative's routine	80%	-	4
	Less time wasted due to attending lengthy or ill-informed meetings	80%	-	4
	Quicker response times	-	100%	4

	Item	% rating as influential (round two)[a]	% rating as influential (round three)[a]	Group median[b]
	No need to attend appointments to deal with admin	-	100%	5
	Increased ability to plan ahead, e.g., preparing an email or document to be sent in advance	-	100%	4.5
Disadvantages / barriers	The possibility that professionals might provide generic or inappropriate advice when providing support via telehealth	80%	-	5
	The potential that support provided via telehealth might mean you have to oversee and manage this more than support provided in-person	80%	-	5
	Professionals not meeting your relative in-person	100%	-	5

Item	% rating as influential (round two)[a]	% rating as influential (round three)[a]	Group median[b]
Professionals being unable to directly observe your relative	80%	-	5
Professionals being unable to influence other people who support your relative	80%	-	5
Professionals having limited ability to effect change	80%	-	5
Professionals lacking the skills to provide support	80%	-	5
Professionals not being proactive	80%	-	5
Support being less in-depth or less well informed	100%	-	5
Possibility that professionals might not get to know your relative as well	100%	-	5

Item	% rating as influential (round two)[a]	% rating as influential (round three)[a]	Group median[b]
Possibility that professionals might not see your relative often enough to notice changes or issues	80%	-	5
Lack of focus from professionals as they may be dealing with multiple clients and might mix people up or not go into much depth	-	100%	4
Concerns about trusting whether professionals know your relative well, are complying with legislation (e.g., the Mental Capacity Act, Equality Act) and are not diagnostically overshadowing due to your relative's disability	-	100%	5
Additional work for families who are already tired	-	100%	4

Item	% rating as influential (round two)[a]	% rating as influential (round three)[a]	Group median[b]

Note. A dash indicates that the item was not presented in that round, either because consensus had already been reached in round two or because it was a new item identified as part of round two and therefore was only presented in round three. [a] Refers to percentage of responses in the round, rather than percentage of total panel. [b] Group median presented for round in which the item reached consensus.

Round Four

Four family carers took part in this round. In round four, participants were presented with a list of the advantages that had reached consensus as being influential and asked to select their top five most influential from this list. They were then asked to select their top two most influential from these five. Results of this exercise can be seen in Table 24 below.

Table 24

Advantages Selected as Panel Members' Top Five or Top Two Most Influential by Panel Two

Advantage	Frequency - top five	Frequency - top two
Less time wasted due to attending lengthy or ill-informed meetings	4	3
Increased ability to revisit any advice that was provided	3	1
Ability for support to be provided more quickly as issues arise	3	1
No need to attend appointments to deal with admin	3	
Increased ability to plan ahead, e.g., preparing an email or document to be sent in advance	2	1

Advantage	Frequency - top five	Frequency - top two
Ability to arrange appointments more easily	2	2
Reduced disruption to your relative's routine	2	-
Quicker response times	1	-

The item selected by the highest frequency of panel members as one of their top five was 'less time wasted due to attending lengthy or ill-informed meetings' (*n*=4) and this item was also selected by the highest frequency of panel members as one of their top two (*n*=3).

During this round, panel members were also asked to suggest solutions to the disadvantages / barriers that had reached consensus as being influential. In order to minimise the number of questions, disadvantages / barriers were grouped thematically as described above.

Disadvantages / Barriers Related to Increased Family Carer Burden. This category included the following items: 'additional work for families who are already tired'; 'the potential that support provided via telehealth might mean you have to oversee and manage this more than support provided in-person'. Solutions suggested by panel members focused on the type and quality of advice provided by professionals. They felt that it is important to ensure that professionals have the opportunity to meet their relative and can therefore provide specific, rather than general advice. Panel members also stated that this advice should be provided by someone who is properly qualified rather than someone with only limited training (e.g., an administrative assistant), and that the use of a keyworker for families would be beneficial. Panel members also suggested ways to minimise any additional burden as a result of the use of telehealth by combining telehealth with in-person support (e.g., home visits) or ensuring that appointments fit within a family's routine by identifying a specific time during the week for sessions. One panel member felt that the Royal Colleges and other regulatory bodies should develop a protocol for the use of telehealth with families which takes into consideration any possible additional burden to families.

Disadvantages / Barriers Related to the Quality of Support. This category included the following items: ‘the possibility that professionals might provide generic or inappropriate advice when providing support via telehealth’; ‘support being less in-depth or less well informed’; ‘lack of focus from professional as they may be dealing with multiple clients and might mix people up or not go into much depth’. The importance of the professional getting to know their relative was highlighted by panel members as a way to improve the quality of support provided, and panel members suggested the use of interactive methods that enable family carers to ask questions. Some panel members felt that change is required at policy level to influence the quality of support provided, and that these issues should be addressed in any protocol developed by the Royal Colleges or other regulatory bodies. Panel members also felt that family carers should be made aware of their right to complain about the quality of support they have received through the NHS England Ask Listen Do project (NHS England, n.d.). One panel member felt that a good professional would be able to avoid these disadvantages / barriers when using telehealth.

Disadvantages / Barriers Related to Professional Practices. Items in this category included: ‘concerns about trusting whether professionals know your relative well, are complying with legislation (e.g., the Mental Capacity Act, Equality Act) and are not diagnostically overshadowing due to your relative's disability’; ‘professionals being unable to influence other people who support your relative’; ‘professionals having limited ability to effect change’; ‘professionals lacking the skills to provide support’; ‘professionals not being proactive’. Family carers suggested combining telehealth with in-person support (e.g., home visits) to overcome these barriers and ensuring that family carers are involved in team meetings. They also felt that professionals should obtain training and experience in the use of telehealth and ensure that there are methods for clients to provide feedback to head office if there are issues relating to professional practice. One panel member felt that these issues were not specific to support provided via telehealth and would also be applicable to support provided in-person.

Disadvantages / Barriers Related to Client-Professional Relationship. Items in this category included: 'professionals not meeting your relative in-person'; 'professionals being unable to directly observe your relative'; 'possibility that professionals might not get to know your relative as well'; 'possibility that professionals might not see your relative often enough to notice changes or issues'. Panel members suggested combining telehealth support with in-person support to maximise the client-professional relationship or using videos and Skype. They felt it would be important to ensure that the professional knows their relative well and trusts the family carer's views or concerns, and to ensure that there is a positive working relationship that does not burden families. Panel members also highlighted that it is important to ensure that telehealth is used only when appropriate (i.e., rather than a way for professionals to "get out of doing things"). Finally, panel members also referred to the benefit of providing a keyworker function similar to that used in relation to the Transforming Care dynamic risk register.

Discussion

Throughout this Delphi consultation, consensus was reached on several items representing advantages and disadvantages / barriers for family carers and professionals relating to the use of telehealth for behavioural support. Notably, results between panels varied considerably both in relation to the types of items identified and the content of items. Family carers reached consensus on fewer items overall than professionals, and on more disadvantages / barriers than advantages. This may suggest that family carers therefore view telehealth support less favourably than support provided in-person. Despite this, all family carers indicated that they would be willing to receive support via telehealth therefore the presence of such disadvantages / barriers may not necessarily influence family carer willingness to use telehealth. Rather, it appeared the critical issue was that support needs to be provided in a way that mitigates these barriers. In contrast, professionals identified more advantages than disadvantages / barriers, suggesting a generally positive perception of the use of telehealth for behavioural support in their professional practice. This is an important finding, given evidence suggesting that clinician acceptance is the key variable influencing uptake of telehealth within a service (Wade et al., 2014).

The content of items identified by both panels also varied considerably, suggesting that different elements of telehealth support may be of importance to different stakeholders. Both panels identified advantages to the use of telehealth and similarly identified benefits relating to the logistics of support such as improved time / scheduling and reduced waiting times. However, some differences also emerged. Professionals focused almost entirely on advantages relating to logistics, additionally identifying reduced travel and cost, improved access to the service, and aspects of the technology itself (e.g., the ability to record sessions). They also felt that the use of telehealth would facilitate family carer / client involvement in support and multi-disciplinary work. In contrast, family carers identified key advantages relating to the nature of support received. Specifically, they felt that being able to receive support more quickly and in a manner that reduced disruption to their relative’s routine was particularly important and also highlighted the benefits of being able to revisit any advice provided to them. These differences highlight that family carers and professionals are likely to value different aspects of telehealth which may have implications for promoting telehealth services.

Significant differences also emerged in the disadvantages / barriers identified by both panels as influential to their use of telehealth. Here, professionals focused mainly on practicalities with the use of telehealth such as the difficulty of delivering specific types of intervention via technology and ethical issues relating to the security of data or providing advice without having met the client. They also emphasised the potential for communication difficulties due to misunderstandings, and difficulty for family carers who might struggle to get their point across, or who lack confidence in the use of technology and prefer in-person support. In contrast, family carers again focused on the nature and quality of support. They highlighted concerns that receiving support via telehealth might mean additional work and management for them. They also felt that the quality of support might be reduced and there might be a range of issues relating to professional practices such as professionals lacking skills, not being proactive, having limited influence when providing support via telehealth, or the risk of diagnostic overshadowing. They also emphasised issues that might arise due to the professional being less able to get to know their relative. Both panels were able to suggest solutions to the barriers / disadvantages identified and these most often involved combining telehealth with in-person support in some format. Other solutions focused on involving others to facilitate support (e.g., keyworkers, others who know the client well, additional professionals), modifying the way support is provided (e.g., modifying communication, using videos for training, using specific technologies such as Skype), providing or seeking additional training in the use of telehealth, and seeking family carer / client feedback. Family carers additionally highlighted system-wide solutions such as the development of national guidance for the use of telehealth with families, changes at policy level, and an emphasis on their rights to complain.

This is the first study to the authors' knowledge that hypothetically (as opposed to retrospectively) explores the social validity of providing behavioural support via telehealth. Previous studies in this field have instead focused on evaluating social validity following delivery of support via telehealth. However, similar findings are reported here to those in retrospective evaluations of social validity. The majority of participants in this study reported being willing to use telehealth for behavioural support, replicating findings in other studies in which families state that they would recommend the use of telehealth (e.g., Fisher et al., 2014). Whilst none of the family carers in this study reported that they would be unwilling to use telehealth, one participant in the professional panel was unwilling to use telehealth which is a similar finding to studies in which a minority of participants report that they would prefer to receive support in-person (e.g., Alnemary et al., 2015; Neely et al., 2016), and suggests that there may be variability in willingness to use telehealth as in other fields (e.g., Choi et al., 2013; Gorst et al., 2014; Sanders, C. et al., 2012; Subramanian et al., 2004). Concerns reported by participants in this study also mirrored issues reported in the literature.

For example, a number of authors identify ethical issues as a concern for professionals and difficulties delivering some interventions via telehealth methodology (e.g., Barkaia et al., 2017; Fischer, Dart, Radley et al., 2016; Machalicek et al., 2010; Suess et al., 2014; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013), both of which were variables highlighted by professionals in this study as influential to their use of telehealth.

However, there are also some key differences between this study and findings from retrospective evaluations of social validity. Technical difficulties are often reported in the literature (e.g., Alnemary et al., 2015; Barkaia et al., 2017; Gibson et al., 2010; Hay-Hansson & Eldevik, 2013; Machalicek et al., 2009a; Machalicek et al., 2009b; Machalicek et al., 2010; Machalicek et al., 2016; Wainer & Ingersoll, 2015) but were not identified in this study as key variables influencing either professional or family carer use of telehealth. Whilst this may reflect a genuine lack of concern by panel members in relation to the potential for technical difficulties, it may also represent panel members' limited experience with the use of technology for this purpose, as only half of panel members had experience of telehealth and this was often through the use of email or telephone which may be less prone to technical difficulties. In addition, although some studies report reduced costs associated with the use of telehealth for professionals (Lindgren et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al., 2013), a variable also identified as important by participants in this study, one study (Lindgren et al., 2016) found increased costs for families as a result of the equipment requirements for telehealth, a factor not considered by participants in this study. Many of the key variables identified by participants in this study (e.g., facilitating family carer / client involvement in support, communication difficulties, concerns about the quality of support) have not been mentioned in other studies in this field, likely reflecting the exploration of hypothetical rather than retrospective use of telehealth for this purpose. These findings therefore provide a unique perspective on the social validity of the use of telehealth for behavioural support and variables likely to influence stakeholder acceptance and uptake of telehealth. However, it is also important to note that whilst this study provides considerable information about advantages and disadvantages / barriers to the use of telehealth for behavioural support, it is possible that other issues relating to the use of telehealth for this purpose exist which were not highlighted here. It is therefore important that researchers and practitioners continue to consult with participants / clients to ensure that telehealth is used in a way that is sensitive to participant / client need, and effectively deals with any issues relevant to the specific context in which telehealth is used.

Limitations and Directions for Future Research

Whilst the findings presented in this study are likely to be useful to both practitioners considering adopting telehealth and family carers offered telehealth for behavioural support, some key methodological limitations should be considered when interpreting results. Firstly, the sample size for panel two (family carers) was smaller than anticipated and therefore results are less robust than those from panel one. The low sample size was a result of difficulties recruiting sufficient numbers of family carers, discussed in detail in other chapters, and participant non-completion of questionnaires in some of the rounds. Whilst the use of an online questionnaire had advantages in relation to flexibility and ease for participants, it likely also meant that some participants found it difficult to identify protected time for completion of questionnaires. The distribution of questionnaires via email may also have influenced completion rate, as participants are likely to vary in how regularly they check their email accounts and may have lost access to their email account during the study. Given the nature of the methodology (i.e., where participation in individual rounds is anonymous) it was not possible to send targeted reminders or telephone non-completers. Linked to the low sample size, the representativeness of the family carer panel was limited as participants were mostly family carers for children who had recently received behavioural support. Future study with family carers is therefore warranted to confirm findings in this study with a larger and more representative sample.

Secondly, the study was advertised and conducted solely via technology (i.e., social media, email, Google Forms) and this may mean that participants agreeing to take part were individuals who are more familiar and accepting of technology generally. This may have implications for the results in that the sample may be skewed towards participants likely to be willing to use technology in their everyday lives and therefore potentially willing to use technology for behavioural support also. This is supported by the relatively high rates of participants reporting use of technology in this study. Whilst the use of technology for the study was necessary in order to facilitate participant recruitment and involvement of a wide range of participants, future studies should aim to involve participants with variable experience of technology and consider avoiding the use of technology for questionnaire completion.

Thirdly, the definition of telehealth used in the study was very broad, including technology which is arguably used regularly for all types of support (e.g., telephone, email) and which most participants had used in the past. This may have influenced participants' willingness to use telehealth given that some of these methodologies are more familiar and already used by participants. Despite this, participants were also asked which methods of telehealth they would be willing to use, and more advanced forms of technology (e.g., videoconferencing) were selected by many participants, suggesting that participants' willingness to use telehealth was not confined to more familiar forms of technology. Fourthly, although participants were asked about their likelihood of using telehealth, their answers were not validated through subsequent behavioural checks to confirm this. There is therefore the potential that whilst participants indicated willingness to use telehealth this may not align with rates of uptake. Furthermore, given the service structure in the UK in which behavioural expertise is scarce, it is questionable whether family carer participants would have a true choice between telehealth and in-person support in practice. Favourable perspectives towards telehealth in this study may therefore represent participants' willingness to accept any form of behavioural support when offered, given the historic lack of such support. Similarly, professionals in this study may be more aware of issues relating to client access to services in the UK and therefore more likely to be open to ways of overcoming this in their professional practice. Future studies could usefully examine uptake and use of telehealth when offered as a genuine choice with in-person support.

Finally, this study did not consult individuals with IDD directly therefore the findings do not represent the perspectives of people with IDD about the use of telehealth. Whilst this was deliberate due to the use of a consultation model in behavioural support as discussed above, this is also an important omission given that variables relevant to clients with IDD were highlighted by both panels (e.g., ease or difficulty for clients with IDD in relation to communicating via technology, reduced disruption to clients' routines). Future research should therefore gather the views of individuals with IDD directly about the use of telehealth in relation to behavioural support both for themselves and when utilised by their relatives.

Practice Recommendations

Despite limitations, it is possible to make some preliminary recommendations for practitioners implementing behavioural support via telehealth. These recommendations arise from variables identified as influential in the present study and are designed both to increase the utility of telehealth support and to increase the likelihood of telehealth being accepted by both professionals and family carers.

1. **Consider combining telehealth with in-person support where possible**. This may be particularly important for individuals who are initially hesitant about the use of telehealth or for complex cases in which greater oversight is needed. This may also facilitate rapport building and practitioners' ability to get to know their clients. Provision of services in-person may not be possible in all cases and this should be discussed with clients at the outset of support.
2. **Incorporate technologies that involve video recordings when using telehealth**. Participants in this study suggested that the use of videos may facilitate consistency

in implementation of interventions, enable practitioners to provide feedback and training, and facilitate rapport and familiarity with clients. Practitioners should therefore consider incorporating technologies which involve video recordings (e.g., video conferencing) when providing support via telehealth.

3. **Take advantage of the opportunity to involve as many stakeholders as possible**. Participants in this study felt that involving additional individuals (e.g., other professionals, others who know the client well) would supplement support and protect against some of the potential disadvantages of telehealth. In addition, participants reported that telehealth offers the opportunity to facilitate training with multiple stakeholders and multi-disciplinary working which may enhance support for families. Practitioners should therefore take advantage of the greater ease of involving multiple stakeholders when using telehealth.
4. **Consider client perspective and family carer confidence**. Participants highlighted that this is likely to be a barrier to the use of telehealth and therefore professionals should consider providing training for family carers in using the technology, seek feedback both formally and informally from clients, and respect client preference if they do not wish to use telehealth.
5. **Develop guidelines for use of telehealth**. Family carers felt that guidelines should be developed for the use of telehealth by national regulatory bodies. However, it is also likely that local guidance will be useful in order to specify what clients can expect from a telehealth service and ensure that all aspects of service delivery are standardised and considered at the outset. Guidelines should describe technology requirements, ethical considerations (particularly those highlighted in this study such as data security), procedures for telehealth meetings, and feedback mechanisms for clients.

6. **Ensure that telehealth is used when appropriate.** Family carer participants in this study expressed concern that telehealth may be used by professionals as a way to avoid offering alternative support in-person. It is therefore important for services to consider their motives for use of telehealth and ensure it is only used when most appropriate for clients. Services should discuss use of telehealth with potential clients ensuring that the rationale for using telehealth, potential benefits, and potential disadvantages / risks are described, with clients able to make an informed choice about the use of telehealth given this information. Whilst it is recognised that some services will not be able to offer alternative support in-person, robust referral mechanisms can ensure that families who do not wish to use telehealth are still able to receive support if this is available locally.

In addition to these guidelines, other authors have provided practice recommendations including those relating to technological requirements or ethical considerations for behavioural support delivered via telehealth (Lee et al., 2015; Peterson et al., 2019; Pollard et al., 2017; Rios et al., 2018; Romani & Schieltz, 2017; Wacker et al., 2016) which should be consulted by practitioners prior to adopting telehealth within their practice. Whilst there are no specific governmental guidelines in the UK at the present time, any service using telehealth will also be required to adhere to all relevant laws governing in-person support and remain up to date with legislation changes or guidance developed in the future.

The guidelines presented here are particularly relevant in the context of the global coronavirus pandemic in early 2020 in which telehealth methodologies were adopted speedily and on a mass scale. The lack of industry specific guidance, and local / national policy focusing on the use of telehealth is particularly concerning in this context given that such services have recently been used frequently, and for a range of purposes, without proper guidance for their appropriate, ethical, and secure use. As a result, the importance of studies such as this which generate guidelines relating to the use of telehealth for specific purposes, and of the development of local and national policy governing telehealth use cannot be overstated.

Conclusion

The results of this study provide important information about the perceptions of family carers and professionals about the use of telehealth for behavioural support. These findings will be vital for practitioners to consider when considering adopting telehealth as a method of service delivery, and for family carers who may be considering whether to accept support provided via telehealth. The study also presents a number of practical steps that can be taken by both professionals and family carers to facilitate the use of telehealth where appropriate, and steps for overarching governing bodies to consider in order to regulate and standardise the use of telehealth within the field. Taken together with the findings of Chapters Two and Three, the empirical studies in this thesis have demonstrated the emergent feasibility of implementing functional assessment and intervention approaches by training family carers both in-person and via telehealth, as well as added important contributions to the literature about the acceptability of telehealth amongst professionals and family carers. The final chapter (Chapter Seven) will synthesise findings from the entire thesis, discuss emerging themes within the findings, and consider broader limitations and directions for future research arising from the thesis more generally.

Chapter Seven

General Discussion and Concluding Comments

Chapter Overview

This chapter will synthesise findings from the thesis in relation to the overall aim which was to "explore the evidence base for the use of function-based interventions (FBIs) with young children with intellectual / developmental disabilities (IDDs) and consider how such approaches can be utilised within a UK context via extensive collaboration (within clinical work) with family carers". Firstly, a summary of the findings in relation to this aim will be provided to contextualise the subsequent discussion and provide a clear overview of results from each element of work within the thesis, as well as highlight how the findings offer a unique contribution to the field. Following this, key additional themes that emerged within the findings will be highlighted and discussed in relation to both the thesis aim and the existing evidence base. Finally, overall limitations will be considered alongside any directions for further research arising from the thesis.

Summary of Findings in Relation to the Thesis Aim

As noted above, the aim of the thesis was to "explore the evidence base for the use of FBIs with young children with IDDs and consider how such approaches can be utilised within a UK context via extensive collaboration (within clinical work) with family carers". This aim recognises the lack of empirical research relating to the use of FBIs with young children with IDD in the UK, and the similar lack of UK research relating to collaborating with and training family carers in these approaches. Furthermore, as outlined throughout it is particularly important within a UK context to consider ways to adapt approaches to fit both within the service and support structure within the UK, and also the cultural context (discussed in detail in Chapters Four and Five). Given the multiple gaps identified in the literature, and the unique contribution of the UK context, the thesis aim is therefore multi-faceted and individual chapters address different parts of the aim. As a result, the following discussion will deconstruct the overall aim and summarise findings from each chapter in relation to their contribution to each element of the overall aim. Specifically, the aim will be deconstructed for discussion as follows;

1. The use of functional assessment (FA) and FBIs with young children with IDD
2. Adaptation of approaches for a UK context
3. Collaboration (within clinical work) with family carers

The Use of Functional Assessment and Function-Based Interventions with Young Children with IDD

This element of the thesis aim is addressed across several chapters which draw together and contribute to the evidence base in this area. Firstly, the theoretical underpinnings for such approaches in relation to challenging behaviour (CB) were examined in Chapter One, highlighting the role of behavioural theory in understanding both the development of CB and relevant intervention approaches. The evidence emphasises the importance of a thorough FA identifying the sources of reinforcement that maintain CB (i.e., access to tangible items / attention, escape from aversive contingencies / environments, sensory stimulation or pain reduction; see Chapter One) in order to design individualised FBIs. It was highlighted that FA and subsequent FBIs are now considered gold standard within the field, with dominant approaches in the UK such as Positive Behaviour Support (PBS: Carr et al., 1999; Gore et al., 2013; Horner et al., 1990) and national guidelines (e.g., NICE, 2015) recommending their use; their importance is therefore clear. Finally, Chapter One recognised that the evidence base for the use of FA and FBI with people with IDD of all ages who display CB is extensive, but that there were no examples within the literature of such approaches being utilised for specifically young children within a UK context.

Following this, Chapter Two examined the evidence base for the use of function-based positive interventions (FBPIs)[3] for CB with specifically young children with IDD, as previous reviews

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[3] Defined as those which did not include punishment procedures and were not solely pharmacological or extinction based (see Chapter Two for more information).

focused on people with IDD of any age, with specific needs / characteristics, or who displayed specific forms of CB (see Chapter Two). This was achieved through a systematic review and meta-analysis examining the use of FBPIs (all of which were preceded by a FA) with children with IDD aged under seven years. The review synthesised findings from 52 single-case design (representing 106 interventions) and eight group design studies, concluding that across the substantial evidence base the use of such approaches is well supported by the research. All interventions achieved medium to high effect sizes, evidencing large reductions in CB and good outcomes following fading / generalisation measures and at maintenance data collection points. Single case design articles focused on interventions delivered directly to the child with IDD and most commonly involved single intervention approaches (the most frequent of which was skills teaching / differential reinforcement of alternative behaviour [ST / DRA]) as opposed to multicomponent interventions. It was noted that the most effective intervention type used within single case design studies varied based on the outcome of interest, as the most effective approach after the main intervention (which was environmental adaptations / noncontingent reinforcement [EA / NCR]) was not necessarily the most effective following generalisation and maintenance measures (for which the most effective intervention was ST / DRA). It was therefore concluded that the specific outcome(s) of interest must be considered when examining the evidence base for any single intervention type. Given that ST / DRA approaches were the most frequently used and therefore had the most extensive evidence base, as well as evidencing good outcomes generally and specifically in relation to generalisation and maintenance, this approach was chosen for subsequent studies in the thesis. For group design articles, the most effective approach was found to be training for family carers (as opposed to training for staff or multiple stakeholder groups), though the low number of group design articles included means that this finding can only be tentatively made. Chapter Two also noted that the evidence base has significant methodological limitations and gaps in the evidence which limit the strength of conclusions that can be made (see Chapter Two for discussion).

However, as noted above, there were no examples found in Chapter Two of the use of such approaches in the UK. Whilst such approaches are undoubtedly used in clinical practice in the UK, there appears to be no examples of their use in the empirical literature for this population. As a result, empirical studies within this thesis aimed to assess the feasibility of the use of such approaches within a UK context. Specifically, Chapter Four aimed to assess the feasibility of the use of FAs and FBIs (specifically, Functional Communication Training [FCT] interventions: Carr & Durand, 1985) with five children with IDD in a UK context, delivered both by the researcher and via training for family carers, and Chapter Five aimed to assess the feasibility of the use of FAs when two family carers were trained in such approaches via telehealth (i.e., the use of technology across distance; see Chapter Three). The results of both studies demonstrated emergent feasibility of conducting FAs both directly with children with IDD and via training for family carers. Differentiated outcomes were achieved for most participants, and, where trained, family carers evidenced high overall fidelity for their implementation of the assessment approaches with their child. This supports the extensive evidence base utilising such assessments with young children with IDD (see Chapter Two) and is novel in demonstrating the use of FAs with this population in a UK context. Some difficulties were encountered in completing the observational elements of the assessments as part of these studies. However, results of observational elements of FAs are rarely reported in the literature for this population therefore it is unclear whether this is a unique finding, or a broader difficulty encountered across the evidence base. Some of the difficulties encountered with the observations also related more generally to challenges encountered in the work and are described further below.

However, it proved more difficult to implement the FCT approaches utilised in Chapter Four for numerous reasons (as discussed in Chapter Four) which often related to unique challenges arising for each participant. As noted above, there were also a number of more general practical challenges encountered in relation to the intervention approaches which are discussed further below. As a result, the interventions did not evidence a reduction in CB in line with the literature examined in Chapter Two (and were therefore not used in Chapter Five). This represents a divergence from the existing evidence base which suggests that these approaches are likely to be effective for this population. There are several potential explanations for this divergence relating to challenges encountered that may have impacted effectiveness (as discussed in Chapter Four and below). However, it is also possible that publication bias (i.e., the non-publication of null results) may partially explain this divergence since it limits the publication of non-effective studies that may outline some of the challenges encountered in implementing FBIs for this population. In the applied behaviour analysis (ABA) literature publication bias has been clearly demonstrated (e.g., Sham & Smith, 2014; Tincani & Travers, 2019) and may be particularly influential as it may result in an over inflation of the estimated effectiveness of an approach. It is also likely to hinder researchers and practitioners in intervention efforts since little information is provided in published studies relating to practical difficulties or to characteristics of non-effective interventions. As a result, the non-effectiveness found in Chapter Four may not be uncommon, however it is difficult to substantiate this claim given that null results are likely to be under reported in the literature.

Despite the difficulties encountered in relation to the FCT interventions in Chapter Four, this thesis has drawn together existing evidence relating to the use of FAs and FBIs with young children with IDD and demonstrated emergent feasibility of their use within the UK. This presents a novel contribution to the field by collating evidence relating to specifically young children with IDD (rather than people with IDD of all ages or those with specific needs / characteristics; see Chapter Two), and demonstrating the use of such approaches within the UK, which had previously been a clear gap in the literature.

Adaptation of Approaches for a UK Context

Given the lack of evidence of the use of FAs and FBIs in the UK, it is also important to consider any adaptations that may be needed when such approaches are implemented in a UK context, therefore this was a second clear focus in the thesis aim. The distinct features of the UK that may require consideration are described throughout the thesis (see, in particular, Chapters Four and Five), and include the relatively small number of behaviourally oriented professionals available to support a wide population of individuals with IDD, the emphasis on stakeholder collaboration and involvement, and a more social model of support when compared to other contexts (e.g., the USA where most of the evidence originates, which often adopts a more medical model; see Chapter Four). This latter point is discussed further in relation to the final element of the thesis aim below, therefore this section will focus particularly on adaptations that may be needed in relation to the small number of behaviourally oriented professionals in the UK.

Throughout the empirical work presented in this thesis, the UK context was considered at all stages. For example, recruitment for all studies took place by utilising methods commonly used in the UK, procedures were designed to be congruent with the type and extent of support typically offered within clinical contexts (for studies one and two), questionnaires were modified to reflect UK terminology etcetera. Given that behavioural approaches are less commonly available in the UK than other contexts as outlined above, extensive work was also undertaken to ensure that such approaches were explained and understandable both to participants and those supporting recruitment. For example, for all studies the researcher met with all individuals involved in supporting recruitment to fully explain the study and answer any questions, information sheets were designed which contained explanations of behavioural approaches, an extensive study manual was devised for studies one and two which outlined behavioural approaches, and significant time was spent with families discussing behavioural approaches prior to beginning study procedures. Whilst much of this work may also be needed in other contexts, this was a significant and important element of the work conducted throughout this thesis and particularly relevant within the UK context. The relative lack of behavioural expertise in the UK, and some evidence of negative perceptions of behavioural approaches (e.g., Milton & Moon, 2012; Milton, 2014; Milton, 2018) was an important consideration; whilst work conducted here aimed to normalise and provide accurate information about these approaches, more work is likely needed in these respects. Nevertheless, it was possible to engage with family carers and professionals throughout this work and both were receptive to their involvement. Significantly, it was possible to train families and work directly with children with IDD as described in studies one and two (Chapters Four and Five), and to involve multiple stakeholders in consultations relating to social validity for study three (Chapter Six, discussed further below). This is an important finding and suggests that such work may fit well within a UK context.

In addition, efforts were made to adapt approaches to ensure that access to behavioural support can be maximised even where behavioural expertise is scarce (as in the UK). This was achieved through a focus on the use of telehealth throughout the thesis, as telehealth may provide a method for professionals to support families across significant distances. The existing evidence base for the use of telehealth in ABA work was outlined in Chapter Three via a systematic review including 20 articles. Given the infancy of research relating to the use of telehealth in ABA the included articles focused on varying approaches, including assessments, skills teaching, and interventions for CB. However, in all instances results were found to be favourable in relation to the outcome of interest, and, where examined, were comparable to support provided in-person. Furthermore, approaches were found to be socially valid (when examined retrospectively, i.e., after participants had received telehealth services), and cost effective, with few technological difficulties encountered. Nevertheless, some issues were noted with fidelity when procedures were implemented by someone who had been trained via telehealth, methodological quality of the evidence base, and generalisability of results (e.g., as all participants were children with IDD), limiting conclusions. Despite this, Chapter Three concluded that there is a promising emerging evidence base for the use of telehealth within ABA work and provided a novel contribution to the field by collating this emerging evidence.

However, there were no examples identified in Chapter Three of the use of telehealth for behavioural work in the UK, and as a result Chapter Five examined the feasibility of its use by training two family carers to conduct FA procedures with their child with IDD. As noted above, both family carers were able to implement procedures with high overall fidelity and it was found to be feasible to conduct training solely via telehealth for this study. Some difficulties were encountered relating to identifying individuals to support family carers in situ (family carer assistants [FCAs]), specific elements of the coaching and training procedures, and data collection where technological difficulties were encountered. However, Chapter Five provides a significant contribution to the field by presenting a first demonstration of the use of telehealth approaches in behavioural support within the UK, an area of emerging research and an approach that may be particularly important for a UK context. This is also significant as the use of telehealth is becoming a more important consideration for the field generally (and indeed, for a number of fields) within the context of the global coronavirus pandemic experienced in 2020. As a result of the pandemic, all in-person support was temporarily suspended, and many practitioners subsequently adopted telehealth speedily on a large scale in order to continue supporting their clients. Studies outlining the use of telehealth (see Chapter Three), exploring feasibility and acceptability in specific contexts (such as Chapters Five and Six), and supporting practitioners to troubleshoot ethical or practical challenges (e.g., Chapters Five and Six, Lee et al., 2015; Peterson et al., 2019; Pollard et al., 2017; Quigley et al., 2019; Romani & Schieltz, 2017) are vitally important to this process.

Whilst the existing evidence base and Chapter Five both outline the utility of telehealth within ABA, it is also important to consider social validity and acceptability amongst stakeholders, since this is likely to influence uptake. To date, all examinations of social validity relating to telehealth in ABA were retrospective in nature, meaning that participants were asked their perceptions after having received telehealth services. This approach is inherently flawed as it may be biased towards those with more favourable views of telehealth as they have agreed to receive support via telehealth and may have experienced positive outcomes for themselves or their child as a result. A more hypothetical examination of social validity was therefore needed in which stakeholders were asked their perceptions without the prospect of receiving telehealth services. This was the focus of Chapter Six which presented the results of a Delphi consultation with 11 professionals and six family carers about the use of telehealth for behavioural support. Both family carers and professionals highlighted advantages to the use of telehealth including easier access to support, logistical benefits (e.g., less time, travel or costs involved), facilitating the involvement of the client with IDD, facilitating multi-disciplinary work, and advantages relating to the technology (e.g., the ability to video record instances of the behaviour, revisit advice provided in writing). However, family carers highlighted less advantages to the use of telehealth suggesting that they felt less favourably about its use overall than professionals.

Both panels also identified a range of disadvantages / barriers to the use of telehealth including concerns about communication difficulties, practical difficulties with delivering interventions via telehealth, ethical issues such as confidentiality, family carer confidence and preference about the use of technology, concerns about increased family carer burden, reduced quality of support, professional practice issues, and rapport building with the client with IDD. Again, both panels highlighted different numbers of disadvantages / barriers with family carers highlighting more than professionals suggesting greater concern about support provided via telehealth. Despite this, both panels were able to suggest potential solutions to the barriers including solutions on an individual level (e.g., offering in-person support also, accessing additional training, modifying communication) and a national level through the production of national guidelines relating to the use of telehealth. The majority of participants suggested that they would be willing to use telehealth either within their own professional practice or as a way to receive support about their relative's behaviour, suggesting generally positive perceptions of the use of telehealth overall. This study was unique in presenting a hypothetical exploration of the social validity of telehealth use in ABA and therefore presents a novel contribution to the field. It also presents a UK perspective which again was a highlighted gap in the literature and therefore a significant addition to the evidence base.

Collaboration (in Clinical Work) with Family Carers

The final significant element of the thesis aim relates to extensive collaboration with family carers. Chapter One strongly argued that family carer collaboration in FAs and FBIs with young children with IDD is a vital component of effective interventions, outlining the evidence base relating to involving family carers in these approaches. A hierarchy of levels of involvement was outlined as follows;

1. Family context being considered by clinicians / researchers but no meaningful involvement of family carers beyond this,
2. Involvement of families in a consultative role and / or implementing interventions after they have been established by clinicians / researchers; and,
3. Family carers taking the lead throughout the process, implementing all elements, and working with clinicians / researchers to analyse results and design interventions (see Chapter One for discussion).

It was argued that this latter model is likely to maximise contextual fit (see below) for families and the likelihood that interventions will be continued over time, as well as evidencing positive outcomes for family carers themselves through increased confidence, knowledge and skills. Chapters Four and Five of this thesis aimed to adopt this extensive model within a UK context by training family carers to implement all elements of the assessment and intervention work with their child with IDD, and to collaborate with family carers for intervention design and evaluation. This was deemed to also be particularly important in a UK context given the sparsity of professionals with behavioural expertise, meaning that family carers may need to take a greater role in work with their child. It also fits well within a UK cultural context which tends to adopt a more social model of support for people with IDD as opposed to a medical model (as discussed above).

The results of Chapters Four and Five demonstrate the emergent feasibility of involving family carers in such an extensive way within the UK. Family carers conducted observations of their child's behaviour, implemented experimental functional analyses (EFAs) with high overall fidelity (i.e., >80% accuracy), collaborated with the researcher to select (Chapter Five) and design (Chapters Four and Five) intervention approaches, subsequently implementing intervention procedures (Chapter Four) with similarly high fidelity. As noted above, challenges were encountered and are discussed in detail below, however emergent results are positive about the extensive involvement of family carers in these approaches. This mirrors results in the literature that describe clear positive outcomes for family carers and children with IDD when family carers are involved in this way (e.g., Fettig & Barton, 2014; Keen & Knox, 2004; Lucyshyn & Horner, 2002).

Chapter Six further built upon the importance of involving and collaborating with family carers by seeking their consultation in a Delphi study examining the social validity of telehealth. Whilst two families were recruited to take part in a telehealth-based study in Chapter Five, a large number were initially interested in the study but did not progress to enrolment. The reasons for this are likely to be varied (see Chapter Five for discussion) and it is likely that the telehealth context played a role in some instances, given that uptake of telehealth is reportedly low in other fields (e.g., Choi et al., 2013; Gorst et al., 2014; Sanders, C. et al., 2012; Subramanian et al., 2004). As a result, the involvement of family carers in Chapter Six provides an important and novel contribution to the field as it provided insight into the perceptions of family carers about the use of telehealth for behavioural support, which may be linked to their likelihood of accepting telehealth services.

Taken together, family carer collaboration is evident across all the empirical work in this thesis. Given the relative lack of such extensive collaboration in the existing evidence base its inclusion here presents an important contribution to the field by describing this work, outlining challenges encountered (see below), and demonstrating emergent feasibility of approaches that could be utilised in work with family carers.

Additional Themes That Emerged From the Findings

As noted above, in addition to clearly meeting the aim of the thesis, several additional themes emerged from the findings. These themes provide further information about the successes and challenges encountered throughout the work and are therefore important to consider in detail to provide other researchers and practitioners with an account of key areas for consideration in similar work. Specifically, the following themes emerged and are discussed below:

1. Additional skills required
2. Contextual fit and flexibility
3. Practical challenges
4. Challenges relating to the research evaluation
5. Tension between research and clinical practice

Additional Skills Required

Throughout the empirical work in this thesis, a range of skills were needed by the researcher; the majority of these were anticipated and related to the behavioural techniques, training / coaching techniques, and research evaluation. However, there were a range of additional skills needed that went beyond the basic implementation of techniques and research evaluation. For example, soft skills (such as rapport building) utilised when working with families, professional collaboration etcetera. Whilst the need for these skills was not unanticipated, their use is not well documented within the behavioural literature and therefore there is little guidance for researchers on the types or extent of skills that may be needed when undertaking similar work. The first additional theme within the findings therefore focuses on these skills to provide practitioners with an overview of this for similar work.

Firstly, as noted above the involvement of family carers in this thesis was invaluable, and families who took part engaged well with the research (though a high percentage of participants dropped out of the research as noted throughout Chapters Four to Six). Their involvement required sensitive consideration, particularly as families across both empirical studies in Chapters Four and Five encountered a range of additional difficulties (such as those outlined in Chapter One) during the research. Despite these difficulties, it was possible to complete the study procedures and family carers were positive about their experiences during the studies. This did, however, require the researcher to utilise a range of skills outside of the research context to support families sensitively and effectively. This included sensitive rapport building, signposting to local services, emotional support and empathy, empowering family carers during training to implement procedures where their confidence was low etcetera. These 'soft skills' are rarely reported in the behavioural literature (with the exception of studies focused on family-centered PBS, e.g., Keen & Knox, 2004), though are well described in other fields (e.g., Lambert, M. J. et al., 1978; Lloyd, C. & Maas, 1992; Schöttke et al., 2017), meaning that their description throughout this thesis is a novel contribution to the behavioural literature. Consideration of these areas is likely to be critically important to the success of any given behavioural approach in which young children with IDD and their families are involved, given the importance of family carers in their child's support and the likelihood of additional difficulties being experienced by families (see Chapter One), and was an important element of successful outcomes reported across the studies in this thesis. It is clear that consideration of these elements is likely to happen in clinical practice and may well underpin successful outcomes reported in the literature, however their description within a behavioural research context is also important to support practitioners in the identification and development of these important skills.

In addition, extensive collaboration was required throughout this work with other professionals in the field. This collaboration served several purposes, including support for recruitment, scientific and ethical review of procedures, clinical supervision, and logistics such as accessing clinic space and resources. Such collaboration is likely to be commonplace in clinical work and multidisciplinary work is often the norm in practice. However, similarly to the skills outlined above, descriptions of the extent of such collaboration in a research context throughout this thesis are novel within the behavioural literature and therefore present a unique contribution to the field.

Contextual Fit and Flexibility

A second theme that emerged within the findings was the importance of contextual fit and flexibility (as far as possible) within the work. For example, it was necessary to adapt procedures (where possible and allowed by ethical approvals) for individual participants. Specifically, the form of communication responses in Chapter Four was varied based on participant need, prompting methods were individualised for each participant, session format was adapted as needed etcetera. These modifications to procedures were possible within the ethical approval and did not compromise the scientific rigour of the studies. However, this level of flexibility could easily be overlooked within research studies given the need for rigour and extensive procedures or protocols. The description of this flexibility is therefore important here as it can highlight areas where flexibility can be incorporated in similar work. This flexibility is likely to have been vital in supporting family carer and participant engagement, though as noted below even greater flexibility was needed at times, representing a tension between clinical work and the research context.

In addition, efforts were made to maximise contextual fit as far as possible. Contextual fit (see Albin et al., 1996) is the extent to which approaches fit within the family context (i.e., with consideration of the family's goals, needs, resources, beliefs etc.) and, though understudied (McLaughlin et al., 2012), may be an important influence on outcomes and the extent to which approaches are continued over time (e.g., Moes & Frea, 2002). Within this thesis several approaches were used to maximise contextual fit as described throughout. For example, procedures were conducted at a location and time that was preferred by family carers, family carers were extensively involved in assessments and intervention approaches which enabled them to comment on adaptations they felt were needed to maximise the extent to which procedures fit within their family context and would be appropriate to their child etcetera. In study two this extended to intervention procedures also, given that family carers were extensively involved in the development of a Behaviour Support Plan (BSP) for their child. Whilst it is likely that contextual fit could have been maximised further outside of a research context, responses to questions relating to this on the Treatment Acceptability Rating Form – Revised (TARF-R, Reimers & Wacker, 1988) in studies one and two suggested that participants felt that approaches fit well within their family context, highlighting that contextual fit was evident. This is an important finding though further examination of ways to maximise contextual fit within a behavioural research context is warranted.

Practical Challenges

As noted above, several practical challenges were encountered in this work relating to implementation of procedures. Whilst challenges were not unexpected, they are rarely documented within the literature and therefore their consideration here provides an important overview for practitioners designing similar studies. Challenges relating to the work completed with individual participants are discussed within Chapters Four and Five as needed, therefore discussion here focuses on challenges common to several participants.

The first practical difficulty encountered related to logistics such as scheduling and resource requirements. Scheduling presented a significant challenge throughout studies one and two and is potentially implicated in the non-successful intervention outcomes reported in Chapter Four. It was not possible to require families to commit to a weekly appointment and there were often extraneous events influencing scheduling such as illness, holidays, inclement weather etcetera. These difficulties are commonplace in practical work and as such are not unexpected here, though are important to highlight given their potential influence on the study results.

In addition, challenges were also encountered in the resources required and available as part of the empirical studies. In study one, the flexibility of study location (i.e., within NHS clinics or family homes) meant that resources needed to be provided by the researcher with some items provided by families where needed (e.g., preferred items). Since some resources were provided by families these naturally varied between participants, representing both an advantage and potential limitation in that resources were not standardised. However, resource needs also presented a practical challenge in that it was not possible to provide an extensive variety of toys / activities during sessions as the researcher was limited to items that could be transported to different locations. This may have impacted outcomes as some participants may have benefited from alternative resource / activity options. Whilst efforts were made to tailor activities and resources for each participant based on family carer report, these were not always successful. This is likely due both to the documented lack of congruence between indirect reports of preferred items and actual preference when examined directly (see Hagopian et al., 2004 for discussion), and different stimulus control conditions which may have impacted participants' behaviour where resources were not the same as those used in daily activities, were in a different location / context, or mediated by a novel individual (the researcher). These difficulties could be overcome by ensuring the use of formal preference assessments for all participants and undertaking more observational work to inform resource selection. However, it is likely that some difficulties may remain since resources for this work needed to be portable or readily available within the home environment. Resources also presented a challenge in study two in which families provided all toys / activities for the child. Whilst this was an advantage since it preserved any existing stimulus control conditions, it also presented a challenge in relation to identifying appropriate activities, particularly for the demand condition of the EFA as participants found it difficult to identify an appropriate activity. Again, these challenges are not unique to this work and are also likely to be relevant in general clinical work.

The second major practical challenge encountered related to the limited person-power available as part of these studies. The researcher worked independently with families, with other individuals involved only in an advisory capacity (e.g., academic or clinical supervisors, speech and language therapists), supportive capacity (e.g., for recruitment), or for interobserver agreement (IOA) data collection. This is likely to be different to such work conducted in clinical contexts where a multi-disciplinary team may be involved, and more than one individual may be available to work directly with a family. This presented a challenge in several ways. For example, it limited the individuals the researcher was able to work with both in terms of absolute number at any one time, and also in terms of their characteristics / needs as individuals presenting severe CB would not have been included due to difficulties keeping the child, family carer and researcher safe during appointments. Furthermore, this also presented challenges relating to data collection as described throughout the thesis, as it was often not possible to collect data in real-time due to the need to directly support participants, therefore data were often collected from video recordings of sessions which were sensitive to technical failure. This also limited capacity for IOA data collection. Whilst the involvement of only one main individual was likely an advantage in relation to rapport building with families and continuity of support, the challenges inherent with this warrant consideration of how others may be involved in sessions. In study two, further individuals were involved and acted as FCAs, though due to challenges relating to the involvement of FCAs (see Chapter Five) this requires further consideration in future work. Other researchers have also sought to involve additional individuals to support participants in this type of clinical work (particularly within a telehealth context, see Barretto et al., 2006; Suess et al., 2016; Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron, 2013) and this is a novel approach within the UK that requires further examination.

Challenges Relating to the Research Evaluation

In addition to practical challenges, several challenges were encountered in relation to the evaluation of approaches throughout the thesis. The most significant challenge encountered related to recruitment and retention efforts which are extensively described in Chapters Four to Six. Recruitment and / or retention of participants was a challenge for all empirical studies included in this thesis and represents a key issue for research more generally, in which low sample sizes are a common limitation influencing generalisability and the strength of conclusions that can be drawn from an individual study. Recruitment challenges in the field of IDD are particularly common and therefore were not unexpected as part of this research. This may have been further exacerbated within the current thesis by the targeted population who may experience a range of difficulties which could limit involvement in research due either to personal characteristics and circumstances (e.g., knowledge, confidence, support available etc.; see Chapter One) or due to the child's CB limiting the family's ability to attend appointments and engage in research. However, the extent of recruitment challenges was not anticipated, and, despite extensive recruitment efforts, the recruitment target was not met in any of the empirical studies.

Furthermore, to facilitate recruitment participant inclusion criteria were sometimes relaxed (as described in the individual chapters), increasing the variability in participant characteristics, and limiting the strength of conclusions. There is minimal research on ways to maximise recruitment efforts specifically for families of children with IDD. However, in a notable exception Adams et al (2017) compared indirect recruitment methods (i.e., telephone, email, or postal recruitment) with in-person recruitment via researchers attending clinics and approaching families in the waiting room. They found that this latter method was significantly more effective for recruiting families and that it did not increase the time commitment for researchers as less follow up efforts were required when in-person recruitment was utilised. Whilst this provides some insight into useful recruitment methods, this approach may only be possible where eligible participants are likely to attend clinics in high enough numbers to justify the time required by researchers. For studies included here, this method was therefore inappropriate as the specific population targeted (i.e., young children with IDD who display challenging behaviour and their families) is unlikely to attend clinics in large enough numbers at any one time, making in-person recruitment prohibitively time consuming. It is possible that other alternative approaches to recruitment might be useful. For example, it may be possible to collaborate more closely with family carers through research advisory groups and coproduced research, which might enable improved recruitment for studies by allowing a more personal approach to participants. However, this hypothesis has not been examined in research and requires empirical validation.

A second challenge encountered in the research evaluation of this work related to the nature of required ethical approval, particularly for studies one and two which involved working directly with young children with IDD who display CB and their families. Whilst ethical approval was granted for both studies in some cases this was a protracted process (taking longer than six months) and limiting the flexibility to make changes to procedures in a prompt way, based on participant need or on results. For example, it was not possible to utilise multiple short sessions for participants in study one which may have been useful for Gary and Donna who did not respond well to extended trial based procedures, or to condition new reinforcers for Billy who had a limited pool of available reinforcers (see Chapter Four for further detail). Whilst it would have been possible to build these types of procedures into the original ethics application, it had not been anticipated at the outset of study one that these might be necessary, and the protracted nature of making amendments to ethical approvals prevented these procedures being incorporated at a later date. Had these issues been anticipated, it would have been possible to obtain approval for these types of procedures at the outset (e.g., via a protocol which detailed a range of different procedures to be utilised based on participant need / characteristics), and avoid the need for subsequent amendments to ethical approvals. This flexibility is an important component of clinical work, and particularly important when working with families who may require sensitive and flexible support as described above, and difficulties in responding flexibly to family / participant need represents a tension between research evaluation in the UK and clinical application as discussed further below.

Finally, some challenges were also encountered in relation to data collection in this thesis, particularly for studies one and two. Data collection was extensive and required considerable time on the part of the researcher, suggesting that studies of this nature may be particularly challenging in contexts in which researcher resources are scarce. However, this is likely to also be a challenge in clinical practice since some of the most laborious data collection related to core data informing the assessments and interventions (e.g., relating to CB) and would therefore also be needed within a clinical context. Furthermore, due to the extensive time required for data collection and the complexity of data collected, it was also difficult to collect IOA data which represents a limitation for both studies one and two (as described within Chapters Four and Five). Whilst it may be possible to design data collection procedures to minimise the time required by researchers / clinicians, this will only be possible in some instances and it is likely that extensive data collection will be needed in all such work of this nature given that clear demonstration of experimental effects is a hallmark of ABA interventions (Baer et al., 1968; Baer et al., 1987). Extensive data collection is also an advantage in that it provides a stronger foundation from which to make clinical decisions and enabled detailed discussions with family carers here which informed clinical work and supported family carer training. The description of the extensivity of data collection required for each study within this thesis presents a novel contribution to the field since published research articles often have only limited space to discuss data collection procedures in detail. As a result, researchers and clinicians can more clearly anticipate and plan for such data collection when undertaking work of this nature.

Tension Between Research and Clinical Practice

The final emergent theme relates to the tension between the need for scientific rigour within research, and clinical practice requirements. Given that the studies involved assessment and intervention for CB for children with IDD and their families, they constituted both research studies and clinical work and therefore tensions relating to this arose in at least two main areas. Firstly, as noted above, the requirement for detailed procedures and protocols as part of ethical approval procedures limited the flexibility able to be adopted within the studies (due in part to difficulties being unanticipated at the outset, and in part to the protracted nature of ethical approval and amendment procedures). This meant that procedures could be only minimally adapted based on individual participant need. As hypothesised throughout the chapters, modifications to procedures may have enabled more successful outcomes for children and their families, but were not possible due to the extensive procedure for making changes to a study which has been approved by a research ethics committee (REC). Whilst attempts were made to build flexibility into ethics applications this was only possible to a certain extent and did not completely mitigate this difficulty.

Given the importance of thorough scrutiny of research by a REC prior to approval, it is difficult to suggest ways to overcome this difficulty in circumstances in which the level of flexibility required is difficult to anticipate at the outset, and this may fall upon individual RECs in relation to the level of flexibility they allow, or in relation to streamlining of procedures for making changes to prior approvals. Despite this, it is also important to consider the extent to which flexibility is appropriate within a research context, given the need to standardise procedures to ensure the necessary strength of conclusions. This represents a tension between research evaluation of approaches and their clinical use, and there are no known examples of this tension being discussed within the empirical literature. Instead, literature often focuses on the translation of interventions demonstrated to be effective in research contexts into practical contexts (i.e., effectiveness versus efficacy, Hunsley & Lee, 2007; Singal et al., 2014). However, the difficulties here related to a more bottom-up approach in which challenges were encountered in evaluating approaches due, in part, to the research context limiting clinical flexibility. Further descriptions of this tension and consideration of ways to overcome this are therefore needed.

Secondly, the context of this work as a research study and not routine clinical support may have contributed to some of the practical difficulties encountered. As described above, flexibility was built into procedures in order to support contextual fit for families, and the researcher communicated this flexibility to families, striving to ensure that procedures were adaptable to family and participant need as far as possible. However, this may have also signalled to participants that this work was not part of routine clinical support and was therefore more flexible in approach. This may have exacerbated difficulties relating to scheduling or participant engagement, since it was viewed as less formal than typical clinical support. This represented a challenge in both studies one and two in that appointments were not conducted with the regularity that would likely be needed for behavioural change or clear FA outcomes and may have therefore impacted results. As noted in Chapters Four and Five, more regular appointments could have been insisted upon however this would have represented a rigid approach that was not sensitive to participant need (e.g., where breaks were needed due to difficulties encountered in participants' personal lives, illness etc.) and may have hindered participation for some families. This is likely to be a difficult balance in clinical work, though may be more easily overcome outside of a research context since procedures can be continued for longer to overcome extended breaks in appointments. The context of this work as a research study may have further exacerbated this difficulty since families were perhaps less likely to be willing for their child to miss school for a research study (as opposed to clearly defined clinical appointments), meaning that scheduling was limited and sessions may not have been conducted at the optimal time for all participants. Whilst this challenge may be difficult to completely overcome, it may be mitigated by more clearly outlining expectations for families at the outset and discussing the importance of regular attendance at appointments. In addition, greater collaboration between researchers and clinicians in the implementation of research studies might also be useful to mitigate these types of issues. For the studies included here, these difficulties could have been more clearly anticipated by the researcher which represents a limitation in the work conducted, although the lack of discussion of these issues in the literature undoubtedly exacerbated this.

Whilst these tensions influenced outcomes in the empirical studies of this thesis, there are no known descriptions of the tension between research studies and clinical work in the literature. It is possible that procedures in other contexts are able to minimise this tension (e.g., through different ethical approval procedures in other countries), however the description of this tension within UK research is an important contribution to the field. It is hoped that this description will stimulate further research in this area and the publication of studies that are able to support researchers and practitioners to avoid or minimise these tensions in practice.

Overall Limitations and Future Research Directions

Limitations and future research directions specific to each chapter are discussed within each chapter's discussion section. As a result, discussion here will focus on limitations relating to the overall thesis and future research directions arising from the work as a whole. Whilst the research provides a novel contribution to the field in several areas as outlined above, there are also some limitations that should be considered when interpreting results. Paramount among these is the nature of the research as a small-scale exploration of feasibility / acceptability, conducted within a relatively low resource context. Whilst initial explorations of feasibility are important, due to challenges already described each study was also smaller in nature than intended. It would have been beneficial to include additional participants (from more diverse demographics) and expand each study to add weight to the conclusions that could be drawn. As a result, the research reported here represents initial explorations of feasibility / acceptability only and undoubtedly requires further refinement of the methods and examination within larger trials. Nevertheless, given the lack of UK specific research in this area this thesis provides a significant contribution to the field which, it is hoped, will act a springboard to generate further research.

In addition to and linked to this, several challenges influenced the effectiveness of the behavioural approaches as discussed throughout. Some of these challenges may have been anticipated had UK specific research been available, whilst others were novel. However, the thesis focused on feasibility rather than effectiveness, and despite these challenges it was possible to draw conclusions about the emergent feasibility of approaches. It is clearly also important to ensure that methods are effective in reducing CB and improving other outcomes relevant to families (e.g., quality of life, family carer confidence / skills) therefore future research should also more clearly target effectiveness and explore ways to maximise effectiveness. Some of the challenges encountered here and the resolutions suggested can provide a starting point for this work and ensure that researchers are provided with initial information about likely difficulties, something which was not available for a UK context prior to this work. However, as noted in Chapters Four and Five, it is possible that some of these practical difficulties may have been overcome had greater collaboration with a range of stakeholders (e.g., clinicians) been built into procedures. The lack of more extensive collaboration with other stakeholders throughout this thesis therefore represents a limitation which could usefully be targeted by future research. Greater collaboration is recognised as useful in evaluating complex interventions, defined by the Medical Research Council (2006) in a number of ways including the number and difficulty of behaviours for those receiving the intervention, the number of outcomes, and the degree of flexibility needed within the intervention. Where an intervention meets this definition (as do the approaches utilised in this thesis), the Medical Research Council's (2006) guidelines provide researchers with methods for maximising the development and evaluation of these interventions, and these guidelines place emphasis on the importance of stakeholder collaboration. For example, case study 14 in the Medical Research Council's (2006) guidelines provides examples of methods for involving stakeholders throughout all stages of a project. This involved partnering closely with relevant organisations, signing a memorandum of understanding about responsibilities, and ensuring that organisations were involved in conducting the study itself (e.g., recruitment, organisation of meetings etc.). These methods resulted in improved recruitment and outcomes throughout the study. Accordingly, the Medical Research Council (2006) recommend that user involvement be included at all stages of a project involving complex interventions, including development, implementation of procedures, and outcome analysis.

Whilst extensive collaboration with family carers was built into the work throughout this thesis, collaboration with other stakeholders was limited to specific purposes (e.g., support for recruitment, supervisory arrangements, collection of IOA data). As noted throughout, some of the practical difficulties encountered here were unanticipated at the outset of the study due in part to the lack of discussion of such issues in the behavioural literature. However, it is likely that clinicians within the field often encounter similar issues in clinical work and may have been able to anticipate these issues at an earlier point. As a result, greater collaboration with clinicians at all stages of the project (including project design) may have enabled the author to be more sensitive to potential difficulties that may arise and to build greater flexibility into the research in order to pre-empt and overcome these difficulties. Furthermore, clinicians could have been involved more extensively in receiving training and supporting family carers themselves which would not only increase capability within the relevant support system for family carers more generally but would also have been more consistent with the context in which support would usually be provided. This may have overcome some of the difficulties encountered here in relation to the context of the research being outside of routine clinical support. Finally, the Medical Research Council (2006) also note that adherence to a strict protocol is likely to be inappropriate in complex interventions where greater flexibility is needed, supporting conclusions here. Future research should consider replicating the approaches utilised here but with significant modifications to enable greater flexibility throughout and to more closely align with the Medical Research Council's (2006) guidance (which is due to be updated in 2021).

Alternative behavioural methodologies could also usefully be explored, given the sole focus on FA and ST / DRA here. Whilst a clear focus was necessary within the small scale context of this work, a number of other approaches were identified as potentially effective in Chapter Two and therefore warrant further examination within a UK context, given that ST / DRA approaches will not be appropriate for every child / family. A more extensive approach would be to examine the use of a full PBS framework with young children with IDD in the UK, in a family centred way (e.g., as in Lucyshyn & Horner, 2002), however again this was beyond the scope of this research and represents an area for further exploration. Such work may present additional challenges when delivered via telehealth given its extensivity, requirement for close multi-disciplinary work, and multi-faceted nature, therefore it is likely that the delivery of such approaches via telehealth will emerge more slowly within the literature.

In addition, future research could usefully examine alternative applications of telehealth methodology within behavioural work in the UK, such as training for professionals who then support families via a consultative model, the use of telehealth when working directly with children rather than via training for others, and the use of alternative telehealth technologies. These areas would require not only practical application and evaluation, but also close examination of social validity and acceptability as in Chapter Six. However, their examination would help to build a body of evidence for the use of telehealth within ABA / PBS in the UK which could be utilised by practitioners, clients, and policy makers alike. It will also be important to consider other factors relating to the use of telehealth specifically, such as supporting those families / children who may be less confident using such technology, examining the appropriateness of technology for a range of children / families / outcomes, and refining a package of methodologies which can be utilised as appropriate. As noted above, the widescale adoption of telehealth amidst the global coronavirus pandemic may provide a platform for some of this work although it remains to be seen whether this will be the case. Finally, the focus within this thesis was solely relating to young children with IDD who display CB (with the exception of Study Three, as outlined in Chapter Six), however clearly ABA and PBS approaches are applicable to a much wider population and target a much broader range of outcomes. Similar exploratory feasibility work is required for such applications both for their general use within the UK but also their use via telehealth, and future research could usefully adopt methodology used here to focus on other relevant areas such as this.

Concluding Comments

It is well known that CB is both prevalent and pervasive in young children with IDD and requires early intervention to improve outcomes, both for the child themselves and their family carers. The involvement of family carers in this work is vital given their unique role in supporting their children, and evidence suggests this is likely to also maximise outcomes. Whilst behavioural interventions for children with IDD who display CB are extensively reported in the literature, including those which involve collaboration with family carers, there is little research evidence of their use within a UK context which may differ in specific ways from other countries. As a result, this thesis aimed to examine the use and adaptation of such approaches within a UK context. As described throughout, the feasibility of the use of FAs and FCT via extensive collaboration with family carers was partially confirmed, and procedures were also modified to be delivered via telehealth. The use of telehealth was also demonstrated to be acceptable to family carers and professionals, though a range of barriers were identified which need careful consideration. Whilst this work is exploratory in nature and provides only emergent evidence of feasibility, it provides a significant contribution to the literature by detailing and evaluating the use of such approaches within a UK context, outlining both the successes and challenges of this. It is therefore hoped that this work will provide a springboard for future research within the UK examining ways to implement and adapt interventions to effectively support children with IDD who display CB.

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Appendices

Appendix A

Modified Criteria Used to Assign Evaluative Method Ratings (Chapter Two)

Rating	Criteria
Strong	6 primary indicators rated as "High" No primary indicators rated as "Unacceptable" At least 3 (for single case designs) or 4 (for group designs) secondary indicators rated as "Present"
Borderline Strong	5 primary indicators rated as "High" No primary indicators rated as "Unacceptable" At least 3 secondary indicators rated as "Present"
Adequate	4 primary indicators rated as "High" No primary indicators rated as "Unacceptable" At least 2 secondary indicators rated as "Present"
Borderline Adequate	3 primary indicators rated as "High" No more than 1 primary indicator rated as "Unacceptable" At least 2 secondary indicators rated as "Present"
Weak	Less than 3 primary indicators rated as "High" or more than 1 rated as "Unacceptable" Less than 2 secondary indicators rated as "Present"

Appendix B

Zero Error Points, % Error, and % Accuracy for 3 Graph Digitizer Software Packages (Chapter Two)

Software Programme	Zero Error Points[a]			% Error[b]			% Accuracy	
	$\bar{x}$	*SD*	Range	$\bar{x}$	*SD*	Range	$\bar{x}$	Range
GetData Graph Digitizer	0.02	0.05	0-0.30	1.23	2.44	0-10.08	98.77	89.92-100
Plot Digitizer	0.02	0.07	0-0.38	1.42	2.84	0-13.07	98.58	86.93-100
WebPlotDigitizer	0.05	0.07	0-0.29	1.52	2.80	0-14.55	98.48	85.45-100

Note. [a] In instances where the raw data point value was zero, a percentage error could not be calculated. Instead, the number of data points that the extracted scores deviated from the raw scores was calculated. [b] For data where the raw data point was not zero.

Appendix C

Evaluative Method Ratings for Included Articles (Chapter Two)

		Primary Indicators									Secondary Indicators									
Study	Design	PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	Rating
Athens & Vollmer (2010)	SC	H	H	-	H	-	-	U	U	A	✓	✗	✗	✗	✗	✗	-	-	-	W
Bearss et al. (2015)	G	H	H	H	H	H	H	-	-	-	✓	-	✓	✓	✓	✓	✓	✓	✓	S
Blair et al. (2006)	SC	U	H	-	H	-	-	A	H	H	✓	✗	✗	✓	✓	✓	-	-	-	BA
Blair et al. (2007)	SC	H	H	-	H	-	-	H	H	H	✓	✗	✗	✓	✓	✓	-	-	-	S

		Primary Indicators									Secondary Indicators									
Study	**Design**	**PART**	**IV**	**CC**	**DV**	**LRQ**	**STAT**	**BL**	**VA**	**EC**	**IOA**	**KAP**	**BR**	**FID**	**G/M**	**SV**	**ES**	**ATR**	**RA**	**Rating**
Blair et al. (2010)	SC	H	H	-	H	-	-	A	A	H	✓	✗	✗	✓	✓	✓	-	-	-	A
Blair et al. (2011)	SC	H	H	-	H	-	-	H	H	H	✓	✗	✗	✓	✓	✓	-	-	-	S
Brookman-Frahzee et al. (2012)	G	H	H	U	H	H	H	-	-	-	✗	-	✗	✗	✗	✓	✗	✓	✗	BA
Call & Mevers (2014)	SC	H	H	-	H	-	-	H	H	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Chadwick et al. (2001)	G	H	H	A	H	H	H	-	-	-	✗	-	✗	✗	✗	✓	✗	✗	✓	A

Study	Design	Primary Indicators									Secondary Indicators									Rating
		PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Cheremshynski et al. (2012)	SC	H	H	-	H	-	-	H	H	H	✓	✗	✗	✗	✓	✓	-	-	-	S
Derosa et al. (2015)	SC	H	A	-	H	-	-	U	U	H	✗	✗	✗	✗	✗	✗	-	-	-	W
Dozier et al. (2007)	SC	H	H	-	H	-	-	A	U	U	✓	✗	✗	✗	✗	✗	-	-	-	W
Durand (1993)	SC	H	A	-	H	-	-	A	H	H	✗	✗	✗	✗	✗	✓	-	-	-	W
Durand (1999)	SC	H	H	-	H	-	-	A	H	H	✗	✗	✗	✗	✓	✓	-	-	-	A
Durand & Carr (1992)	SC	A	H	-	H	-	-	A	U	H	✗	✗	✗	✗	✓	✗	-	-	-	W

		Primary Indicators									**Secondary Indicators**									
Study	**Design**	**PART**	**IV**	**CC**	**DV**	**LRQ**	**STAT**	**BL**	**VA**	**EC**	**IOA**	**KAP**	**BR**	**FID**	**G/M**	**SV**	**ES**	**ATR**	**RA**	**Rating**
Durand et al. (2013)	G	H	H	H	H	H	H	-	-	-	✗	-	✗	✗	✗	✓	✗	✓	✓	BS
Falcomata & Gainey (2014)	SC	H	H	-	H	-	-	U	H	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Feldman et al. (2002)	SC	H	A	-	H	-	-	U	U	A	✓	✗	✗	✓	✓	✓	-	-	-	W
Feldman & Werner (2002)	G	H	A	H	H	H	H	-	-	-	✗	-	✗	✗	✓	✓	✓	✓	✓	BS
Fettig et al. (2015)	SC	H	H	-	H	-	-	A	U	U	✓	✗	✗	✓	✓	✓	-	-	-	W

Study	Design	Primary Indicators									Secondary Indicators									Rating
		PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Fisher et al. (2004)	SC	H	H	-	A	-	-	A	A	H	✓	✗	✗	✗	✗	✓	-	-	-	BA
Fisher et al. (2000)	SC	H	H	-	H	-	-	A	U	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Frea et al. (2001)	SC	H	H	-	H	-	-	U	U	A	✓	✗	✗	✗	✗	✓	-	-	-	W
Gore & Umizawa (2011)	G	H	H	U	H	H	H	-	-	-	✗	-	✗	✗	✗	✓	✗	✗	✗	W
Hagopian et al. (2000)	SC	H	H	-	H	-	-	A	H	H	✓	✗	✗	✗	✗	✗	-	-	-	W

Study	Design	Primary Indicators									Secondary Indicators									Rating
		PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Hagopian et al. (1994)	SC	H	H	-	H	-	-	U	H	H	✓	✗	✗	✗	✓	✓	-	-	-	BA
Hagopian et al. (1998)	SC	U	H	-	A	-	-	U	A	H	✓	✗	✗	✗	✓	✗	-	-	-	W
Hammond et al. (2011)	SC	H	H	-	H	-	-	U	H	H	✓	✗	✗	✗	✓	✓	-	-	-	BA
Hanley et al. (1997)	SC	H	H	-	H	-	-	U	A	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Hanley et al. (2005)	SC	H	H	-	H	-	-	U	U	U	✓	✗	✗	✗	✗	✗	-	-	-	W

		Primary Indicators									Secondary Indicators									
Study	**Design**	**PART**	**IV**	**CC**	**DV**	**LRQ**	**STAT**	**BL**	**VA**	**EC**	**IOA**	**KAP**	**BR**	**FID**	**G/M**	**SV**	**ES**	**ATR**	**RA**	**Rating**
Higgins et al. (2012)	SC	H	H	-	H	-	-	U	H	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Koegel et al. (1998)	SC	H	H	-	H	-	-	U	A	H	✗	✗	✗	✗	✓	✓	-	-	-	BA
Lalli et al. (1997)	SC	H	H	-	H	-	-	U	A	H	✓	✗	✗	✓	✓	✓	-	-	-	BA
Lalli & Kates (1998)	SC	H	H	-	H	-	-	A	A	H	✓	✗	✗	✓	✓	✓	-	-	-	A
Lalli et al. (1999)	SC	H	H	-	A	-	-	U	U	U	✓	✗	✗	✓	✗	✗	-	-	-	W
Lambert et al. (2012)	SC	U	H	-	H	-	-	A	A	H	✓	✗	✗	✓	✗	✓	-	-	-	BA

Study	Design	Primary Indicators									Secondary Indicators									Rating
		PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Long et al. (2005)	SC	H	H	-	H	-	-	A	H	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Lorimer et al. (2002)	SC	H	H	-	H	-	-	U	U	U	✗	✗	✗	✗	✗	✓	-	-	-	W
Marcus, Swanson et al. (2001)	SC	U	H	-	H	-	-	U	U	U	✗	✗	✗	✗	✓	✓	-	-	-	W
Marcus & Vollmer (1996)	SC	A	H	-	H	-	-	U	A	H	✓	✗	✗	✗	✗	✗	-	-	-	W
McIntyre (2008)	G	H	H	U	A	H	H	-	-	-	✓	-	✗	✓	✗	✓	✗	✗	✗	BA

Study	Design	Primary Indicators									Secondary Indicators									Rating
		PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
O’Neill & Sweetland-Baker (2001)	SC	H	H	-	H	-	-	A	U	A	✓	✗	✗	✗	✓	✓	-	-	-	BA
Piazza et al. (2000)	SC	H	H	-	H	-	-	U	H	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Radstaake et al. (2013)	SC	H	H	-	H	-	-	A	U	A	✗	✓	✗	✗	✗	✓	-	-	-	BA
Radstaake et al. (2012)	SC	H	H	-	H	-	-	U	U	A	✗	✓	✗	✗	✓	✓	-	-	-	W
Reynolds et al. (2011)	G	U	A	U	H	H	H	-	-	-	✗	-	✗	✗	✗	✓	✗	✓	✗	W

		Primary Indicators									Secondary Indicators									
Study	**Design**	**PART**	**IV**	**CC**	**DV**	**LRQ**	**STAT**	**BL**	**VA**	**EC**	**IOA**	**KAP**	**BR**	**FID**	**G/M**	**SV**	**ES**	**ATR**	**RA**	**Rating**
Ringdahl et al. (1997)	SC	H	H	-	H	-	-	U	U	U	✗	✗	✗	✗	✗	✗	-	-	-	W
Rispoli et al. (2014)	SC	H	H	-	H	-	-	U	A	H	✓	✗	✗	✓	✓	✓	-	-	-	BA
Roberts et al. (1995)	SC	H	H	-	H	-	-	U	A	H	✓	✗	✗	✓	✗	✓	-	-	-	BA
Robertson et al. (2013)	SC	H	H	-	H	-	-	A	H	H	✓	✗	✗	✗	✗	✓	-	-	-	A
Saini et al. (2015)	SC	H	H	-	H	-	-	U	U	U	✗	✗	✗	✗	✗	✗	-	-	-	W

Study	Design	Primary Indicators									Secondary Indicators									Rating
		PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Schieltz et al. (2011)	SC	H	H	-	H	-	-	A	A	U	✗	✗	✗	✗	✗	✓	-	-	-	W
Slocum & Vollmer (2015)	SC	H	H	-	A	-	-	U	U	U	✗	✗	✗	✗	✗	✗	-	-	-	W
Steege et al. (1990)	SC	H	H	-	H	-	-	A	H	H	✓	✗	✗	✗	✗	✗	-	-	-	W
Volkert et al. (2009)	SC	H	H	-	H	-	-	A	A	A	✓	✗	✗	✗	✗	✓	-	-	-	BA
Vollmer et al. (1994)	SC	A	H	-	H	-	-	U	A	H	✓	✗	✗	✗	✓	✓	-	-	-	BA

Study	Design	Primary Indicators									Secondary Indicators									Rating
		PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Vollmer et al. (1999)	SC	H	H	-	H	-	-	H	A	H	✓	✗	✗	✗	✗	✓	-	-	-	A
Wacker et al. (2011)	SC	H	H	-	H	-	-	A	A	A	✓	✗	✗	✗	✓	✓	-	-	-	BA
Wacker, Harding et al. (2013)	SC	H	H	-	H	-	-	A	H	H	✓	✗	✗	✓	✗	✓	-	-	-	BS
Wilder et al. (2005)	SC	H	H	-	H	-	-	H	H	H	✗	✗	✗	✗	✗	✗	-	-	-	W

		Primary Indicators									Secondary Indicators								
Study	**Design**	**PART**	**IV**	**CC**	**DV**	**LRQ**	**STAT**	**BL**	**VA**	**EC**	**IOA**	**KAP**	**BR**	**FID**	**G/M**	**SV**	**ES**	**ATR**	**RA**	**Rating**

Note. **Design** – SC = single case design, G = group design. **Primary indicators** – PART = Participant characteristics, IV = Independent variable, CC = Comparison condition, DV = Dependent variable, LRQ = Link between research question and analysis, STAT = Statistical analyses, BL = Baseline conditions, VA = Visual analysis, EC = Experimental control. H = High, A = Acceptable, U = Unacceptable. **Secondary indicators** – IOA = Interobserver agreement, KAP = Kappa, BR = Blind raters, FID = Fidelity, G / M = Generalisation / maintenance, SV = Social validity, ES = Effect size, ATR = Attrition, RA = Random assignment. **Ratings** – W = Weak, BA = Borderline adequate, A = Adequate, BS = Borderline strong, S = Strong.

Appendix D

Overview of Included Single Case Design Articles (Chapter Two)

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
Athens & Vollmer (2010)	The effectiveness of variations in reinforcement dimension (duration, quality, delay) during differential reinforcement procedures	Reversal	Kenneth (male, aged 6 years) with autism. Relevant behaviour topographies: aggression, property destruction Lana (female, aged 4 years with autism). Relevant behaviour topography: aggression	Experimental	Skills teaching / differential reinforcement of alternative behaviour (ST/DRA)	Weak
Blair et al. (2010)	The effectiveness of individualised positive behaviour support (PBS) in	Multiple baseline across	Alex (male, aged 3 years with Pervasive Development Disorder [PDD]). Relevant behaviour topography:	Multiple descriptive	Multiple	Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	school settings	participants	aggression			
Blair et al. (2011)	The effectiveness of family-school collaboration and individualised PBS	Multiple baseline across participants	Bora (female, aged 4.5 years with autism and mental retardation). Relevant behaviour topography: self-injury Hasu (male, aged 5.5 years with autism and mental retardation). Relevant behaviour topographies: aggression, self-injury	Combined descriptive and experimental	Multiple	Strong
Blair et al. (2006)	The effectiveness of functional behaviour assessment and function based interventions (FBIs)	Multiple baseline across	Mina (female, aged 5 years with severe mental retardation). Relevant behaviour topographies:	Combined descriptive and experimental	Multiple	Borderline Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	in school settings in Korea	participants	aggression, property destruction Nari (female, aged 5 years with severe mental retardation). Relevant behaviour topography: aggression Hyun (male, aged 5 years with severe mental retardation). Relevant behaviour topography: aggression, self-injury			
Blair et al. (2007)	The effectiveness of FBIs in inclusive school	Multiple baseline across	Minsu (male, aged 6 years with mental retardation and autism). Relevant behaviour	Combined descriptive and	Multiple	Strong

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	placements	tasks	topographies: aggression, property destruction, self-injury	experimental		
Call & Mevers (2014)	The influence of establishing operations for positive reinforcement on CB	Reversal	Jett (male, aged 6 years with PDD, cerebral palsy, and developmental delay). Relevant behaviour topographies: aggression, property destruction	Experimental	ST/DRA	Weak
Cheremshynski et al. (2013)	The effectiveness of culturally informed PBS	Reversal	Ken (male, aged 5 years with ASC). Relevant behaviour topography: property destruction	Multiple descriptive	Multiple	Strong
Derosa et al.	The influence of duration of exposure to establishing	Combined multi-	John (male, aged 4 years with autistic disorder and	Experimental	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
(2015)	operation on the effectiveness of functional communication training (FCT)	element and reversal	disruptive behaviour disorder not otherwise specified). Relevant behaviour topographies: aggression, property destruction Frank (male, aged 5 years with autistic disorder and impulse control disorder not otherwise specified). Relevant behaviour topographies: aggression, property destruction			
Dozier et al. (2007)	Preference for FCT or environmental enrichment	Reversal	Michael (male, aged 6 years with autism). Relevant	Experimental	ST/DRA Environmental adaptations /	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			behaviour topography: self-injury		noncontingent reinforcement (EA/NCR)	
Durand (1999)	Generalisation of FCT outcomes with voice output communication aids to new settings with untrained individuals	Multiple baseline across participants	Matt (male, aged 5.5 years with moderate cerebral palsy and moderate mental retardation). Relevant behaviour topography: self-injury Mike (male, aged 3.5 years with severe mental retardation). Relevant behaviour topographies: self-injury, property destruction	Combined descriptive and experimental	ST/DRA	Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
Durand (1993)	The use of voice output communication aids during FCT and child emotional responses.	Multiple baseline across participants	Michelle (female, aged 5.5 years with cerebral palsy and moderate mental retardation). Relevant behaviour topography: Aggression Joshua (male, aged 3.5 years with severe mental retardation). Relevant behaviour topography: aggression	Descriptive	ST/DRA	Weak
Durand & Carr (1992)	Comparison of the effectiveness of FCT and time out with new teachers not trained in the	Multiple baseline across participants	Sam (male, aged 5 years 2 months with borderline mental retardation). Relevant behaviour	Experimental	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	intervention procedures		topography: property destruction			
Falcomata & Gainey (2014)	The effects of variations of noncontingent reinforcement	Multi-element	Lena (female, aged 4 years with autism). Relevant behaviour topography: self-injury	Experimental	EA/NCR	Weak
Feldman et al. (2002)	Evaluation of an established community treatment program	Multiple baseline across participants	Julie (female, aged 3 years 8 months with global developmental delay and seizure disorder). Relevant behaviour topography: property destruction Kevin (male, aged 6 years 8 months with global developmental delay).	Varied for each participant: either combined descriptive and experimental, or multiple descriptive.	Multiple	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			Relevant behaviour topographies: self-injury, aggression Ben (male, aged 2 years 8 months with global developmental delay). Relevant behaviour topographies: self-injury, aggression Paul (male, aged 5 years 10 months with cerebral palsy and severe developmental delay, seizure disorder and hypotonic quadriplegia). Relevant behaviour			

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			topography: property destruction Roger (male, aged 3 years 5 months with developmental delay and autism). Relevant behaviour topographies: property destruction, self-injury, aggression Bridget (female, aged 4 years with global developmental delay, seizure disorder, encephalitis, and asthma). Relevant behaviour topography: self-injury Mark (male, aged 5 years 5			

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			months with global developmental delay and seizure disorder). Relevant behaviour topographies: property destruction, aggression Sean (male, aged 1 year 10 months with developmental delay and neurofibromatosis). Relevant behaviour topographies: property destruction, self-injury Rachel (female, aged 2 years 1 month with global			

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			developmental delay). Relevant behaviour topographies: property destruction, self-injury Jesse (male, aged 6 years with global developmental delay and autism / PDD). Relevant behaviour topographies: property destruction, self-injury, aggression			
Fettig et al. (2015)	The effectiveness of FBIs implemented by parents	Multiple baseline across participants	Jack (male, aged 3 years 10 months with autism and hypoxic-ischemic encephalopathy). Relevant	Multiple descriptive	Multiple	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			behaviour topography: aggression			
Fisher et al. (2004)	Comparing the effectiveness of extinction, extinction with noncontingent reinforcement (with reinforcer maintaining behaviour), and extinction and noncontingent reinforcement with competing stimuli	Combined reversal and multi-element	Katy (female, aged 5 years with moderate to severe mental retardation). Relevant behaviour topographies: aggression, self-injury.	Experimental	EA/NCR	Borderline Adequate
Fisher et al. (2000)	The effectiveness of procedures for delaying reinforcement during FCT	Reversal	Ken (male, aged 3 years with cerebral palsy and profound mental retardation).	Experimental	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			Relevant behaviour topographies: aggression, self-injury, property destruction			
Frea et al. (2001)	The effectiveness of a picture exchange for reducing CB	Multiple baseline across activities	Tim (male, aged 4 years with autism and moderate mental retardation). Relevant behaviour topography: aggression	Unclear	ST/DRA	Weak
Hagopian et al. (2000)	The evaluation of engagement as a measure of item preference, the effectiveness of extinction with noncontingent reinforcement, and	Reversal	Jack (male, aged 4 years with autism and severe mental retardation). Relevant behaviour topographies: aggression, self-injury Emily (female, aged 4 years	Experimental	Differential reinforcement of other behaviour (DRO)	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	variables influencing behaviour during reinforcement schedule thinning		with severe to profound mental retardation and seizure disorder). Relevant behaviour topographies: self-injury, aggression, property destruction			
Hagopian et al. (1994)	The evaluation of schedule effects during noncontingent reinforcement	Combined multiple baseline across participants and reversal	Laurie (female, aged 4 years with PDD and mild mental retardation). Relevant behaviour topographies: aggression, self-injury, property destruction. Lynn (female, aged 4 years with PDD and moderate mental retardation).	Experimental	EA/NCR	Borderline Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			Relevant behaviour topographies: aggression, self-injury, property destruction Wanda (female, aged 4 years with PDD and moderate mental retardation). Relevant behaviour topographies: aggression, self-injury, property destruction Glenda (female, aged 4 years with PDD and severe mental retardation). Relevant behaviour topographies:			

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			aggression, self-injury, property destruction			
Hagopian et al. (1998)	The effectiveness of punishment and extinction with FCT in an inpatient setting	Reversal	Case 17 (gender not stated, aged 5 years 11 months with severe mental retardation). Relevant behaviour topographies: self-injury, aggression, property destruction	Experimental	ST/DRA	Weak
Hammond et al. (2011)	The effects of signalling reinforcement during DRO	Reversal	Seth (male, aged 6 years with learning and hearing impairments). Relevant behaviour topography: aggression	Experimental	DRO	Borderline Adequate

Author/Year	**Article focus**	**Design**	**Included participant details**	**Assessment type**	**Intervention category**	**Quality rating**
Hanley et al. (1997)	The effectiveness of and preference for noncontingent reinforcement or FCT	Combined multi-element and reversal	Tony (male, aged 4 years with cerebral palsy, seizure disorder, learning and speech delays). Relevant behaviour topographies: aggression, property destruction	Combined descriptive and experimental	ST/DRA EA/NCR	Weak
Hanley et al. (2005)	The effectiveness of and preference for FBI with and without punishment	Combined multi-element and reversal	Jay (male, aged 5 years with moderate mental retardation, autism and a seizure disorder). Relevant behaviour topographies: self-injury, aggression, property destruction	Experimental	ST/DRA EA/NCR	Weak
Higgins et al.	Evaluate establishing	Reversal	Malik (male, aged 5 years	Experimental	EA/NCR	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
(2012)	operation of client position on self-injury and the effectiveness of manipulation of antecedent position and noncontingent reinforcement		with Duane syndrome, Goldenhar syndrome, hydrocephalus, stereotypic movement disorder, mental retardation). Relevant behaviour topography: self-injury			
Koegel et al. (1998)	Examine the effects of antecedent manipulations and FCT on aggression directed towards siblings, child affect, parent affect, and stranger comfort level	Multiple baseline across participants	Child 1 (female, aged 5 years 10 months with autism). Relevant behaviour topography: aggression Child 2 (male, aged 4 years 3 months with mixed developmental disorders and autistic-like characteristics).	Descriptive	Multiple	Borderline Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			Relevant behaviour topography: aggression Child 3 (male, aged 4 years 10 months with autism). Relevant behaviour topography: aggression			
Lalli et al. (1997)	Evaluate effectiveness of noncontingent reinforcement with and without extinction	Multiple baseline across participants	Donny (male, aged 3 years with mild developmental delays). Relevant behaviour topography: aggression	Experimental	EA/NCR	Borderline Adequate
Lalli & Kates (1998)	Assess whether CB was maintained by toys or attention, and effectiveness of treatments	Reversal	Dave (male, aged 2.5 years with mild developmental delay). Relevant behaviour topographies: self-injury,	Experimental	EA/NCR	Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	based on this		aggression. Carter (male, aged 3.5 years with mild developmental delay). Relevant behaviour topographies: aggression, property destruction Dan (male, aged 3 years old with mild developmental delay). Relevant behaviour topographies: self-injury, aggression			
Lalli et al. (1999)	Evaluate competing concurrent schedules of reinforcement for escape-	Reversal	Jay (male, aged 3 years with mild developmental delay). Relevant behaviour topography: Property	Experimental	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	maintained behaviour		destruction			
Lambert et al. (2012)	Evaluate the effectiveness of FCT based on teacher-conducted trial-based functional analyses	Multiple baseline across participants	Chris (female, aged 3-4 years with developmental delay). Relevant behaviour topography: aggression Pat (female, aged 3-4 years with developmental delay). Relevant behaviour topographies: aggression, property destruction Danny (male, aged 3-4 years with developmental delay). Relevant behaviour topography: aggression	Experimental	ST/DRA	Borderline Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
Long et al. (2005)	Effectiveness of noncontingent reinforcement with competing or arbitrary stimuli for automatically reinforced behaviour	Reversal	Janelle (female, aged 5 years with profound mental retardation and cerebral palsy). Relevant behaviour topography: self-injury	Experimental	EA/NCR	Weak
Lorimer et al. (2002)	The effectiveness of social stories in the home setting to address CB	Reversal	Gregg (male, aged 5 years with mild to moderate autism). Relevant behaviour topographies: aggression, property destruction	Multiple descriptive	ST/DRA	Weak
Marcus, Vollmer et al. (2001)	The effectiveness of a parent training protocol for interventions for socially mediated behaviours	Multiple baseline across participants	Joe (gender not stated, aged 3-5 years with developmental and speech delays). Relevant behaviour	Varied across participants: either combined descriptive and	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			topographies: self-injury, property destruction Joel (gender not stated, aged 3-5 years with developmental and speech delays). Relevant behaviour topographies: self-injury, property destruction Tabatha (gender not stated, aged 3-5 years with developmental and speech delays). Relevant behaviour topography: aggression	experimental, or multiple descriptive		
Marcus &	The effectiveness of noncontingent	Reversal	Rob (male, aged 4 years with profound mental	Experimental	EA/NCR	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
Volmer (1996)	reinforcement with DRA		retardation). Relevant behaviour topography: aggression			
O'Neill & Sweetland-Baker (2001)	The role of contingencies in generalisation following FCT	Multiple baseline across participants	Randall (male, aged 6 years with autism and severe mental retardation). Relevant behaviour topographies: aggression, property destruction	Experimental	ST/DRA	Borderline Adequate
Piazza et al. (2000)	The effects of matched stimuli on automatically reinforced behaviour	Combined multi-element and reversal	Betsy (female, aged 6 years with Attention Deficit Hyperactivity Disorder [ADHD] and severe mental retardation). Relevant behaviour topography:	Experimental	EA/NCR	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			property destruction			
Radstaake et al. (2013)	The effectiveness of FCT implemented by teachers for children with Angelman Syndrome	Reversal	Cody (male, aged 6 years with Angelman Syndrome, severe ID and epilepsy). Relevant behaviour topographies: aggression, self-injury, property destruction	Experimental	ST/DRA	Borderline Adequate
Radstaake et al. (2012)	The effectiveness of FCT for children with Angelman Syndrome.	Reversal	Child A (male, aged 6 years with Angelman Syndrome and severe ID). Relevant behaviour topography: aggression Child B (female, aged 5 years with Angelman Syndrome,	Experimental	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			severe ID and epilepsy). Relevant behaviour topographies: aggression, property destruction Child C (male, aged 5 years with Angelman Syndrome and severe ID). Relevant behaviour topography: aggression			
Ringdahl et al. (1997)	The effectiveness of environmental enrichment on automatically reinforced behaviour	Reversal	David (male, aged 3 years with a developmental disability). Relevant behaviour topography: self-injury. Barry (male, aged 5 years	Experimental	Multiple (David) EA/NCR (Barry)	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			with a developmental disability). Relevant behaviour topography: self-injury			
Rispoli et al. (2014)	Evaluate method for identifying function of behaviour related to changes in routine and the use of FCT with extinction and schedule thinning.	Multiple baseline across participants	Timmy (male, aged 4 years with PDD-NOS). Relevant behaviour topography: property destruction John (male, aged 3 years with ASC). Relevant behaviour topography: aggression Diego (male, aged 3 years with PDD-NOS). Relevant behaviour topographies:	Experimental	ST/DRA	Borderline Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			aggression, self-injury			
Roberts et al. (1995)	Comparing the effectiveness of differential negative reinforcement of alternative or other behaviour	Combined multi-element and reversal	Mary (female, aged 4 years with severe mental retardation). Relevant behaviour topography: self-injury	Combined descriptive and experimental	ST/DRA DRO	Borderline Adequate
Robertson et al. (2013)	The effectiveness of FBIs implemented by parents at home	Reversal	Jeff (male, aged 5 years 6 months with ASC). Relevant behaviour topographies: aggression, self-injury, property destruction	Experimental	Multiple	Adequate
Saini et al. (2015)	Clarify results of inconclusive EFA and evaluate effectiveness of an intervention based on	Reversal	Isaac (male, aged 5 years with ASC, disruptive behaviour disorder and pica). Relevant behaviour	Experimental	EA/NCR	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
	results		topographies: aggression, self-injury, property destruction			
Schieltz et al. (2011)	Evaluate the effects of FCT on nontargeted behaviour		Juan (male, aged 3 years 11 months with autism and developmental delay). Relevant behaviour topographies: aggression, self-injury Cam (male, aged 2 years 11 months with developmental delay). Relevant behaviour topographies: self-injury, aggression Bud (male, aged 3 years 6	Experimental	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			months with ASC and mild mental retardation). Relevant behaviour topographies: aggression, self-injury Kevin (male, aged 2 years 3 months with developmental delay and viral induced asthma). Relevant behaviour topographies: aggression, self-injury			
Slocum & Vollmer (2015)	Comparing positive and negative reinforcement for compliance without extinction	Combined multi-element and	Braiden (male, aged 4 years with ASC). Relevant behaviour topography: aggression	Experimental	ST/DRA	Weak

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
		reversal	Milo (male, aged 4 years with developmental delay). Relevant behaviour topography: aggression			
Steege et al. (1990)	The effectiveness of an intervention involving the use of microswitches for self-injurious behaviour	Multiple baseline across tasks	Ann (female, aged 3.5 years with profound mental retardation). Relevant behaviour topography: self-injury	Experimental	ST/DRA	Weak
Volkert et al. (2009)	Resurgence following DRA	Reversal	Sam (male, aged 5 years with autism / developmental disability). Relevant behaviour topography: aggression, property destruction	Experimental	ST/DRA	Borderline Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			Max (male, aged 5 years with autism / developmental disability). Relevant behaviour topographies: aggression, property destruction Conner (male, aged 5 years with autism / developmental disability). Relevant behaviour topography: aggression			
Vollmer et al. (1994)	The role of stimulus preference in interventions following inconclusive functional analyses	Reversal	Korey (male, 3 years with multiple disabilities). Relevant behaviour topography: self-injury	Experimental	EA/NCR	Borderline Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
Vollmer et al. (1999)	Evaluate the effects of treatment challenges during differential reinforcement	Reversal	Kyle (male, aged 4 years with severe to profound mental retardation). Relevant behaviour topography: aggression	Combined experimental and descriptive	ST/DRA	Adequate
Wacker et al. (2011)	Evaluate the effects of treatment challenges during differential reinforcement	Reversal	Jose (male, aged 4 years 4 months with Fragile X Syndrome and moderate ID). Relevant behaviour topographies: aggression, property destruction, self-injury	Experimental	ST/DRA	Borderline Adequate
Wacker, Harding et al. (2013)	Evaluation of resurgence of negatively reinforced behaviour during FCT	Reversal	Rose (female, aged 3 years 4 months with mild ID). Relevant behaviour	Experimental	ST/DRA	Adequate

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
			topographies: aggression, property destruction, self-injury			
			Kurt (male, aged 2 years 4 months with mild ID). Relevant behaviour topographies: aggression, property destruction, self-injury			
			Jasper (male, aged 1 year 8 months with developmental delay). Relevant behaviour topographies: aggression, property destruction, self-injury			

Author/Year	Article focus	Design	Included participant details	Assessment type	Intervention category	Quality rating
Wilder et al. (2005)	Evaluate the effectiveness of noncontingent reinforcement without extinction	Reversal	Raley (female, aged 3 years 4 months with autism, gastrointestinal reflux and food allergies). Relevant behaviour topography: self-injury	Experimental	EA/NCR	Weak

Appendix E

Overview of Included Group Design Articles (Chapter Two)

Author (Year)	Training for	Participants	Design	CB Measure	Intervention	Main results (relating to CB)
Bearss et al. (2015)	Family carers	180 family carers	Randomised control trial (RCT) with active control group receiving parent education only Mixed within and between groups: parent training (*n*=89), parent education (*n*=91)	Aberrant Behavior Checklist irritability scale (ABC: Aman et al., 1985)	Parent training – 11 sessions delivered individually to family carers lasting 60-90 minutes. Up to two optional sessions, one home visit, and up to six coaching sessions. Based on behavioural principles. Parent education – 12 sessions lasting 60-90 minutes and one home	Significant (p < .001) decrease in irritability scores for parent training in comparison to active control group (parent education). Between group effect size: Δ = 0.62 (95% CI: 0.32 to 0.92)

Author (Year)	**Training for**	**Participants**	**Design**	**CB Measure**	**Intervention**	**Main results (relating to CB)**
					visit. Based on psychoeducation only, no behaviour management techniques.	
Brookman-Frazee et al. (2012)	Staff	13 therapist - family dyads	Quasi-experimental Repeated measures	Social Skills Improvement System – Competing problem scale (SSIS: Gresham & Elliott, 2008)	Trained therapists in AIM-HI (evidence-based package of interventions delivered to families of children with ASC: Brookman-Frazee & Drahota, 2010)	Decrease in total score on SSIS from baseline to follow up (*p* < .05) Decrease in scores on Hyperactivity, Internalising Problems, and ASC Behaviours subscales from baseline to follow up (*p* < .05) Δ = 0.53 (95% CI: -0.25 to 1.32)
Chadwick et al. (2001)	Both family	62 family carers 13 teachers	Experimental Between groups: group	Disability Assessment Schedule (Holmes et	5-7 session programme for family carers based on	Greater reduction in severity of behaviour for individual group post

Author (Year)	Training for	Participants	Design	CB Measure	Intervention	Main results (relating to CB)
	carers and staff		training (*n*=15), individual training (*n*=23), no intervention control group (*n*=24), teachers (*n*=13)	al., 1982)	behavioural principles, delivered in a group or individually Two-day workshop for teachers based on understanding CB	intervention (*p* < .05) No difference between groups in overall severity or frequency of behaviour Greater number of less severe and less frequent behaviour problems for individual group post intervention (*p* < .05) Between group effect sizes for severity: Δ (group) = 0.10 (95% CI: -0.62 to 0.81), Δ (individual) = 0.13 (95% CI: -0.45 to 0.71) Between group effect sizes for

Author (Year)	Training for	Participants	Design	CB Measure	Intervention	Main results (relating to CB)
						frequency: Δ (group) = -0.29 (95% CI: -1.01 to 0.43), Δ (individual) = -0.37 (95% CI: -0.95 to 0.22)
Durand et al. (2013)	Family carers	35 family carers	RCT Mixed within and between groups: PBS (*n*=17), Positive Family Intervention (PFI, *n*=18)	Scales of Independent Behavior-Revised (Problem behaviour section) (SIB-R: Bruininks et al., 1996) Observations	8 x 90-minute session programme delivered to individual family carers; either PBS only, PFI which consisted of PBS plus optimism training	Decrease in observed problem behaviour (Δ = 1.89, 95% CI: 1.32 to 2.45) and SIB-R scores (Δ = 2.02, 95% CI: 1.45 to 2.60) across both groups post intervention ($p < .05$) Greater reductions post intervention for PFI group on SIB-R scores ($p < .05$, Δ = 2.28, 95% CI: 1.44 to 3.12) but not observed behaviour Within group effect sizes for observed

Author (Year)	Training for	Participants	Design	CB Measure	Intervention	Main results (relating to CB)
						behaviour: Δ (PBS) = 1.83 (95% CI: 1.03 to 2.64), Δ (PFI) = 2.18 (95% CI: 1.35 to 3.00) Within group effect sizes for SIB-R: Δ (PBS) = 1.69 (95% CI: 0.91 to 2.47), Δ (PFI) = 2.28 (95% CI: 1.44 to 3.12)
Feldman & Werner (2002)	Family carers	36 family carers	Quasi-experimental Between groups: graduate group (*n* = 18, completed training up to 5 years earlier), control group (*n*=18)	Child Behavior Management Survey (CBMS, devised for study)	Individual parent training based on behavioural principles delivered over 3-6 months by a behaviour consultant. Waiting list control group.	Decrease in CBMS problem rating scores for graduate group ($p < .05$, Δ = 0.66, 95% CI: -0.01 to 1.33) Fewer child problem behaviours for graduate group ($p < .05$, Δ = 0.63, 95% CI: -0.04 to 1.29)
Gore &	Both	49 family carers	Quasi-experimental	Challenging Behaviour	Two workshops based on	Decrease in frequency ($p < .001$, Δ =

Author (Year)	Training for	Participants	Design	CB Measure	Intervention	Main results (relating to CB)
Umizawa (2011)	family carers and staff	33 teaching staff	Mixed between and within groups	Checklist (CBC: Harris et al., 1994)	PBS and FCT. Workshop 1 delivered to family carers and teaching staff separately, workshop 2 delivered simultaneously.	.76, 95% CI: 0.45 to 1.08), severity (*p* < .05, Δ = 0.58, 95% CI: 0.27 to 0.89), and management difficulty (*p* < .05, Δ = 0.69, 95% CI: 0.37 to 1.00) of behaviour one month after intervention Within groups effect sizes for frequency: Δ (teachers) = 0.79 (95% CI: 0.29 to 1.29), Δ (family carers) = 0.60 (95% CI: 0.19 to 1.00) Within groups effect sizes for severity: Δ (teachers) = 0.51 (95% CI: 0.02 to 1.00), Δ (family carers) = 0.65 (95% CI:

Author (Year)	Training for	Participants	Design	CB Measure	Intervention	Main results (relating to CB)
						0.24 to 1.05) Within groups effect sizes for management difficulty: Δ (teachers) = 0.58 (95% CI: 0.08 to 1.07), Δ (family carers) = 0.56 (95% CI: 0.25 to 1.07)
McIntyre (2008)	Family carers	25 family carers	Quasi-experimental Repeated measures	Child Behavior Checklist 1½-5 (CBCL: Achenbach, 2000) Observations	Adapted version of the Incredible Years parent training series (Webster-Stratton, 2001)	Reduction in observed inappropriate child behaviour post intervention (*p* = .052, Δ = 0.29, 95% CI: -0.26 to 0.85) No significant change on CBCL scores (Δ = 0.03, 95% CI: -0.52 to 0.59)
Reynolds et al. (2011)	Both family carers	30 family carers 173 staff	Quasi-experimental Mixed within and	ABC (Aman et al., 1985)	Three full day and two half day training workshops delivered to teams	Decrease in ABC scores post intervention (*p* < .05) Within groups effect sizes: Δ

Author (Year)	Training for	Participants	Design	CB Measure	Intervention	Main results (relating to CB)
	and staff		between groups		(including family carers and professionals) who supported each child	(professionals) = 0.32 (95% CI: 0.10 to .53), Δ (family carers) = 0.40 (95% CI: -0.11 to 0.91)

Appendix F

Evaluative Method Ratings for Included Articles (Chapter Three)

Study	Design	T/C	Primary Indicators									Secondary Indicators									Rating
			PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Alnemary et al (2015)	SC	T	U	H		H			U	U	A	✘	✘	✘	✘	✓	✓				W
Barkaia et al. (2017)	SC	T	H	H		H			A	U	U	✓	✘	✘	✘	✘	✘				W
		C	H	H		H			A	U	U	✓	✘	✘	✘	✘	✘				W
Barretto et al. (2006)	SC	C	H	H		H			H	H	A	✘	✘	✘	✘	✘	✓				W
Fischer, Dart, Radley et al. (2016)	SC	T	U	A		A			H	H	H	✓	✘	✘	✘	✘	✓				BA
		C	U	A		H			A	U	U	✓	✘	✘	✘	✘	✓				W

Study	Design	T/C	Primary Indicators									Secondary Indicators									Rating
			PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Fisher et al. (2014)	G	T	U	H	A	H	H	U				✓		✓	✗	✗	✓	✗	✓	✓	W
Gibson et al. (2010)	SC	C	H	H		H			H	H	H	✓	✗	✗	✓	✗	✓				S
Hay-Hansson & Eldevik (2013)	G	T	H	H	H	H	H	U				✓		✗	✗	✓	✓	✓	✓	✓	BA
Higgins et al. (2017)	SC	T	H	H		H			U	A	H	✓	✗	✗	✗	✓	✓				BA
	SC	T	H	A		H			H	A	H	✓	✗	✗	✗	✗	✓				A

Study	Design	T/C	Primary Indicators									Secondary Indicators									Rating
			PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Knowles et al. (2017)		C	H	A		H			U	A	U	✓	✗	✗	✗	✗	✓				W
Lindgren et al. (2016)	G	C	H	A	H	A	H	H				✓		✗	✗	✗	✓	✗	✗	✗	A
Machalicek et al. (2009a)	SC	C	H	H		H			U	U	U	✓	✗	✗	✓	✗	✓				W
Machalicek et al. (2009b)	SC	C	H	H		H			A	H	H	✓	✗	✗	✗	✗	✓				A
Machalicek et al. (2010)	SC	T	H	H		H			U	A	H	✓	✗	✗	✓	✓	✓				BA

Study	**Design**	**T/C**	**Primary Indicators**									**Secondary Indicators**									**Rating**
			PART	**IV**	**CC**	**DV**	**LRQ**	**STAT**	**BL**	**VA**	**EC**	**IOA**	**KAP**	**BR**	**FID**	**G/M**	**SV**	**ES**	**ATR**	**RA**	
Machalicek et al. (2016)	SC	C	H	H		H			U	U	U	✓	✗	✗	✗	✗	✓				W
Neely et al. (2016)	SC	T	H	H		H			U	H	H	✗	✗	✗	✓	✓	✓				BA
		C	H	A		H			H	A	H	✓	✗	✗	✓	✓	✓				A
Suess et al. (2014)	SC	T	U	H		H			U	U	A	✓	✗	✗	✗	✓	✓				W
		C	H	H		H			A	U	U	✓	✗	✗	✗	✓	✓				W
Suess et al. (2016)	SC	C	H	H		H			A	A	A	✓	✗	✗	✗	✗	✓				BA

Study	Design	T/C	Primary Indicators									Secondary Indicators									Rating
			PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron (2013)	SC	C	U	H		H			A	A	A	✓	✗	✗	✓	✗	✓				W

Study	Design	T/C	Primary Indicators									Secondary Indicators									Rating
			PART	IV	CC	DV	LRQ	STAT	BL	VA	EC	IOA	KAP	BR	FID	G/M	SV	ES	ATR	RA	
Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al. (2013)	SC	C	H	H		H			A	A	A	✓	✗	✗	✗	✗	✓				A
Wainer & Ingersoll (2015)	SC	T	U	H		A			H	U	U	✓	✗	✓	✗	✓	✓				W
		C	U	A		H			H	U	U	✓	✗	✗	✗	✓	✓				W

Study	**Design**	**T/C**	**Primary Indicators**									**Secondary Indicators**									**Rating**
			PART	**IV**	**CC**	**DV**	**LRQ**	**STAT**	**BL**	**VA**	**EC**	**IOA**	**KAP**	**BR**	**FID**	**G/M**	**SV**	**ES**	**ATR**	**RA**	

Note. **Design** – SC = single case design, G = group design. T / C – T = Trainee outcomes, C = Client outcomes. **Primary indicators** – PART = Participant characteristics, IV = Independent variable, CC = Comparison condition, DV = Dependent variable, LRQ = Link between research question and analysis, STAT = Statistical analyses, BL = Baseline conditions, VA = Visual analysis, EC = Experimental control. H = High, A = Acceptable, U = Unacceptable. **Secondary indicators** – IOA = Interobserver agreement, KAP = Kappa, BR = Blind raters, FID = Fidelity, G / M = Generalisation / maintenance, SV = Social validity, ES = Effect size, ATR = Attrition, RA = Random assignment. **Ratings** – W = Weak, BA = Borderline adequate, A = Adequate, BS = Borderline strong, S = Strong.

Appendix G

Overview of Included Studies (Chapter Three)

Study	Participants	Training Focus	Training Methods	Outcomes
Alnemary et al. (2015)	Trainees: 4 special education teachers in Saudi Arabia Clients: 1 child aged 12 years with ASC who displayed challenging behaviour (CB)	Experimental functional analysis (EFA)	Group training lasting 3 hours via videoconferencing Simulated EFA If fidelity criterion met – analysis conducted with child If fidelity criterion not met – individual coaching via videoconferencing for specific session type	Fidelity increased across study for all trainees Only 1 trainee met mastery criterion for all conditions by the end of the study, but displayed very low fidelity in actual analysis with child

Study	Participants	Training Focus	Training Methods	Outcomes
Barretto et al. (2006)	Trainees: 1 teacher, 1 adoptive mother. Other individuals present during assessment Clients: 1 child aged 5 years with ASC & 1 child aged 1 years with multiple disabilities. Both children displayed CB	EFA	In session coaching via videoconferencing Adoptive mother also received instructions via telephone and in writing before session	Social functions identified for each child Result not verified using function-based intervention (FBI)
Barkaia et al. (2017)	Trainees: 3 therapists Clients: 3 children with ASC aged 4-6 years	Mand and echoic training	Initial training (1-2 hours via videoconferencing) involving spoken and written descriptions and practice exercises In session coaching via videoconferencing	Therapist target behaviours (correct command sequences, positive consequences) increased during coaching Child mands and echoics increased during coaching

Study	Participants	Training Focus	Training Methods	Outcomes
Fischer, Dart, Radley et al. (2016)	Trainees: 3 teachers Clients: 3 children with disruptive behaviour. 1 had ADHD, 1 had ASC.	Differential reinforcement of alternative (DRA) or other behaviour (DRO). The Good Behaviour Game (GBG) added to DRA for one child.	Initial training provided via videoconferencing as part of a problem analysis Interview	Teacher integrity high for all participants during DRA/DRO. Integrity dropped below 50% on introduction of the GBG but increased again following performance feedback. Academic engagement was targeted for two children and increased during DRA, although with variable results for one child even after the addition of the GBG. Disruptive behaviour was targeted for one child and decreased during DRO.

Study	Participants	Training Focus	Training Methods	Outcomes
Fisher et al. (2014)	Trainees: 8 family carers, half of whom were placed in control group No clients	Discrete trial teaching and incidental teaching	17 e-modules lasting 40-60 minutes 6 scripted role plays with confederate (supervisor observed and provided feedback via videoconferencing)	Significant increase in percentage of trials implemented correctly by trainees compared to control group Significant increase in percentage of skills mastered by trainees compared to control group
Gibson et al. (2010)	Trainees: 1 teacher, 1 teaching assistant Clients: 1 child aged 4 years with Autism who displayed CB	FCT	Initial training lasting 45 minutes via videoconferencing Trainees provided with task analysis of procedures	Child elopement decreased from over 90% of sessions during baseline to 5% of sessions in final intervention phase

Study	Participants	Training Focus	Training Methods	Outcomes
Hay-Hansson & Eldevik (2013)	Trainees: 16 school / preschool staff (7 received training in-person) Clients: 4 children with ASC and moderate developmental delay, 2 children with moderate developmental delay	Discrete trial teaching	3 training sessions via videoconferencing lasting 15 minutes each	Significant increase in trainee skills for both groups No differences in fidelity between groups
Higgins et al. (2017)	Trainees: 3 direct care staff Clients: 3 children with ASC aged 4-5 years	Multiple stimulus without replacement preference assessments	Initial training via videoconferencing including written instructions, reviewing videos with feedback, and scripted role plays with confederate Additional tailored training for specific steps not implemented with fidelity during post training assessments	Fidelity high for all participants when practicing with confederate or child Fidelity maintained 1-2 months post training

Study	Participants	Training Focus	Training Methods	Outcomes
Knowles et al. (2017)	Trainee: Special education teacher Clients: 4 children (aged 8-9 years) with emotional and behavioural disorders or other health conditions. Whole class CBs recorded	Interventions provided within a Positive Behaviour Intervention and Support (PBIS) model: praise (contingent and noncontingent), prompting and precorrection, opportunities to respond	Online training modules Written feedback provided via email after every observation and biweekly videoconferencing coaching session involving feedback and video self-modelling	Teacher target behaviours increased following training. Whole class CBs decreased
Lindgren et al. (2016)	Trainees: 94 family carers (including 52 who received training in-person) Clients: 94 children with ASC or other developmental disabilities	EFA and FCT	3 groups: training delivered in-person, training delivered via telehealth at a regional clinic, training delivered via telehealth in the family home	At least one function identified for each participant following EFA Behaviour reduced by over 90% on average during FCT but results variable (range = 47.4-100%).

Study	Participants	Training Focus	Training Methods	Outcomes
			Telehealth groups: weekly 1-hour training sessions via videoconferencing and participants asked to practice at home	No significant difference between groups but slightly higher percentage reduction scores if training was delivered in the family home
Machalicek et al. (2009a)	Trainees: 3 graduate students Clients: 3 children aged 34 months – 7 years with ASC / Pervasive Development Disorder (PDD)	Paired choice preference assessments	Provided with task analysis of procedure and instructed to practice In session coaching via videoconferencing	100% trainee accuracy in implementing preference assessment Preferred toys identified for each child and verified with subsequent intervention
Machalicek et al. (2009b)	Trainees: 3 graduate students	EFA	In session coaching via videoconferencing	Social function identified for all children

Study	Participants	Training Focus	Training Methods	Outcomes
	Clients: 2 children aged 7 and 11 years with ASC who displayed CB			Results verified by FBI
Machalicek et al. (2010)	Trainees: 6 teachers Clients: 6 children aged 6 years with ASC who displayed CB	EFA	Provided with written explanation of procedures In session coaching via videoconferencing	High but variable trainee fidelity across EFA sessions
Machalicek et al. (2016)	Trainees: 3 family carers Clients: 2 children with autism (aged 8 and 16 years). 1 child with Fragile X Syndrome and autism (aged 9 years). All displayed CB	EFA. Antecedent strategies (social narratives, timer), FCT, DRA, differential negative reinforcement of alternative behaviour	Initial training via videoconferencing involving written task analyses, video modelling and practice with child	EFA results differentiated for each child Intervention comparisons resulted in reduced CB for each child across all intervention strategies

Study	Participants	Training Focus	Training Methods	Outcomes
Neely et al. (2016)	Trainees: 3 undergraduate students Clients: 2 children with ASC (aged 4 and 5 years), 1 child with PDD (aged 8 years)	Incidental teaching	Online module Delayed feedback provided via videoconferencing sessions based on videotapes of earlier clinical sessions	All trainees met fidelity criterion within 6 sessions Child communication responses increased and maintained or increased at 2 and 4 month follow ups
Suess et al. (2014)	Trainees: 3 family carers Clients: 3 children aged 2 years 7 months to 3 years 3 months with PDD. All children displayed CB	EFA and FCT	2 x 1-hour training sessions via videoconferencing Parent manual In session coaching via videoconferencing	Social functions identified for all children following EFA FCT generally effective but variable for one child Trainee fidelity variable for each participant

Study	Participants	Training Focus	Training Methods	Outcomes
Suess et al. (2016)	Trainees: 5 family carers. Parent assistants also used. Clients: 5 children with ASC aged 2.5-7.1 years who displayed CB	EFA and FCT	1-hour initial group meeting via videoconferencing 1-hour meeting via videoconferencing for EFA 3 x 15-minute videoconferencing sessions for FCT In session coaching Weekly homework tasks and encouraged to practice FCT at home	Function identified for 4/5 children following EFA Average 65.1% reduction in behaviour during FCT but individual results variable Significantly lower incidence of behaviour during FCT compared to baseline
Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle,	Trainees: 20 family carers. Parent assistants also used.	EFA	Initial training via videoconferencing Parent manual In session coaching via videoconferencing	Social functions identified for 18 children Results verified for 13 children in Wacker, Lee, Dalmau, Kopelman,

Study	Participants	Training Focus	Training Methods	Outcomes
Pelzel, & Waldron (2013)	Clients: 20 children aged 29-80 months with ASC or PDD. All children displayed CB			Lindgren, Kuhle, Pelzel, Dyson et al. (2013)
Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al. (2013)	Trainees: 18 family carers – some of whom also took part in Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron (2013) Clients: 17 children aged 29-80 months with ASC or PDD (some of whom also took part in Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron [2013]). All children displayed CB	FCT	Weekly 1-hour videoconferencing training with in-session coaching Provided with written instructions Asked to practice at home	Large reductions in CB for all participants (average 93.5% reduction)

Study	Participants	Training Focus	Training Methods	Outcomes
Wainer & Ingersoll (2015)	Trainees: 5 family carers Clients: 5 children with ASC aged 29-59 months	Reciprocal imitation training	Online modules Supplemental manual Given homework and encouraged to practice 3 x 30-minute coaching sessions via videoconferencing	Trainee knowledge increased 4/5 trainees met fidelity criterion and maintained this at follow up Child imitation rates variable, 4/5 maintained higher levels at follow up than at baseline

Appendix H

Technical Set Up and Difficulties Reported in Each Article (Chapter Three)

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
Alnemary et al. (2015)	Videoconferencing	Host site (University) Laptop Webcam Microphone Remote site (School) Desktop computer Webcam Microphone Multimedia projector	Skype (videoconferencing) Microsoft PowerPoint (presentations)	Slow or inconsistent connection Interruptions to internet connection Volume issues

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
Barretto et al. (2006)	Videoconferencing	Host site (University) Iowa Communications Network (ICN) – fibre optic network for videoconferencing connecting a range of sites across Iowa Television monitor Desktop computer Camera – zoomed in on speaker at host site when microphone activated Touch to speak microphones Multimedia projector Touchscreen monitor to switch sites Videotape recorder	Microsoft PowerPoint (presentations)	None reported

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Remote sites (School or Department of Human Services office) ICN Television monitor Desktop computer Camera Touch to speak microphone Multimedia projector		
Barkaia et al. (2017)	Videoconferencing, telephone calls	Host site (University) & remote site (Participant's homes) Laptops Cameras	Skype (videoconferencing) Viber (audio telephone call) Dropbox (file transfer)	Variable quality internet connection Noise interference

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Telephones Wireless internet Headphones		
Fischer, Dart, Radley et al. (2016)	Videoconferencing	Host sites (Universities) Laptop or desktop computer Remote site (Schools) Laptop computer or iPad Digital video camera	VSee (videoconferencing) Box (file transfer)	None reported
Fisher et al. (2014)	Videoconferencing & 17 e-modules	Host site (University medical centre) Not specified Remote site (Participant's home or library)	GoToMeeting (videoconferencing) University Blackboard website (online training)	None reported

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Computing equipment not specified Webcam Bluetooth headset Wired internet connection		
Gibson et al. (2010)	Videoconferencing	Host site (University) Notebook computer with integrated microphone Webcam Wireless internet connection Remote site (Preschool) Netbook computer with integrated microphone	Skype (videoconferencing)	Inability of webcam to pan, tilt, or zoom during observation

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Webcam Wired internet connection In ear headphone to listen to consultant during intervention		
Hay-Hansson & Eldevik (2013)	Videoconferencing	Host site (Videoconferencing centre at hospital) Video unit Camera (could be remotely controlled) Microphone Screen Wired internet connection Remote site (Preschool / School) Laptop	Movi (videoconferencing)	Blurred picture Ambient light obscuring view of materials through camera Unstable network (connection lost 4/7 times: 1 time for wired connection and 3 times for wireless)

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Webcam with built in microphone External speakers Wired or wireless internet connection Video camera (to record sessions)		
Higgins et al. (2017)	Videoconferencing	Host site (University medical centre) Laptop computer High definition webcam Remote site (University medical centre) Laptop computer 2 x high definition webcams Document scanner Headset with attached microphone	Adobe Connect (videoconferencing and file transfer)	None reported

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
Knowles et al. (2017)	Videoconferencing and online training modules	Host site (University) MacBook laptop with built in webcam and microphone Wireless internet Remote site (School) iPad with built in microphone Wireless internet	Skype (videoconferencing) iMovie (screen capture) Private and unlisted YouTube account (training modules) Microsoft PowerPoint (training modules)	None reported
Lindgren et al. (2016)	Videoconferencing	Host site (Telehealth centre at hospital) Desktop computer Video monitor Webcam Headset	Not specified	None reported

Article	**Telehealth Methodology**	**Hardware**	**Software**	**Technical Difficulties**
		Remote site (Regional clinics) High speed internet Remote site (Participant’s home) Laptop Webcam Ethernet cable Internet connection provided if required		
Machalicek et al. (2009a)	Videoconferencing	Host site (University) iMac desktop with built in camera and microphone Remote site (School)	iChat (videoconferencing and recording of sessions)	Participants inadvertently changing the settings of the equipment Child’s behaviour interfered with equipment (e.g., due items being

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		MacBook laptop with integrated microphone Webcam Cable and wireless internet connection		thrown at it, screaming and interrupting communications) Children had varying interest in equipment
Machalicek et al. (2009b)	Videoconferencing	Host site (School) MacBook Webcam (with integrated microphone) Wireless internet connection Remote site (Different room in same school) MacBook Webcam (with integrated microphone)	iChat (videoconferencing)	The webcam sometimes required positional adjustment

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Wired internet connection		
Machalicek et al. (2010)	Videoconferencing	Host site (University) iMac desktop computer with integrated webcam and microphone Wireless internet connection Remote site (School) MacBook laptop Webcam Bluetooth headset Wireless internet connection	iChat (videoconferencing)	Internet connection was lost during 5 trials (less than 1% of trials)
Machalicek et al. (2016)	Videoconferencing	Host site (University) & remote site (Participant's homes)	iChat (videoconferencing) eCamm (call recording)	Connection difficulties

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		MacBook with built in or external webcam Wired and wireless internet Integrated microphones		Dropped videoconferencing calls Poor visual /audio quality Inability of camera to be portable when child and family carer left the room Child interested in engaging with trainer and sometimes responded (e.g., protested) to trainer’s communication with family carer

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
Neely et al. (2016)	Videoconferencing & online modules	Host site (Location varied) Computer with integrated microphone and webcam Remote site (University supported Autism clinic) iPad mini to record sessions MacBook with integrated camera and microphone	VSee (videoconferencing) Internet based training module (see Franzone, 2010)	None reported
Suess et al. (2014)	Videoconferencing	Host site (Telehealth centre in a hospital) Desktop computer Video monitor Webcam Headset	Skype (videoconferencing) Debut (view and record sessions)	None reported

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Remote site (Participant's home) Laptop Webcam Wired internet connection		
Suess et al. (2016)	Videoconferencing	Host site (Telehealth centre at hospital) Desktop computer Video monitor Webcam Headset Remote site (Regional clinic) Laptop Webcam	Not specified	None reported

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, & Waldron (2013)	Videoconferencing	Host site (Telehealth centre at hospital) Desktop computer Video monitor Webcam Headset Remote site (Regional paediatric clinics) Not specified	Software enabling host site to control remote site cameras	None reported
Wacker, Lee, Dalmau, Kopelman, Lindgren, Kuhle, Pelzel, Dyson et al. (2013)	Videoconferencing	Host site (Telehealth centre at hospital) Desktop computer Video monitor Webcam Headset	Software enabling host site to control remote site cameras	None reported

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
		Remote site (Regional paediatric clinics) Not specified		
Wainer et al. (2015)	Videoconferencing & online training module	Host site (not specified) Not specified Remote site (Participant's home) Computer Webcam Internet connection	Internet based password protected videoconferencing software Commercially available screen recording software Online Reciprocal Imitation Training website (training module)	Difficulty accessing videoconferencing program Difficulty maintaining child's engagement in front of camera Difficulty accessing online training module website using different devices, e.g., iPhones

Article	Telehealth Methodology	Hardware	Software	Technical Difficulties
				Poor internet connection effecting video playback in online module

Appendix I

Study Advertisement Wording for Study One (Chapter Four)

Are you a family carer of a child with an intellectual disability (aged under 9) living in Kent, East Surrey, or East Sussex who displays challenging behaviour, such as self-injury, aggression, or damaging things in their environment?

Serena Brady (a PhD researcher at the Tizard Centre, University of Kent) is undertaking a research study which aims to support children to develop communication that can replace their challenging behaviour.

The study involves finding out why a child displays the behaviour and implementing an intervention to teach the child a communication response (e.g. a sign for “break”) that can replace the challenging behaviour. The study also involves training a family carer to implement the intervention with their child.

If you are interested in taking part in the study or would like to know more, please contact Serena by email (sb773@kent.ac.uk) or phone (01227 827 446) and she will be happy to discuss the study with you in detail.

Appendix J

Participant Information Sheet (Chapter Four)

PARTICIPANT INFORMATION SHEET

Conducting Functional Communication Training with young children with intellectual disabilities

Dear family carer,

You are being invited to take part in a research project conducted by Serena Tomlinson (formerly Brady) who is a PhD student in Intellectual and Developmental Disabilities at the Tizard Centre, University of Kent. Her academic supervisors are Dr. Nick Gore and Prof. Peter McGill (contact details below) and she also receives clinical supervision from Dr. Ciara Padden. Please read the following information before deciding whether you would like you and your child to take part in the project, and please contact Serena using the details below if you have any questions. The project has received ethical approval from the London-Bromley Research Ethics Committee on 14th January 2016.

What is the project about?

Children with intellectual disabilities sometimes find it difficult to communicate with those around them. This can result in them displaying behaviours that can be described as challenging (for example, hurting themselves, hurting others, or damaging property). Whilst there is a lot of research about how to help children to communicate, and avoid displaying these behaviours, there are few known examples in the UK of this support being provided.

The current project therefore aims to use an evidence based intervention (called Functional Communication Training: FCT) with children under the age of 9 who have an intellectual disability, do not use a lot of speech (e.g. 2-3 word phrases or less), and display behaviours that can be described as challenging. FCT involves finding out why the child displays these behaviours, and teaching them a way to communicate which can replace the behaviours in meeting their needs. The project also aims to teach family carers how to implement FCT with their children.

What will the project involve?

We have spaces for eight family carers to take part with their children (i.e. one family carer and one child per family). The first eight family carers will be enrolled into the study and there will also be a waiting list for other family carers. Family carers on the waiting list will be contacted if any of the family carers who are enrolled do not continue to take part. This means **you may be placed on a waiting list and may not receive the intervention.** If you are placed on the waiting list you will be told and it should **not** affect the support you receive from other professionals, so you can still get support for your child’s behaviour from other professionals.

The eight family carers who are enrolled will be assigned to one of two groups on a first come first served basis. For one group, the researcher will do all the procedures in stages 1 & 2 (see below), whilst for the other group the researcher will train the family carer to do these procedures. If you are in the group where the researcher will do stage 1 & 2 procedures, you will also be offered training on these procedures after the end of the study. All family carers will receive resources relating to assessment and intervention procedures, and will be taught how to do FCT with their child. Family carers will be taught how to do this in up to four 1-hour appointments with the researcher at different time points (see attached project flowchart).

The project will involve a number of stages which all participants will take part in. Procedures will take place at either an NHS site that you already attend with your child, or at your home. A brief summary of each of these stages is provided below, and you can find further information on the attached flowchart.

1. <u>Assessment</u>

In order to understand when, where, and why your child displays challenging behaviour the researcher will work with you to undertake some assessments. This will include some questionnaire measures, observations, and experimental analyses.

2. <u>Intervention</u>

During the intervention, your child will be taught a way to communicate which can replace their challenging behaviour. The researcher will work with you and a speech and language therapist to identify the best method of communication to teach your child. After the last session you will be asked to complete some assessment measures again and send these back to the researcher using a pre-paid envelope.

3. Maintenance

After the last intervention session you will be asked to continue conducting FCT with your child at home for 10-15 minutes per day, 5 days per week, for 6 weeks. The researcher will visit you at home every other week to do an observation and answer any questions you might have about conducting FCT. You will be asked to videotape these sessions (you will be provided with a video camera for this purpose) and to keep a record after each session. The researcher will collect the videos and records from you at each observation. This is to allow the researcher to see how you are implementing the intervention and help you if there are any parts of the intervention you are finding difficult to implement. You will be able to contact the researcher by phone or email at any point during this time if you need to talk to them about conducting FCT.

4. Follow up

One final meeting and observation will be arranged after the six-week maintenance period. During this meeting the researcher will discuss your child’s progress with you and tell you how to continue the intervention in the future. You will be asked to complete some assessment measures again, and will have the opportunity to ask any questions you might have.

What are the potential benefits of taking part?

The possible benefits of taking part for you, as a family carer, include:

1. Learning about why your child displays challenging behaviour and how to assess this
2. Learning about how to support your child to develop communication alternatives to challenging behaviour
3. Receiving a manual and resources tailored to your child which you can use both now and in the future

The possible benefits of taking part for your child include:

1. Increased communication skills, and receiving resources for communication (if these are needed)
2. Reduced challenging behaviours which may be harmful to them, you, property, or may be limiting their opportunities to take part in activities.

What are the potential risks if I take part?

The research has been carefully designed to minimise any risks and burdens to taking part. There is a risk to you/your child from their behaviour (if, for example, their behaviour involves hurting themselves or others), particularly during procedures such as the functional analysis (see flowchart) when the behaviour has to occur on to identify when / why it happens, or the initial stages of the intervention before your child has learnt the new communication response. These procedures will, however, be conducted in a highly controlled environment in order to minimise risks. Furthermore, the researcher will work with you to develop specific criteria to end a session if your child's behaviour becomes too frequent or intense and there is any risk to you/your child (and a plan for what to do to help your child become calmer if a session is ended for this reason). Due to the nature of the procedures it is likely to be possible to identify how to stop the behaviour and terminate the session; therefore the risk can be immediately removed.

As with any intervention, there is also the chance that it might not be effective. If this happens, the researcher will work with you to try and make the intervention more effective. If it is not possible to make the intervention effective, you and your child will be withdrawn from the study (as it would not be right to continue the intervention if it is not working) and the professional who supports you and your child will be told so that they can help you. Even if the intervention is not effective at reducing your child's behaviour, you are likely to learn strategies to help your child's behaviour more generally and your child might learn some new ways to communicate as a result of taking part in the study.

Taking part in the project will require a time commitment from you in order to complete all stages of the project, however sessions will be arranged at a time most convenient to you and, where possible, at a location that is convenient for you.

We hope that taking part in the research will be useful to both you and your child. If at any point, however, you have any concerns about the research or the conduct of the researcher you can make a complaint by contacting the researcher themselves or their academic supervisors (details below). You can also complain to someone outside of the research team by contacting the University of Kent Director of Research Services, Simon Kerridge (01227 823229; s.r.kerridge@kent.ac.uk; Room Reg 106, Registry, University of Kent, Canterbury, Kent, CT2 7NZ).

Your option to take part in the project

If you are interested in taking part, how to indicate this is detailed at the end of this information sheet. Indicating willingness to take part does not necessarily mean that you will be able to take part in the study, as spaces are limited and there are specific inclusion criteria. However, the researcher will discuss this with you and complete a screening questionnaire with you to ensure that the study is suitable for you and your child.

You do not have to take part in the project. The support you or your child receives will not be affected by whether you choose to take part; however a professional who routinely supports your child (e.g. a paediatrician, psychologist etc.) will be informed that you are taking part in the project and of your child’s progress. If you choose to take part and later change your mind then that’s ok.

If you do decide that you want your child to take part you and your child will remain anonymous. The researcher will give you a unique number to use in place of your name on any questionnaires and all of the data will be safely stored and only accessed by the researcher and her supervisory team. Anything that you say to the researcher will also be confidential, however if any concern is raised regarding the safety or your child, confidentiality would be broken and the relevant authorities would be notified, as with all other NHS appointments.

You will be asked to provide the researcher with contact details (e.g. name, address, phone number etc.) to enable them to contact you throughout the study but these will be stored in a locked filing cabinet and only accessed by the researcher. You will also be asked if it is OK for the researcher to keep these details for up to three years after the end of the study to allow them to contact you in the future to see how you and your child are doing. However you don’t have to consent to this to take part in the project and if you don’t want the researcher to keep your details they will be destroyed after the end of the study.

We hope to present the results of the research at conferences and publish them in an academic journal, however you and your child will not be identified in any publications, presentations, or reports relating to the project.

Video recordings

The researcher would like to take video recordings of all of the sessions in order to help them collect data on your child’s behaviour and communication; however you can still take part in the project if you don’t want to be video recorded. If you agree to being video recorded, these recordings will be safely stored and only seen by the researcher and her supervisory team.

If you agree to be video recorded, you will also be asked if you are happy for the videos to be used when training other family carers to do FCT with their children in the future. In these videos you and your child will not be named. You do not have to agree to this in order to take part in the project, and if you are happy to be videoed but don’t want these videos to be used to train others then that’s ok too.

The next steps

If you are interested in taking part then please contact the researcher by returning the reply slip below using the pre-paid envelope, or via telephone or email. The researcher will then discuss the study with you, complete the screening questionnaire, answer any questions you may have, and detail the next steps.

Who to contact

Main researcher: Serena Tomlinson (formerly Brady) sb773@kent.ac.uk 01227 827 446

Academic supervisors:	Dr. Nick Gore	n.j.gore@kent.ac.uk	01227 827 755
	Prof. Peter McGill	p.mcgill@kent.ac.uk	01227 823 838
Clinical supervisor:	Dr. Ciara Padden	c.m.padden@kent.ac.uk	01227 824 640

Address: Tizard Centre, Cornwallis East, University of Kent, Canterbury, CT2 7NF.

Thank you for taking the time to read this information.

REPLY SLIP

If you would like the researcher to contact you in order to discuss the study further, please fill in this slip and return it to the researcher using the pre-paid envelope provided.

Name:

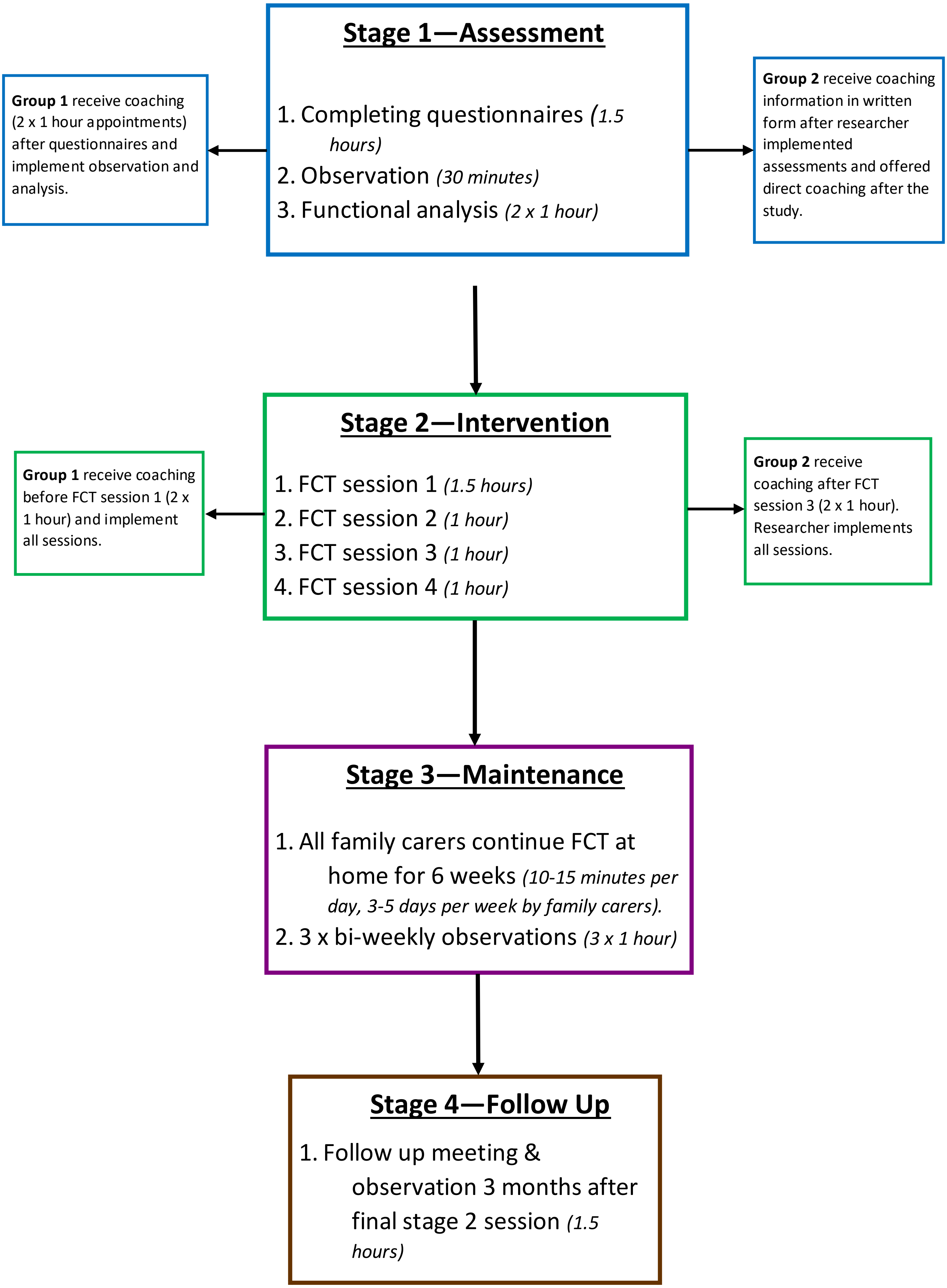
Address:

Home phone number:

Mobile number:

Email address:

Project Flowchart



Stage 1—Assessment

1. Completing questionnaires *(1.5 hours)*
2. Observation *(30 minutes)*
3. Functional analysis *(2 x 1 hour)*

Group 1 receive coaching (2 x 1 hour appointments) after questionnaires and implement observation and analysis.

Group 2 receive coaching information in written form after researcher implemented assessments and offered direct coaching after the study.

Stage 2—Intervention

1. FCT session 1 *(1.5 hours)*
2. FCT session 2 *(1 hour)*
3. FCT session 3 *(1 hour)*
4. FCT session 4 *(1 hour)*

Group 1 receive coaching before FCT session 1 (2 x 1 hour) and implement all sessions.

Group 2 receive coaching after FCT session 3 (2 x 1 hour). Researcher implements all sessions.

Stage 3—Maintenance

1. All family carers continue FCT at home for 6 weeks *(10-15 minutes per day, 3-5 days per week by family carers).*
2. 3 x bi-weekly observations *(3 x 1 hour)*

Stage 4—Follow Up

1. Follow up meeting & observation 3 months after final stage 2 session *(1.5 hours)*

Appendix K

Example Fidelity Task Analyses and Data Sheets (Chapter Four)

Functional Analysis: Tangible Session

	10s Interval																													
Tangible Step	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Allows 30 seconds access to the item																														
Takes item away and says “my turn” or equivalent																														
Withholds item unless target behaviour shown																														
Returns item within 2 seconds if target behaviour occurs																														

Baseline Session: Tangible Function

	10s Interval																													
Baseline Step	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Allows 30s access to item																														
Withholds item (or removes new items)																														
Ignores / neutrally blocks all target behaviour																														

Communication Training: Tangible Function

	10s Interval																													
Teaching Step	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Removes item and says “my turn” or equivalent																														

	10s Interval																													
Teaching Step	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Immediate appropriate level of physical prompt																														
Provides 30 seconds of access to item following communication response																														
If applicable: Ignores / neutrally blocks TB, 5 second change over delay																														

Appendix L

Modified Functional Assessment Interview (Chapter Four)

[REDACTED]

[REDACTED]

[REDACTED]

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Appendix M

Study Manual for Study One (Chapter Four)

Conducting Functional Communication Training with young children with intellectual disabilities

FAMILY CARER MANUAL

Researcher contact details: sb773@kent.ac.uk, 07943 555 427 (Monday – Friday, 9am-7pm)

Using this manual

This manual is to be used alongside the researcher's support during the study. It gives you more detail about each part of the project and can help to remind you about how to do each technique. You can use the timeline in Appendix 1 of this manual to remind yourself about the different stages of the project.

The manual contains lots of sections about the different stages of the project. The researcher will give you each section of the manual when you need it during the study. The manual is yours to keep so that you can go back over it if you need to, or write notes on it to help you remember.

The researcher will go through each section with you and teach you how to do the things in the manual. There is a glossary at the back which explains some of the terms used throughout the manual. Any terms that are in **bold** are listed in the glossary. You can also ask the researcher questions by email (sb773@kent.ac.uk) or telephone (07943 555 427, 9am-7pm) if you have any questions or need help with any of the techniques.

Table of Contents

1. Understanding Behaviour

What is behaviour?

Behaviour is everything we do or say. This includes things like walking, running, talking, using the telephone, eating, drinking etc.

We learn different behaviours as we are growing up because of the effect that our behaviour has on other people, or on the world around us (also called the environment). The examples in Box 1 below explain this in a bit more detail.

Box 1 – Examples of how behaviour is learnt

Example 1 – Communication

At first, a young baby can only communicate with those around them by crying when they need something. People respond by trying to figure out why the baby is crying (e.g. are they hungry, tired, needs a hug or their nappy changed?). Over time, the baby's parents learn what the different cries or movements mean because the baby stops crying when the parents have provided what they need. At the same time, because of their parent's reactions, the baby learns that people respond differently to certain cries or movements. As a result, they are more likely to use specific movements / sounds for different things because they help them to get what they need.

The same process happens when they start to babble and this eventually leads to them learning to talk because people respond differently to sounds that are similar to words (e.g. "da-da", "ma-ma" etc.). You can see here how the baby has learnt to make certain sounds or movements because of the *way other people react to them*.

Example 2 – Avoiding danger

To begin with, a young child does not understand when something might be dangerous, like a hot oven. Over time, they learn not to touch a hot oven either because those around them react negatively if they go near it ("No, don't touch that, it's hot!"), or because they touch it one day and it hurts. In this example, *other people's reactions and / or the natural outcomes of behaviour* help the child to learn that the oven could be dangerous and to avoid touching it.

A functional understanding of behaviour

All behaviours are learnt in this way – because of the effect that they have on the world around us (the environment), or because of how other people react to them. We learn to use the behaviours that result in us getting things we want or need (either from other people, or the environment), or to escape / avoid things that are unpleasant.

We call this the role or **function** of behaviour. We *all* need to have our needs met, to access things we like, and to escape / avoid things we don't like – we use our behaviour to do this. In the examples above, one child cries or babbles to have their needs met, and another avoids a painful experience or other people's negative reactions by not going near the oven. This is called the **functional understanding of behaviour.**

Understanding difficult behaviours

Children with disabilities sometimes find it harder to learn things. This can include communication or other types of behaviour. For many reasons, they sometimes display difficult behaviours like hurting themselves, hurting others, or damaging things around them. Because they have difficulty learning to communicate, they might be more likely to use these difficult behaviours to meet their needs.

For example, if a child does not know how to ask for a drink they might get upset and hit their head. When trying to comfort them someone might give the child a drink, which meets the function of the child's behaviour. In future, the child will be more likely to hit their head when they need a drink because this has led to them getting a drink in the past.

These sorts of interactions happen all the time and are completely normal – remember, we *all* need to be able to have our needs met, have access to things we like and to escape / avoid things that we don't like. As we learn more ways to communicate, we become less likely to use other behaviours (like crying) because communication is quicker and easier. However, if children find it difficult to learn ways to communicate they might continue to use other types of behaviours instead. This can sometimes include the difficult behaviours described above.

The functional understanding of behaviour means that we should look at these difficult behaviours in the same way as other behaviours – they serve important functions for the child. Our job is to figure out what that function is and help them to communicate it in a different way.

Functions of behaviour

There are four main functions of behaviour. We can think of these as communication messages because the function tells us about what the child needs. The common functions are;

- To gain **attention** from others (this can be *any* type of attention, not just positive).
- To gain access to something that they want or need, called a **tangible** – e.g. food, drinks, toys, activities etc.
- To **escape** something difficult – e.g. difficult tasks, requests from others, a room that's too hot/noisy/bright etc.
- To get **sensory** stimulation

"I want to play with you"
"I want your attention"
"I need you"

"I want / need that"
"Please give that to me"
"I'm hungry / thirsty / bored"

"I don't like that"
"This is too hard, please help"
"Please don't do that"

"I'm under stimulated"
"I'm bored"

The function of a behaviour is not usually linked to what the behaviour looks like. Any behaviour can have one or more of the functions above. Sometimes the same behaviour will have different functions depending on the situation, and different behaviours can serve the same function. This is why it is so important to use a range of different ways to try and work out the function of the behaviour so that we are sure we have it right. Box 2 (below) tells you more about the functions of behaviour.

Box 2 - about the functions of behaviour

Lots of different behaviours can sometimes serve the *same function*. For example, instead of pouring ourselves a glass of water, we could make a cup of tea, buy a drink from a shop, or ask someone to make us a drink. These behaviours all help us to get a drink.

The same behaviours can sometimes serve a *different function*. For example, we might pour a drink because we are thirsty, or because someone has asked us to pour a drink for them.

Figuring out the function

We can work out the function of behaviour by using a range of tools to look at what happens before and after the behaviour – this is called a **functional assessment**. Once we know the function, we can focus on teaching the child a way to communicate their needs, e.g. tapping a card which says “drink”. The child would then be able to use communication to tell others around them what they need, rather than difficult behaviours.

Functional assessment in this study

In this study, we will use three main tools to do a functional assessment;

1. A **Functional Assessment Interview**, to get information about what the behaviour is, when it happens, as well as about your child’s skills and abilities
2. An **Observation**, so that we can see the behaviour in real life and check what we learnt during the interview
3. A **Functional Analysis**, which is a way for us test out specific situations to see if they are related to the behaviour.

These three tools together will help us to work out the function of your child’s behaviour. We can then design a way to help them learn to use communication instead.

2. The Functional Assessment Interview

The first stage of working out the function of your child's behaviour is to complete the Functional Assessment Interview.

The interview has 9 parts and will take about an hour to complete. The researcher will complete the interview with you during the study, but it is also in Appendix 2 of this manual in case you need to go back to it after the end of the study. You can use it in the future if you need to, and you can complete it with other people who interact with your child to get more information about the behaviour.

Why do we need to do the interview?

The interview helps us to work together to understand your child's skills and abilities, their behaviour and the difficult behaviours that you want to focus on (called the **target behaviours**). It also helps us to think of what might be the function of those behaviours.

SECTION A – this section focuses on describing the behaviour. It asks about how often the behaviour happens. It will also ask about how hard it is to manage the behaviour safely.

SECTION B – this section focuses on identifying all the things that your child does throughout the day. We will make a note of which of these your child likes or dislikes.

SECTION C – this section focuses on when the behaviour is most likely and least likely to happen. This helps us to identify the things that often happen before the target behaviour. We call things that happened a while before the target behaviour (like a poor night's sleep, being hungry etc.) the **setting events.** The things that happen immediately before the target behaviour are called the **antecedents**.

SECTION D – this section focuses on the things that often happen after the target behaviour. We call these things the **consequences**.

SECTION E – this section focuses on the things your child can already do that might have the same consequences as the target behaviour.

SECTION F – this section focuses on the ways that your child communicates things that they want or need.

SECTION G – this section focuses on important things to know about when working with your child.

SECTION H – this section focuses on things that your child likes, e.g. food items, toys etc.

SECTION I – this section helps us to summarise what we found out during the interview into one statement. This is called a **summary statement**. It tells us when the behaviour is likely to happen and what happens afterwards (see Box 1).

Box 1: Examples of summary statements related to each function of behaviour

Attention function

"When Sarah is alone she will start to hit herself to gain adult attention."

"When his mum is on the phone, Jack begins to throw his toys at his brother to get his mum's attention."

Tangible function

"When Caleb doesn't eat much breakfast and he sees his friends eating something he will hit other children to get their food."

"When Emily can't reach her favourite toy she will bang her head on something until someone gives her the toy."

Escape function

"When Danny is doing mathematics and is given a question to do he will bite others to avoid having to do the question."

"When Tom has had a bad night's sleep and is asked to do a task such as put his shoes away, he begins throwing and breaking things around him; others ignore this behaviour meaning he avoids having to do the task."

Sensory function

"When Ellie is alone, she will pick her skin to gain sensory input."

Summary statement:

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Using the results

We will use the results of this interview in different stages of the study.

1. We will use section A to clearly ***define*** the target behaviour. This is important so that we know exactly what we are looking for when we observe the behaviour during the rest of the study. The researcher will help you to define the behaviour during the study, and there is space for you to write the definition below.
2. We will use section C to identify the best time to ***observe*** the behaviour. The best time is when the behaviour is most likely to occur.
3. We will use the summary statement and the information about your child's favourite items to think about what the ***function*** of the behaviour might be. See Box 1 above for examples of summary statements for different functions. We will check the statement during the observation and test it in the functional analysis.
4. We will use information about your child's favourite items in the ***functional analysis***.
5. We will use the information about your child's skills, reinforcers, and communication to ***design the communication intervention***.

Defining behaviour

It is really important that we define the behaviour in a very detailed and specific way. This is because we will often need to count or time the behaviour, so it will be really helpful to know what we count as the behaviour and what we don't count as the behaviour. We might identify more than one target behaviour if we think that some behaviours always happen together.

The researcher will help you to define the target behaviour(s) during the study. You can write the definition below to remind yourself and to refer back to later as an example of how you might define a behaviour.

Definition of behaviour(s): (e.g., slapping their head with an open hand hard enough to be heard or to leave a visible mark.)

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3. Safety Criteria & Support Plan

Like with most things, we will need to see your child's behaviour in order to assess and understand it. This means that we will sometimes be trying to make the behaviour happen. This is common when supporting children who display difficult behaviours, and is the same as when a doctor needs to see/hear something (e.g. a cough) to be able to say what is wrong.

However, it is important to consider how to keep your child and yourself safe during the study when the behaviour happens. We have carefully designed the procedures to minimise any risks. We will also make sure that you and your child are safe by making criteria to end a session if your child's behaviour reaches a certain point where it is a risk to them or others.

The researcher will work with you to make these criteria and you can write them here to remind yourself of them throughout the study. You can also use this in the future to remind you of the type of criteria you could use.

A session / observation will be stopped if: (e.g. "Sarah hits herself more than 3 times in 20 seconds, or she leaves a mark or bruise on her skin" or "Danny tries to bite more than once in 20 seconds")

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Support plan

If a session/observation is stopped because your child's behaviour meets the criteria above, it is important that we support them to become calmer. The researcher will work with you to identify the best ways to do this for your child. You can write these here:

Support plan: (e.g. give Danny a drink, give him some space, remove all demands etc.)

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Remember, you can always contact the researcher using the details on the first page of this manual to discuss what happened, but don't do this until your child has calmed down and everyone is safe.

4. Functional Assessment Observation

After we have completed the Functional Assessment Interview, the next step is to observe the behaviour in a structured way.

We will do one 30 minute observation of the behaviour and we will videotape this observation so that we can go back over it later if we need to.

Why do we need to do the observation?

The observation helps us to clearly define the behaviour so that we know what we are looking for and how to collect data on it throughout the study. It also helps us to confirm our summary statement about the behaviour by looking at what happens before and after the behaviour. It is a way for us to check what we found during the interview before we try and test it out in the functional analysis

When to observe?

The best time to observe is the time that the target behaviour (i.e. the behaviours we have decided to focus on) is most likely to happen. We identified this in section C of the Functional Assessment Interview.

How to observe?

During the observation just let your child do what they would normally do, try not to get involved if possible. If you need to get involved because the behaviour only happens with you, that's ok as we'll also be filming the observation.

We will use a form called the Functional Assessment Observation Form to help us keep track of what happens when we observe. The form is described in detail below. It is best to fill out the form during the observation, however if you can't do this (for example, because the behaviour only happens when you are interacting with your child) you can fill out the form from the video afterwards.

SAFETY FIRST!

Remember to always think about the safety criteria whenever you are working with your child during the study. If your child's behaviour meets these criteria, or you feel that you or your child are unsafe, you **must** stop the observation and do the things we identified that can help your child calm down. We can always redo the observation another time if we need to – the safety or your child, yourself, and anyone else around is the most important thing. Remember that you can always contact the researcher afterwards if you need to talk about what happened, but make sure that your child has calmed down and everyone is safe before you do this.

The form

The form is in Appendix 3 and the researcher will give you a copy of the form.

The next page shows you what the form looks like. It also has arrows to show the different parts of the form. After this, instructions are given for how to fill in the form. The researcher will go through this with you when you meet with them, but the information in this section will help to remind you about what to do.

[REDACTED]

Filling out the form

1. On the top of the form write:
    a. Your child's name
    b. Your name
    c. The date
    d. The observation start time
    e. The observation end time
    f. The activity your child was doing
2. Write the target behaviours we are looking for in the behaviour section.
3. Begin watching your child and what they are doing.
4. When you see any of the behaviours we are looking for, write '1' in the event box, and put a tick in every column that applies to the behaviour (i.e. behaviours observed, antecedents, and consequences) that applies to that event. Remember, you can add antecedents/consequences to the form if you need to.
    a. An event is an instance of the target behaviour(s) happening.
    b. More than one target behaviour/antecedent/consequence might happen during an event – put a tick in all of boxes that apply.
    c. Only consider something a new event if it is more than 10 seconds since the last target behaviour happened.
5. Repeat for each new event.
6. Add up how many events are listed in each column and write this under the columns.

Example form

Below is an example of Danny's functional assessment observation form. We can see that across a 30 minute observation during maths, Danny displayed 7 instances of behaviour.

- The most common **behaviours** were biting and pinching.
- The most common **antecedent** was a demand or request presented to him.
- The most common **consequence** was escaping the demand.

[REDACTED]

This observation confirms our summary statement that Danny's biting functioned to escape demands because the behaviour often happened during difficult tasks, and often resulted in Danny being given a break.

Using the results

The researcher will discuss the results of the observation with you and help you to interpret them. You can use the results in a number of ways;

- To identify the **target behaviours** that happened most often, and which ones happened together.
- To identify the most common thing that happened before a behaviour (the **antecedents**).
- To identify the most common thing that happened after the behaviour (the **consequences**).

It might be helpful to look at each type of behaviour individually if you observed lots of types of behaviour. For Danny's form, it might be useful for us to also look at the other behaviours he displayed, such as when he hit himself or others. We could look at what happened before and after these specific behaviours, rather than just looking at the most common antecedents and consequences overall.

You can use this to identify what you think the function is. Look back over the summary statement and see if the observation results agree with this. If they don't, that's ok – the researcher will discuss this with you and we can still test out what we think the function is in the next step (see below).

5. Functional Analysis

What is a functional analysis?

A functional analysis is a way to test what the function of your child's behaviour is. We do this by setting up carefully controlled **conditions** to see when the behaviour happens.

Why do we need to do a functional analysis?

A functional analysis allows us to systematically test what the function of your child's behaviour is. It gives us more confidence that we know what the function is. This is important because if we get the function wrong, we might pick the wrong communication response to teach and the intervention might not work.

Functional analysis conditions

There are usually four or five types of condition in a functional analysis. The conditions set up situations that are related to one of the functions of behaviour. This is to see if the behaviour happens more in one type of condition than another. The conditions are;

Play
The child has access to the adult's attention and their favourite toys / items. They are not asked to do anything. This condition serves as a control condition to see how much the target behaviour occurs when the child has access to all the things they like. We use this condition to compare to other conditions.

Demand
The child is asked to do something they find difficult (called a **demand**). If they display the behaviour, they are given a break from the demand. This tests the escape function as the child can escape from demands by displaying the behaviour.

Alone (only if target behaviour is self-injury or property destruction)
The child is alone in a room (with an adult watching from another room) to see whether they display the behaviour when they are by themselves. This tests the sensory stimulation function as the behaviour happens when the child is alone or not receiving interaction without anything else to do.

Attention
The child is told that the adult needs to do some work and they will be with them in a minute. If they display the behaviour, the adult gives them attention. This tests the attention function as the child can get attention from others by displaying the behaviour.

Tangible
The child is allowed to play with or eat their favourite item for 30 seconds at the beginning of the session. The item is then taken and they are told they can have it back in a minute. If they display the target behaviour, they are given the item. This tests the tangible function as the child can get something they like by displaying the behaviour.

How we use the results of a functional analysis

After conducting a functional analysis, the results can be used to identify the function of the behaviour. For the analysis in this study, we collect data on how long after the start of the condition the behaviour happens (see below for more detail). We can then identify the function by looking at how quickly the behaviour usually happens in each type of condition. We can also compare this to the play condition which acts as a control to show us how quickly the behaviour happens when all the things that might be related to the function of the behaviour are already available to your child.

If the behaviour occurs more quickly in one type of condition than the other conditions, this shows us that the function related to that condition is the function of the behaviour. For example, if the function of a behaviour was to gain attention we would expect to see the behaviour happen quickly in the attention condition after the child is told that the adult has to do some work and cannot give them attention.

Danny's functional analysis results are shown in Box 3 to give you an example of how we identify the function.

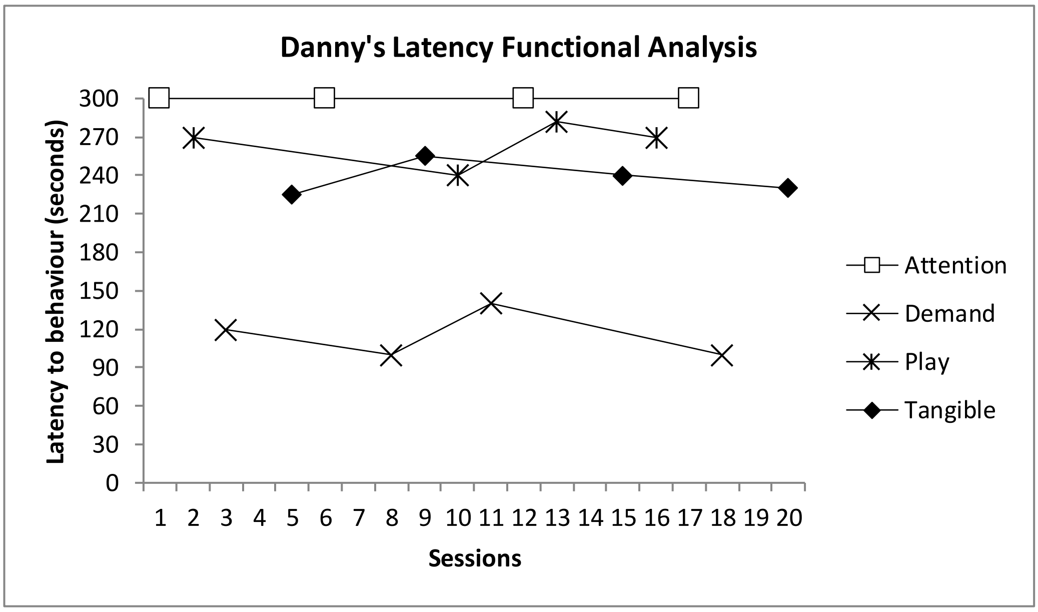
Box 3: Danny's functional analysis

Remember that we thought Danny's biting functioned to escape from demands (difficult maths questions). His summary statement was: **"When Danny is doing mathematics and is given a question to do he will bite others to avoid having to do the question."**

We did a functional analysis with Danny and found that he tried to bite the adult after;

- Around 2 minutes in the demand condition.
- Around 4 minutes and 30 seconds in the play (control) condition.
- Around 4 minutes in the tangible condition.

Biting did not occur in the attention condition. We drew a graph of these results which you can see below.



The graph really makes it clear that Danny displayed biting much more quickly in the demand conditions than in any of the other conditions. This confirms our theory that his biting functions to allow him to escape from demands. We can now use this information to design an intervention to teach him to ask for a break from demands, or for help with difficult questions.

Conducting the analysis

If you are doing the analysis as part of the study, this section will explain how to do this. If you are not doing the analysis in the study you can use this section in case you need to do an analysis in the future.

SAFETY FIRST!

Remember to always think about the safety criteria whenever you are working with your child during the study. If your child's behaviour meets these criteria, or you feel that you or your child are unsafe, you **must** stop the session and do the things we identified that can help your child calm down. We can always redo the session another time if we need to – the safety or your child, yourself, and anyone else around is the most important thing. Remember that you can always contact the researcher afterwards if you need to talk about what happened, but make sure that your child has calmed down and everyone is safe before you do this.

What you will need

The table below lists the items you will need to do the analysis and which items the researcher will supply if you're doing the analysis as part of the study. The researcher will supply most of the items however you *may* need to provide the toys/items your child likes, and the activity that they find difficult if the researcher does not have equivalent items.

Item	**Supplied by researcher**	**Possibly supplied by you**
1. *A stopwatch*	✓	
2. *A room that is quiet and doesn't have a lot of distractions (i.e. without lots of toys around).*	✓	
3. *Your child's favourite items for the tangible condition (i.e. those we identified during the Functional Assessment Interview)*		✓
4. *Items that your child likes but that aren't their favourite for the attention condition*		✓
5. *Activities that your child finds a bit difficult to do for the demand condition*		✓
6. *Papers that you can pretend to be using to work in the attention condition*	✓	
7. *The order of conditions written down and a pen to mark these off as you do them*	✓	

How to do the conditions

The conditions should be done in a random order. If you are doing the analysis during the study, the researcher will tell you what order to conduct the conditions in. You only need to do the alone condition if the target behaviour is self-injury or property destruction.

Each condition will last 5 minutes if the target behaviour doesn't happen and less than this if the behaviour does happen as we will stop the condition as soon as the behaviour happens. There will be a 1 minute break between each condition where your child can play with some toys (but not their favourites).

If you are doing the analysis during the study, it will be conducted over two 1 hour appointments.

Detailed instructions for how to do each type of condition are written below. The researcher will also be with you during the analysis if you are doing it as part of the study. Appendix 4 gives you an easy to use breakdown of the steps for doing each type of condition – you can use this during the analysis to remind yourself of what to do.

Play

- Make sure there are lots of toys that your child likes to play with in the room, including their favourites
- Allow your child to play with the toys. You can play with them if they want you to.
- Roughly every 30 seconds give your child some attention – e.g. play with them, comment on what they are doing, or praise them if they're playing appropriately
- Ignore any target behaviours (unless they meet the safety criteria, if they do – end the condition). If you need to, block the behaviour so that you or your child don't get hurt. 1 minute after a target behaviour or 5 minutes after the start of the session (whichever comes first), end the session and start the next condition after a 1 minute break
- If they don't display the target behaviour within 5 minutes, have a 1 minute break and then start the next session

Tangible

- Have your child's favourite item (e.g. a toy, food etc.) in the room
- Allow your child to play with / eat the item for 30 seconds then take it away and tell them they can have it in a minute.
- If the target behaviour happens – say "ok you can have it back" and give them the item. If this is a toy, allow them to play with it for 30 seconds. If it is a food item, allow them to eat it. After a 1 minute break, start the next condition
- If the target behaviour doesn't happen, end the condition after 5 minutes. Have a 1 minute break before the next condition

Demand

- Have activities that your child finds difficult to do (e.g. putting blocks into a shape sorter). Make sure these can be done for 5 minutes.
- Ask them to do the activity, e.g. "Danny, please put these blocks in here". If they don't do the activity within 2 seconds, show them how to. If they still don't do the activity within 2 seconds, help them to do it by moving their hands.
- If the target behaviour happens, say "ok you don't have to", stop asking your child to do the task and remove the items. Turn away from your child for 30 seconds. End the condition and allow them to have a break for 1 minute. Start the next condition.
- If the target behaviour doesn't happen, end the condition after 5 minutes. Have a 1 minute break before the next condition.

Attention

- Have some items that your child likes to play with but are not their favourite items.
- Tell them that they can play with the toys and that you need to do some work for a minute.
- Pretend that you are doing some work, e.g. writing or reading.
- If the target behaviour happens, say "no don't do that, it'll hurt you / me" and physically comfort them, e.g. by touching their shoulder. Start the next condition after a 1 minute break.
- If the target behaviour doesn't happen, end the condition after 5 minutes. Have a 1 minute break before the next condition.

Alone (only if the target behaviour is self-injury or property destruction)

- Your child should sit in a room by themselves, without any toys or distractions. Make sure you can still see them (e.g. through a window or door).
- If the target behaviour happens ignore it or block it if you need to. End the session 1 minute after the behaviour or 5 minutes after the start of the session (whichever comes first). Have a 1 minute break and then start the next session.
- If the target behaviour doesn't happen, end the session after 5 minutes. Have a 1 minute break before the next session.

Collecting data

We need to collect data during the analysis so we can see which condition the behaviour happens quickest in. The researcher will give you a data sheet for this and it is also in Appendix 5.

We will use a stopwatch to collect the data. Start the stopwatch at the beginning of each session and stop it when you see the target behaviour or after 5 minutes if you do not see the target behaviour. Write the time on the data sheet next to the condition.

It is best if you collect data during the sessions, however if this is difficult you can use the video afterwards to collect the data.

Graphing the results

As we saw in Danny's example, the easiest way to look at the results is in a graph.

Appendix 6 includes some graph paper with pre-drawn graphs on. The researcher will graph the results for you during the study, however there are some instructions on how to do this in Appendix 6 if you need to do it after the study.

Interpreting the results

The researcher will help you to interpret the results during the study. You can interpret the results by looking at the graph to see if the behaviour usually happens more quickly in one condition than the others, like in Danny's graph above. Appendix 7 shows some examples of the types of graphs you might see and how we would interpret the results.

You might find that the behaviour seems to have 2 functions – that's ok. We will focus on one function during the study.

You might find that the behaviour doesn't seem to have a function and happens quickly in many of the sessions. This might suggest that it has a sensory stimulation function (as the behaviour happens all the time), or it might suggest that we need to do some more assessments. If this happens, the researcher will discuss this with you and help you. If you are conducting the analysis after the study it is advised that you seek additional support from someone with expertise in behavioural analysis to interpret this. You can find someone by contacting the UK Society for Behaviour Analysis.

6. Functional Communication Training - Introduction

What is Functional Communication Training?

As we saw above, sometimes children with learning disabilities find it harder to learn ways to communicate, so they might need some extra help with this. **Functional communication training** (FCT) is a structured way of teaching your child to use communication, instead of difficult behaviours, to get their needs met.

During FCT, we use the information from the assessments we conducted to identify a **communication response** to teach your child that serves the same function (and meets the same needs) as the target behaviour. We also stop responding to the target behaviour (i.e. we ignore it) and only respond to the communication response. In this way, your child learns that the communication response is now the way to meet their needs, not difficult behaviour.

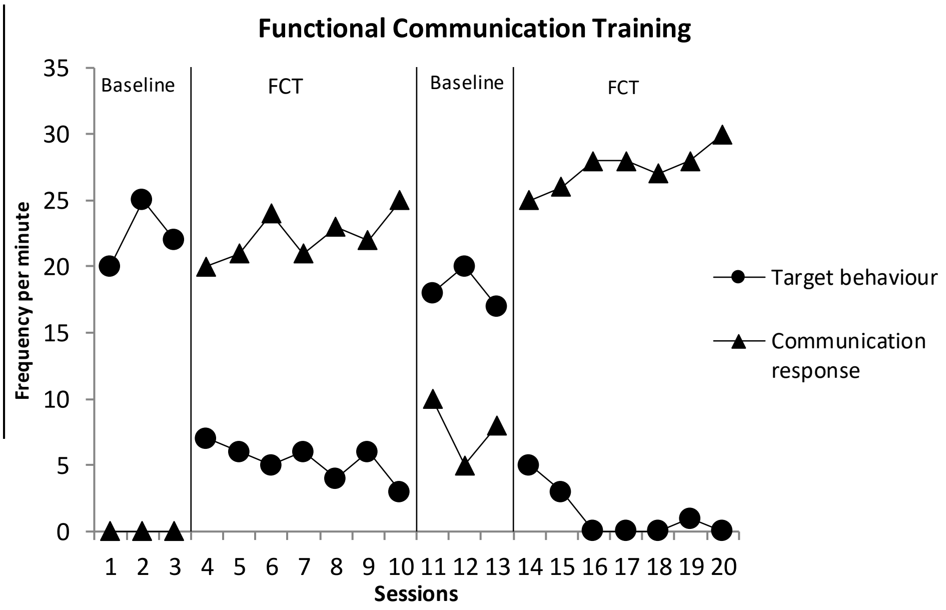
Box 4 (below) gives an example of Danny's FCT intervention.

Box 3: Danny's functional analysis

Remember that all of our assessments showed that Danny's biting functioned to escape demands. We did FCT with Danny to teach him to ask for a "break" from demands, rather than getting a break by biting others.

We started by deciding which communication response to teach Danny. Because Danny already used some picture cards to communicate, we decided to teach Danny to tap a card that had the word "break" written on it. We taught Danny to use the card by asking him to do maths questions, and immediately moving his hands to touch the card and letting him have a break. Over time, we reduced the amount of help we provided until Danny was touching the card by himself.

After this, we started FCT. First, we collected some data on how often Danny tried to bite when asked to do mathematics questions (this is the **baseline** phase). After this, we asked Danny to do some mathematics questions and only gave him a break when he touched the card (the FCT phase). Over time Danny stopped trying to bite and started using the card more often. To check that it was FCT that resulted in Danny biting less we redid some baseline sessions and then did some final FCT sessions. You can see the results of Danny's FCT below.



Danny's graph shows us that the FCT was effective in helping him learn to use communication (touching a "break" card) to get a break from tasks he finds difficult. By the end of the intervention, he was not trying to bite others and was using the card often. The adults supporting Danny can now gradually increase how many questions Danny must do before he gets a break to make sure that he still does some important maths questions as well as having a break when he needs one.

Identifying a communication response

During the study, the researcher will help you to identify a communication response to teach to your child. We choose a response based on:

1. What the ***function*** of the target behaviour is (which we identified during the assessments we conducted) so that it meets the same needs as the behaviour does.
2. How your child ***currently communicates*** so that we use the type of communication they already use.
3. Advice from a ***speech and language therapist*** who works with the researcher or who already works with your child.

When your child first learns the response, they might still show difficult behaviour because this has helped them meet their needs in the past. This is normal, and if we are careful in what communication response we choose and how we teach it to your child we can make it more likely that they will use the response rather than difficult behaviour. We do this by:

1. Making sure that the response meets the same ***need*** as the target behaviour
2. Making the response ***easier*** to do than the target behaviour by making sure that your child can easily perform it. For example, if they are using a card or switch we make sure it is nearby, that the manual sign is not too difficult to do, or that the phrase is short such as "break please" etc.
3. Making sure that the response is ***effective*** by responding to it every time your child uses it at first, and no longer responding to the target behaviour (i.e. we ignore the target behaviour, and provide reinforcement for the communication response instead). This helps your child to learn that communication is the way to get their needs met now, not difficult behaviour.

You can write the communication response that the researcher helped you to identify for your child in the box below.

Communication response: (e.g., touching a card that says "break", or making the manual sign for "break")

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7. FCT during the study

The steps below describe how we will do FCT during the study. You might only begin doing FCT at step 3 as the researcher might do steps 1 and 2, but you can use these notes to understand how all the steps would be done in case you need to do them in the future. Appendix 8 also describes the procedures step by step, which you can use during the study.

The researcher will tell you which steps to do and when during the study.

SAFETY FIRST!

Remember to always think about the safety criteria whenever you are working with your child during the study. If your child's behaviour meets these criteria, or you feel that you or your child are unsafe, you **must** stop the session and do the things we identified that can help your child calm down. We can always redo the session another time if we need to – the safety or your child, yourself, and anyone else around is the most important thing. Remember that you can always contact the researcher afterwards if you need to talk about what happened, but make sure that your child has calmed down and everyone is safe before you do this.

What you will need

You will need the following things to do FCT:

Item	Supplied by researcher	Supplied by you
1. *Sheets to collect data about how often the target behaviour and communication response happen during the baseline sessions and FCT sessions (see Appendix 11)*	✓	
2. *Sheets to collect data on how much help your child needs to do the response during the teaching sessions (see Appendix 10)*	✓	
3. *A room that is quiet and doesn't have a lot of distractions (i.e. without lots of toys around).*	✓	
4. *A stopwatch, to time the sessions*	✓	
5. *Session logs for the maintenance stage*	✓	
6. *A camera and tripod to record the sessions*	✓	

You might also need:

Item	Supplied by researcher	Possibly supplied by you
1. *A communication card or switch, if your child needs these for the communication response (your child will be able to keep this after the end of the study)*	✓	
2. *Tasks your child finds a bit difficult (e.g. the one we used during the functional analysis), if the target behaviour functions to escape demands*	✓	
3. *Papers that you can pretend to work on and toys that your child likes (but not their favourites), if the target behaviour functions to access attention*	✓	
4. *Your child's favourite toys, if the target behaviour functions to access tangible items*		✓

Step 1: Collecting baseline data

The first thing we need to do is to collect some baseline data on how often the target behaviours and communication response happen before we do FCT. This gives us something to compare to when we start FCT, so that we know the intervention is effective. This is really important because we need to know how well FCT is working so that we can change it if we need to.

We will conduct 3 sessions (lasting 5 minutes each) in order to collect baseline data in the following way:

BASELINE

1. Conduct the session in the same way as the functional analysis condition that was related to the function of your child's behaviour.
    a. For this study, we identified that your child's behaviour functions to access **tangible** items therefore we will conduct the session in the same way as the 'tangible' functional analysis condition by allowing your child to play with the item for around 30 seconds (or eat a small piece) and then taking it and saying "my turn" or saying "you can have the rest in a minute".
2. If the target behaviour happens, ignore it. You can block it if you need to so that you or your child don't get hurt, but don't say anything to your child when you do this – instead, continue to withhold the item. Put a tally mark on the data sheet every time the target behaviour happens during the session.
    a. Remember the safety criteria– if your child's behaviour meets this criteria you **must** stop the session and follow the support plan.
3. If your child uses the communication response, ignore it (for these baseline sessions only). Put a tally mark on the data sheet every time the communication response happens during the session.
4. End the session after 5 minutes and give your child a 2 minute break.
5. Repeat these steps 2 more times.

The researcher will draw the results on a graph so that we can see how often the target behaviour and communication response happen before FCT. There is also some graph paper and instructions in Appendix 12 so that you can do this yourself after the study if you need to.

Step 2: Teaching the communication response

Before we can do the FCT sessions, we need to teach your child how and when to use the communication response. We do this in a very structured way to make sure that it is easy for them to learn. We will teach the response in 5 minute sessions with a 2 minute break in between each session.

You can follow the steps below to teach your child the response. The way you will teach the communication response will depend on the function of the target behaviour and communication response you are trying to teach. The procedures below are specific to the target behaviours and function that we are focusing on during the study for your child. Teaching procedures for target behaviours with different functions are given in Appendix 9 so that can use these in the future if you need to.

1. Allow your child to play with the item for around 30 seconds (or eat a small piece) and then take it and say “my turn” or “you can have the rest in a minute”
2. **Immediately** prompt them to do the communication response by saying “more” and also signing “more”. As soon as they sign “more” give them the item back for 30 seconds (or allow them to eat a small piece).
3. If your child shows the target behaviour before you prompt them to do the communication response, wait 5 seconds and then prompt them.
4. Repeat these steps throughout the session, but gradually reduce how much you prompt your child each time:
    a. To begin with, you will need to say “more” and sign “more” (**full prompt**) every time
    b. After three full prompts, you can try saying “more” without also signing “more” (**0.5 prompt**) and waiting 1 second to see if they sign “more”. If they don’t sign “more”, do 3 more full prompts. If they do sign “more”, do 2 more 0.5 prompts.
    c. After 3 x 0.5 prompts where they sign “more”, you can try not saying anything after you take the item (**independent trial**) and waiting 2 seconds to see if they sign “more” by themselves. If they don’t, do 3 more 0.5 prompts before you try an independent trial again.
5. If the target behaviour occurs before you prompt them, wait 5 seconds and then prompt them.
6. Continue to give your child the item back for 30 seconds (or allow them to eat a small piece) **immediately** after they sign “more”, regardless of how much help you provided.
7. Each time they sign “more”, circle on the data sheet whether it was independent (i.e. you didn’t use a prompt), partially prompted (i.e. you used a 0.5 prompt), or fully prompted (i.e. you said and signed “more”).
8. After 5 minutes, end the session and give your child a 2 minute break before you start the next session.

You can finish the teaching sessions after 3 x 5 minute sessions where you don’t need to use a prompt more than 20% of the time (e.g. more than 2 times for every 10 communication responses).

Step 3: FCT sessions

After your child has learnt the communication response and is using it without your help, you can start conducting the FCT sessions. Each session will last 5 minutes with a 2 minute break in between each session. During this step, you will conduct up to 8 sessions in each appointment. Use the instructions below to conduct the sessions:

FCT

1. Conduct the session in the same way as the functional analysis condition that is related to the function of the target behaviour. For this study, this will be the **tangible** condition.
2. Don’t use any prompts, wait for your child to sign “more”
3. If you see the target behaviour, ignore or block it without talking to your child. Place a tally mark on the data sheet every time the target behaviour occurs.
4. If your child signs “more”, **immediately** give the item back for 30 seconds (or allow them to eat a small piece). Place a tally mark on the data sheet every time the communication response occurs.
5. Repeat these steps throughout the session. After 5 minutes, end the session and give your child a 2 minute break before starting the next session.

If your child does not use the communication response for 3 x 5 minute FCT sessions in a row, go through the teaching procedures again. If your child still does not use the communication response, the researcher will discuss this with a speech and language therapist and help you to identify whether we can make the response easier for your child to use.

The researcher will draw the results on a graph to see how well FCT is working to reduce the target behaviour and increase your child’s use of the communication response.

If your child shows the target behaviour 80% less often during 3 FCT sessions in a row than they did during the baseline sessions, the researcher will ask you to conduct 3 new baseline sessions. This is to check that the FCT intervention resulted in the reduction in behaviour, rather than something else. After this, the researcher will ask you to implement more FCT sessions for the remainder of the appointment.

8. Continuing FCT at home

After four FCT appointments, the researcher will ask you to continue doing FCT with your child at home for ***15 minutes per day, 3-5 days per week*** (for 6 weeks). This means doing 3 FCT sessions in the same way as described above, 3-5 days per week. During this time, you can phone or email the researcher (between 9am and 7pm) for help and advice.

You should also respond to the communication response if your child uses it outside of the FCT sessions during this stage – this will help them learn to use it in more situations. If your child is using a communication aid (e.g. card or switch), you should make this available outside of the FCT sessions to allow your child to use it frequently and in different situations.

SAFETY FIRST!

Remember to always think about the safety criteria whenever you are working with your child during the study. If your child's behaviour meets these criteria, or you feel that you or your child are unsafe, you **must** stop the session and do the things we identified that can help your child calm down. We can always redo the session another time if we need to – the safety or your child, yourself, and anyone else around is the most important thing. Remember that you can always contact the researcher afterwards if you need to talk about what happened, but make sure that your child has calmed down and everyone is safe before you do this.

The researcher will ask you to keep a log of these sessions and will give you a form for this. These logs will help the researcher to know how the sessions are going and are for you to identify any areas that you'd like to ask the researcher about or that you might want to go over again in this manual.

The researcher will also ask you to video these sessions so that they can check how you are implementing FCT (so that they know how to help you) and to collect data on how often the behaviour and communication response happen during the sessions. The researcher will lend you a camera and tripod for this purpose.

Observations

Every 2 weeks, the researcher will visit you at home to do a 30 minute observation of you conducting FCT with your child. This observation is to help the researcher give you advice about doing the intervention and to make sure that you are happy with everything. At these appointments, the researcher will also collect the videos and session logs from you. There will be 3 of these observations. After all 3 observations have been done, you should continue FCT at home whenever you can and respond to the communication response when your child uses it. This will help to make sure your child continues to use the communication response.

There will be one final appointment around a month and a half after the final observation. In this appointment the researcher will do one more observation and will give you advice on how to continue implementing FCT with your child in the future.

Glossary

Antecedents: the things that happen immediately before a target behaviour.

Baseline sessions: sessions during FCT where we ignore the target behaviour *and* communication response to see how often the target behaviour normally happens. This is so we can compare the results during FCT sessions to the baseline sessions to check that FCT is working.

Communication response: the response we will teach your child during FCT that serves the same function as the target behaviour, e.g. touching a card that says “break” if the behaviour functions to escape demands.

Condition: the name given to a specific type of session during a functional analysis, for example, attention, tangible, play, alone, demand etc. The sessions of a particular condition are always conducted in the same way.

Consequences: the things that happen immediately after a target behaviour.

Demand: a request or instruction that the individual does not like or finds a bit difficult to do.

Function: the name given to the outcome that a target behaviour achieves for the person. For example, if the behaviour results in the person getting a drink, we call this a tangible function.

Functional analysis: an experimental procedure which uses carefully controlled conditions to identify the function of a target behaviour.

Functional assessment: the name given to a range of assessments used to identify the function of a behaviour. For example, an observation, interviews with those who know the person etc.

Functional communication training: a structured way of teaching your child a communication response that they can use instead of difficult behaviours to meet their needs. It involves teaching a communication response and ignoring target behaviours, so that your child learns that they should use the communication response to meet their needs.

Functional understanding of behaviour: the understanding that all behaviours serve a purpose for the individual displaying them, even difficult behaviours.

Latency: for this study this means how long after the start of the functional analysis condition the target behaviour happens.

Observation: watching to see when the behaviour happens and what happens before / after it.

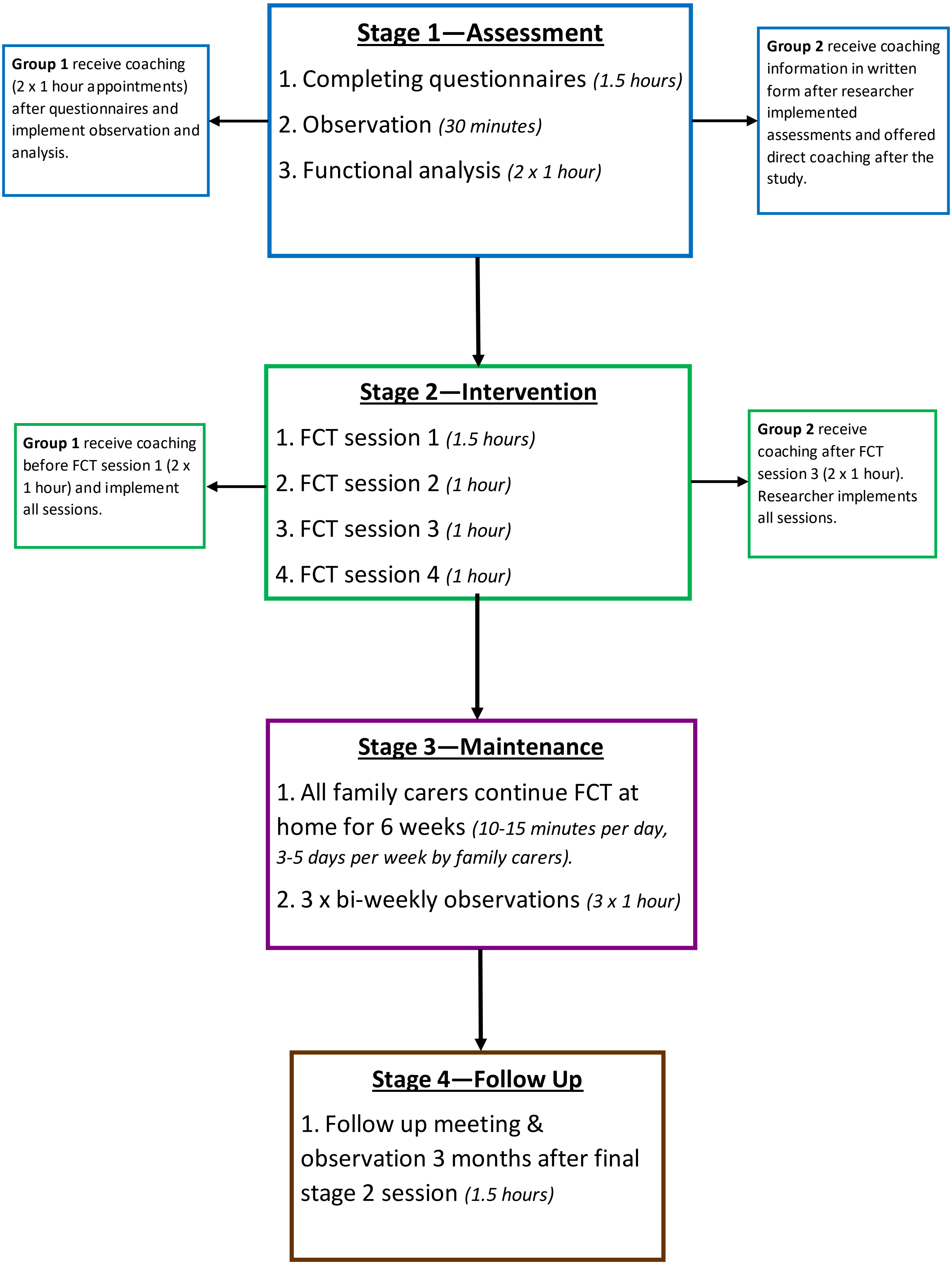
Setting events: the things that happen before a target behaviour, but not necessarily immediately before, that may make the target behaviour more likely. For example, getting a poor night’s sleep, being hungry, being in pain, having a busy day etc.

Summary statement: a sentence that states the target behaviours, setting events, antecedents, consequences.

Tangible: the name given to an item (e.g. food, drink, activity, toy) that the individual likes.

Target behaviour: the specific behaviour or behaviours that we are looking for. In this study, this is a specific type of difficult behaviour, e.g. hitting/kicking.

Appendix 1 – Study timeline



Stage 1—Assessment

1. Completing questionnaires *(1.5 hours)*
2. Observation *(30 minutes)*
3. Functional analysis *(2 x 1 hour)*

Group 1 receive coaching (2 x 1 hour appointments) after questionnaires and implement observation and analysis.

Group 2 receive coaching information in written form after researcher implemented assessments and offered direct coaching after the study.

Stage 2—Intervention

1. FCT session 1 *(1.5 hours)*
2. FCT session 2 *(1 hour)*
3. FCT session 3 *(1 hour)*
4. FCT session 4 *(1 hour)*

Group 1 receive coaching before FCT session 1 (2 x 1 hour) and implement all sessions.

Group 2 receive coaching after FCT session 3 (2 x 1 hour). Researcher implements all sessions.

Stage 3—Maintenance

1. All family carers continue FCT at home for 6 weeks *(10-15 minutes per day, 3-5 days per week by family carers).*
2. 3 x bi-weekly observations *(3 x 1 hour)*

Stage 4—Follow Up

1. Follow up meeting & observation 3 months after final stage 2 session *(1.5 hours)*

Appendix 2 – Functional Assessment Interview

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Appendix 3 – Functional Assessment Observation Form

[REDACTED]

Appendix 4 – Functional Analysis Conditions

Attention condition

Setting: you and your child are in a room with a range of toys that they like (but not their favourites) freely available

1. Tell your child to play with the toys and that you have some work to do.
2. Start the stopwatch.
3. Pretend to work, e.g. by reading a magazine.

If your child **displays any of the target behaviours** – stop the stopwatch and say something like "no don't do that, you'll hurt yourself!" and touch them to comfort them, e.g. on the shoulder. Write the time from the stopwatch on the data sheet.

End the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.

Demand condition

Setting: you and your child are in a room with some activities your child finds a bit difficult, e.g. putting shapes in a shape sorter

1. Tell your child to do the activity.
2. Start the stopwatch.
3. If they don't do the activity within 2 seconds, show them how to.
4. If they still don't do it after another 2 seconds – repeat the instruction and help them to do it by physically guiding them.
5. Praise them when they do the activity.
6. Repeat steps 1-5 until the end of the session.

If your child **displays any of the target behaviours** – stop the stopwatch and say "ok you don't have to". Turn away from your child for 30 seconds and remove items. Do not ask them to keep doing the activity. Write the time from the stopwatch on the data sheet.

End the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.

Alone (only if the target behaviour is self-injury / property destruction)

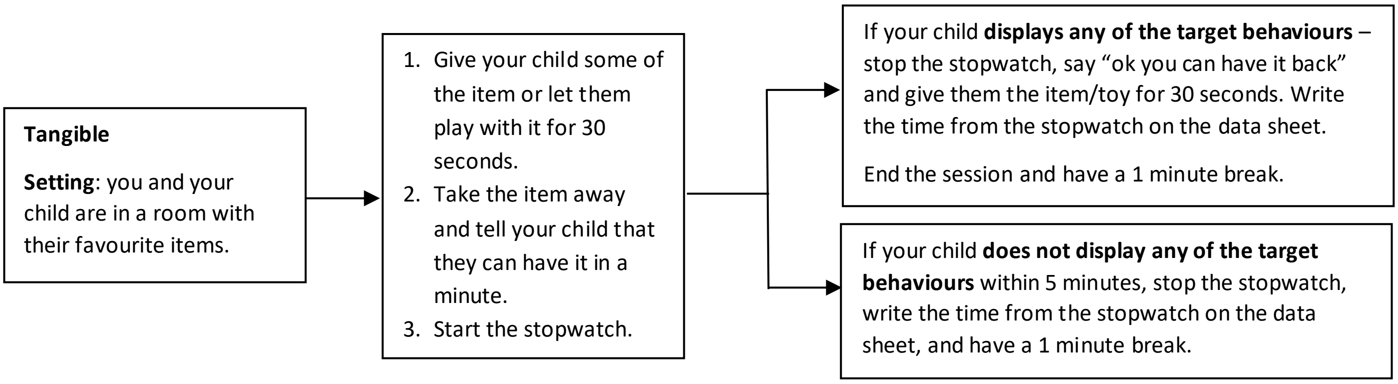
Setting: your child is in a room alone without any toys or other people. This should be somewhere where you can still see your child (e.g. through a door or window)

1. Start the stopwatch.
2. Observe your child.

If your child **displays any of the target behaviours** – stop the stopwatch and ignore / block the behaviour. Write the time on the data sheet.

Continue the session for 1 minute after the behaviour or until 5 minutes after the start of the session (whichever comes first), then end the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.



Tangible

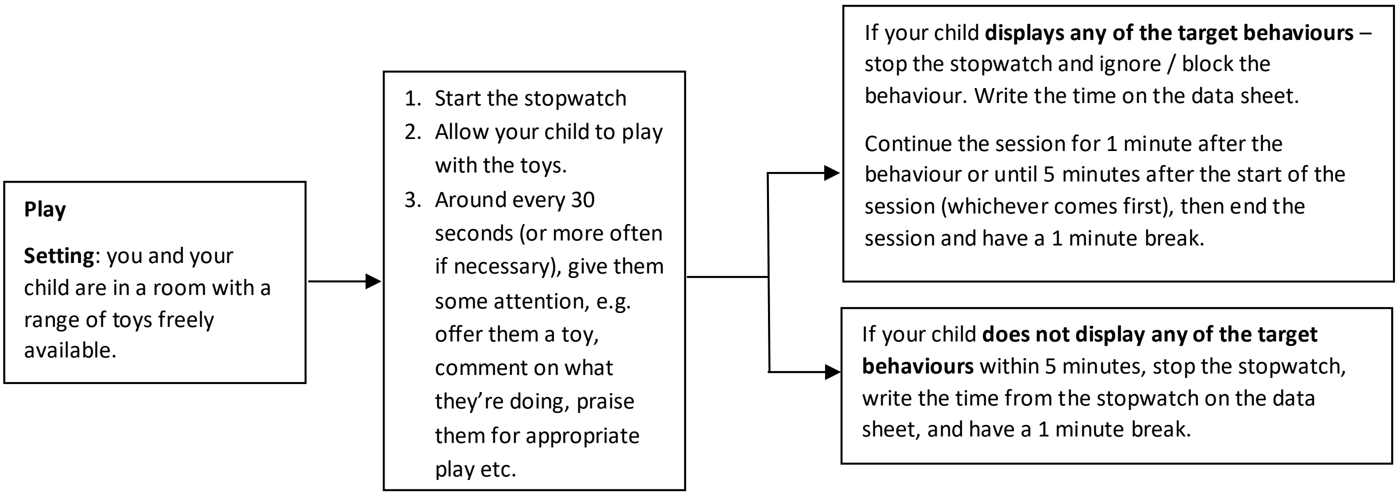
Setting: you and your child are in a room with their favourite items.

1. Give your child some of the item or let them play with it for 30 seconds.
2. Take the item away and tell your child that they can have it in a minute.
3. Start the stopwatch.

If your child **displays any of the target behaviours** – stop the stopwatch, say "ok you can have it back" and give them the item/toy for 30 seconds. Write the time from the stopwatch on the data sheet.

End the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.



Play

Setting: you and your child are in a room with a range of toys freely available.

1. Start the stopwatch
2. Allow your child to play with the toys.
3. Around every 30 seconds (or more often if necessary), give them some attention, e.g. offer them a toy, comment on what they're doing, praise them for appropriate play etc.

If your child **displays any of the target behaviours** – stop the stopwatch and ignore / block the behaviour. Write the time on the data sheet.

Continue the session for 1 minute after the behaviour or until 5 minutes after the start of the session (whichever comes first), then end the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.

Appendix 5 – Functional Analysis Data Sheet

The table below can be used to record how long after the start of a session (the **latency**) the behaviour happens during the functional analysis. You can change the order of the conditions if you need to, but remember they should be in a **random** order and each condition must be done **four** times.

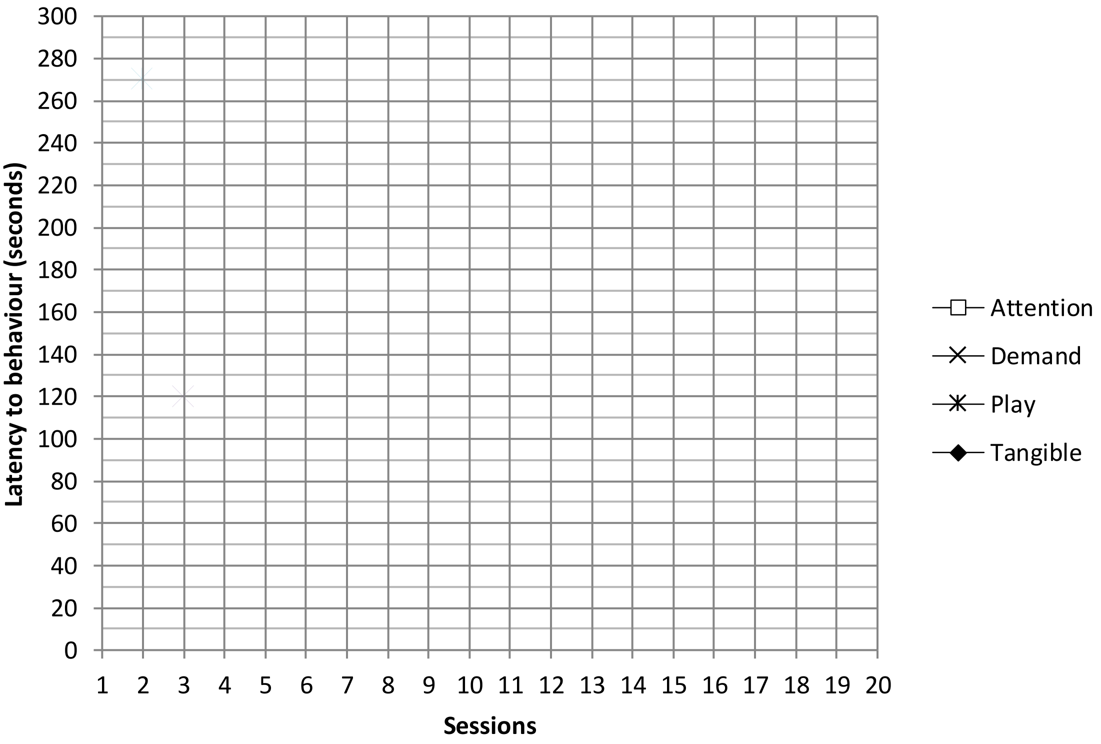
Session	Condition type	Latency to behaviour (minutes & seconds)
1	Play	
2	Demand	
3	Tangible	
4	Attention	
5	Alone*	
6	Demand	
7	Attention	
8	Play	
9	Tangible	
10	Alone*	
11	Attention	
12	Tangible	
13	Demand	
14	Alone*	
15	Play	
16	Tangible	
17	Demand	
18	Play	
19	Alone*	
20	Attention	

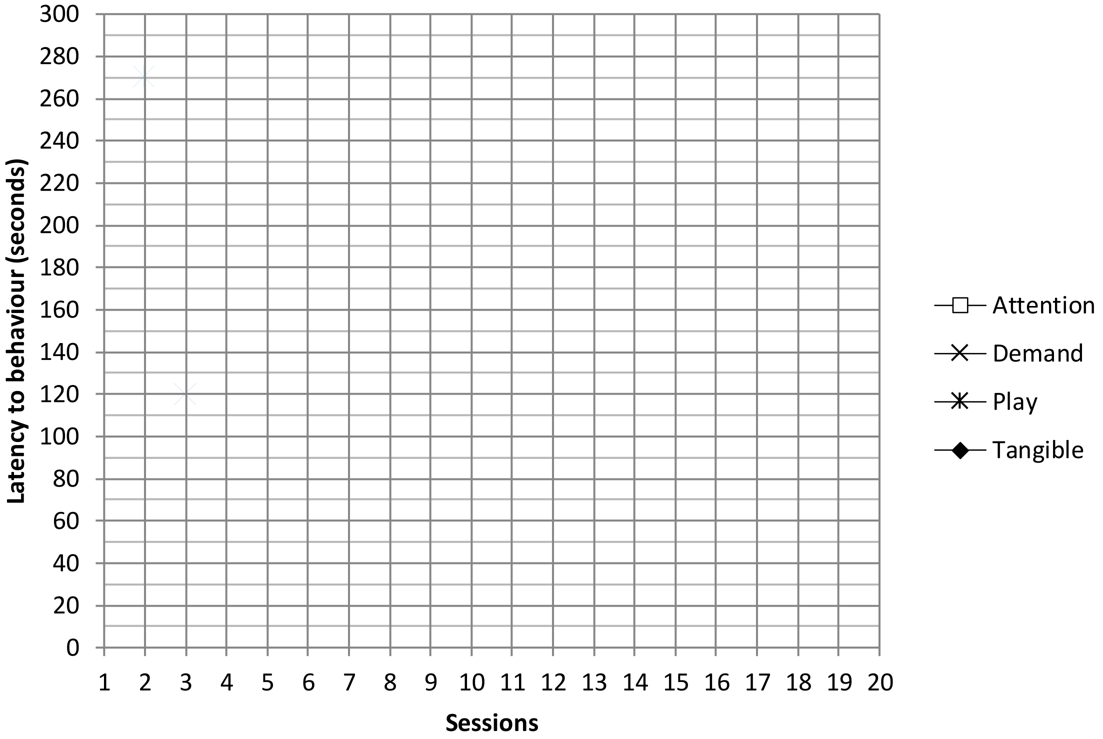
***only do the alone sessions if the target behaviour is self-injury or property destruction**.

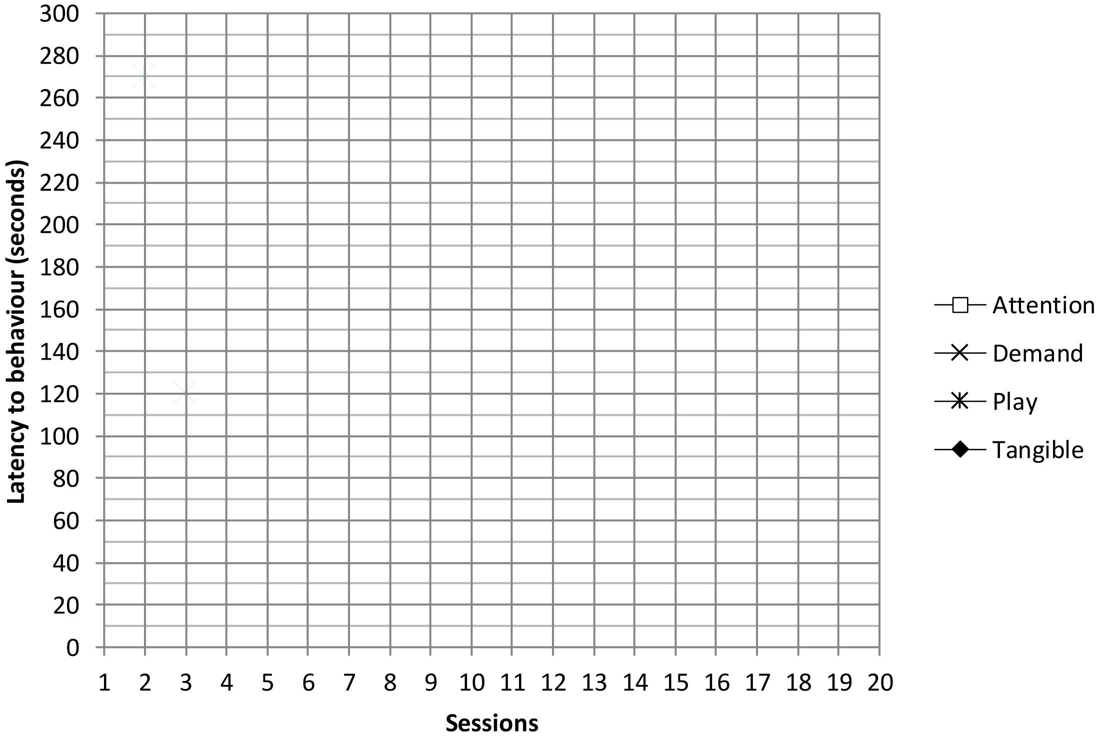
Appendix 6 – Graphing the results of a functional analysis

To graph the results of the functional analysis;

1. **1.** Convert the time to seconds by multiplying the number of minutes by 60 and adding on the number of seconds. E.g. for 4 minutes 22 seconds you would do 4 x 60 = 240 + 22 = 262.
2. **2.** Do one condition at a time.
   - **a.** Use the correct symbol for that condition (listed on the graph templates) and draw the symbol at the relevant point on the graph for that session. E.g. if the data above was for session 3, you would draw the symbol in line with 3 on the bottom axis and 262 on the side axis. If the target behaviour did not occur during the session, draw the symbol at 300 seconds.
   - **b.** Do this for each session of that condition (there will be 4 per condition).
   - **c.** Connect the points for sessions of the same condition type with a line.
3. **3.** Do this for every condition type, i.e. demand, alone, play, tangible, attention.




Latency to behaviour (seconds)
300
280
260
240
220
200
180
160
140
120
100
80
60
40
20
0
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
Sessions
Attention
Demand
Play
Tangible


Latency to behaviour (seconds)
300
280
260
240
220
200
180
160
140
120
100
80
60
40
20
0
1
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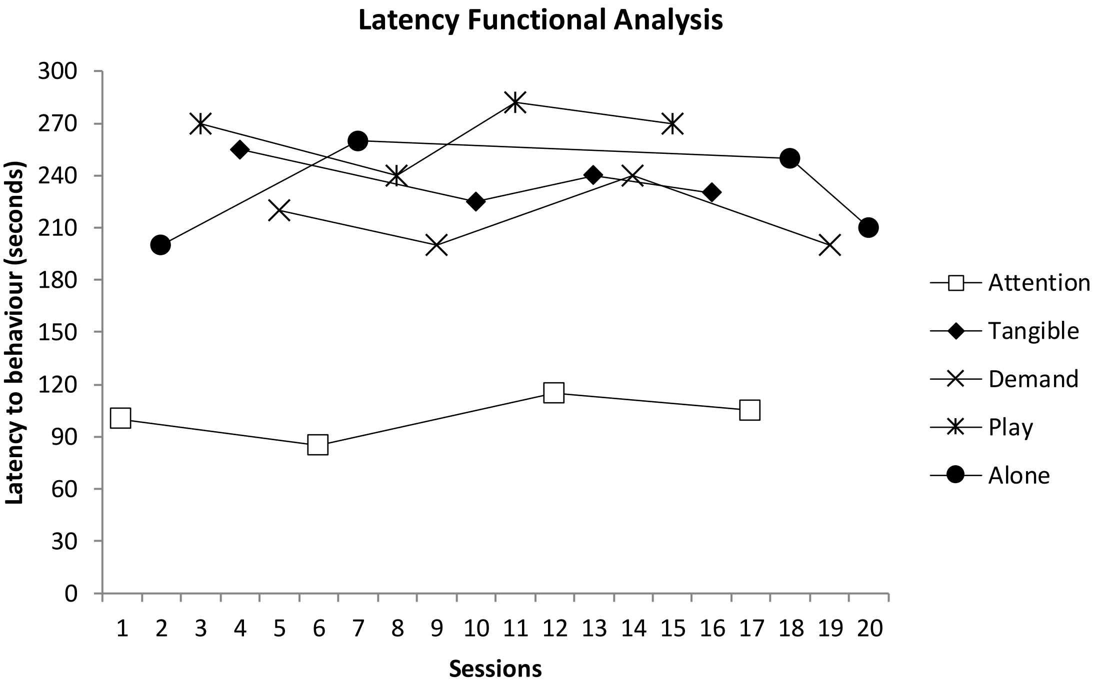
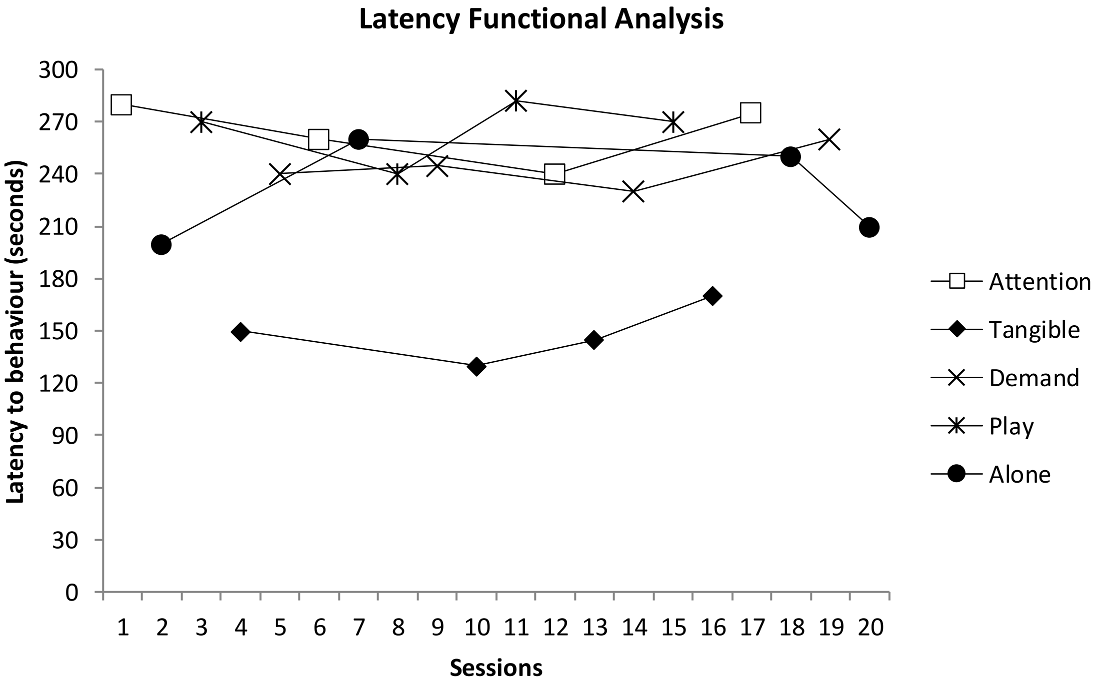
16
17
18
19
20
Sessions
Attention
Demand
Play
Tangible

Appendix 7 – Functional analysis graph examples

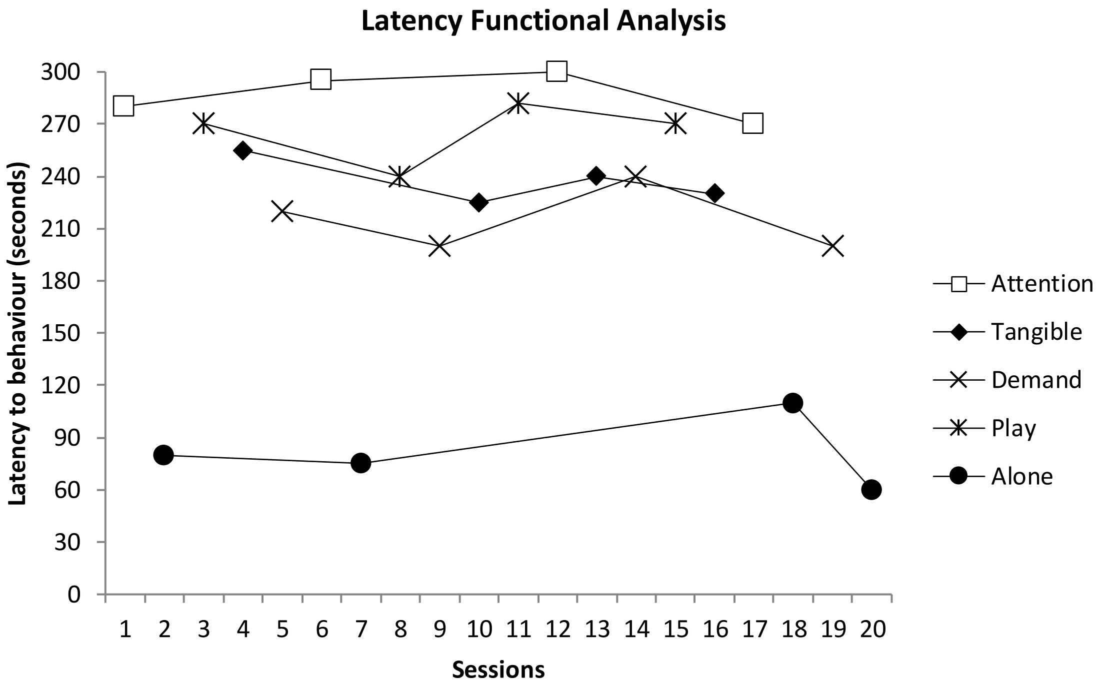
This graph indicates that the behaviour functions to gain **attention**, as it occurred more quickly in the attention conditions than in any other condition.



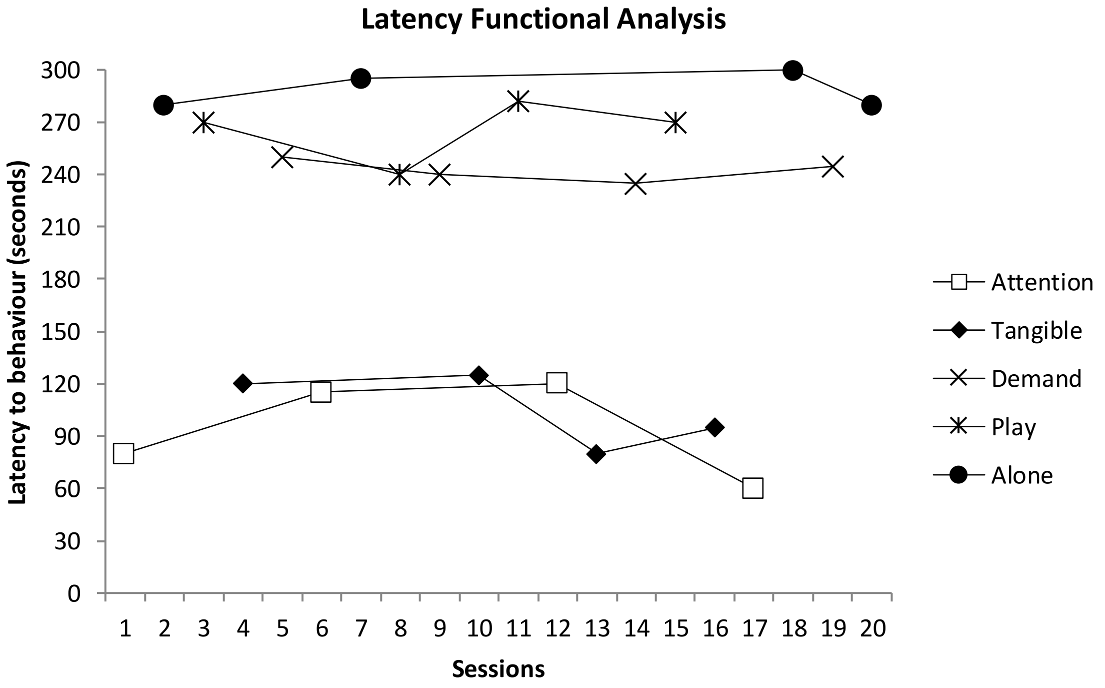
This graph indicates that the behaviour functions to gain access to an item the child likes, as it occurred more quickly in the **tangible** conditions than in other conditions.



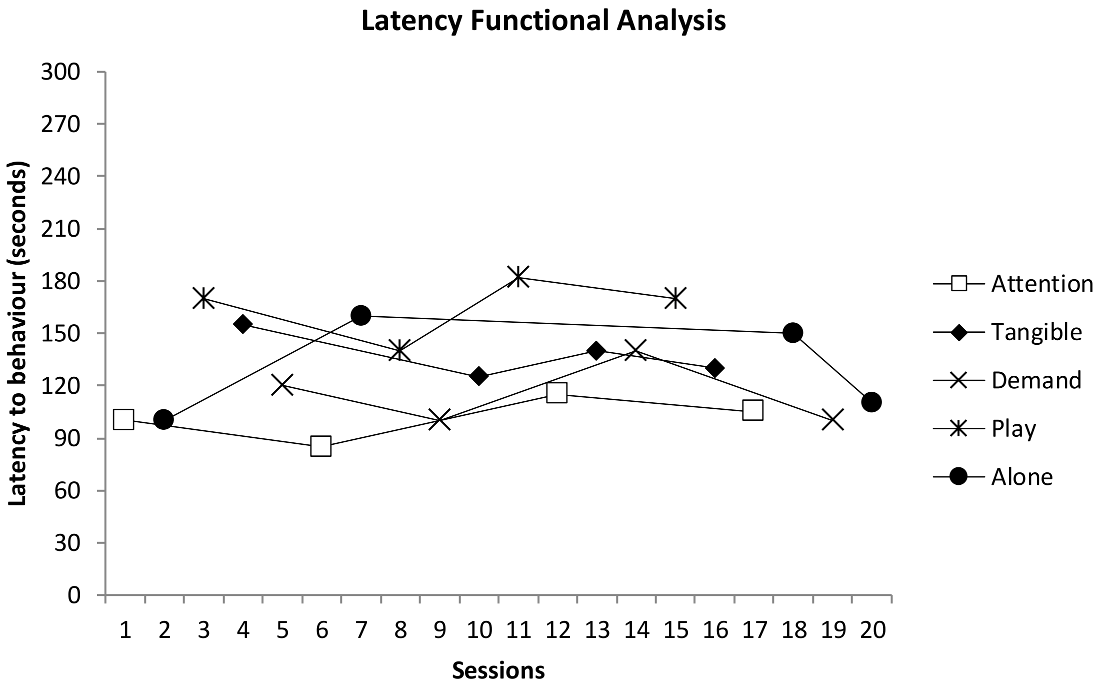
This graph indicates that the behaviour functioned to gain **sensory stimulation**, as it occurred more quickly when the child was alone than in other conditions.



This graph indicates that the behaviour has **multiple functions** (access to items the individual likes and attention) as behaviour occurred more quickly in attention and tangible conditions than in other conditions.



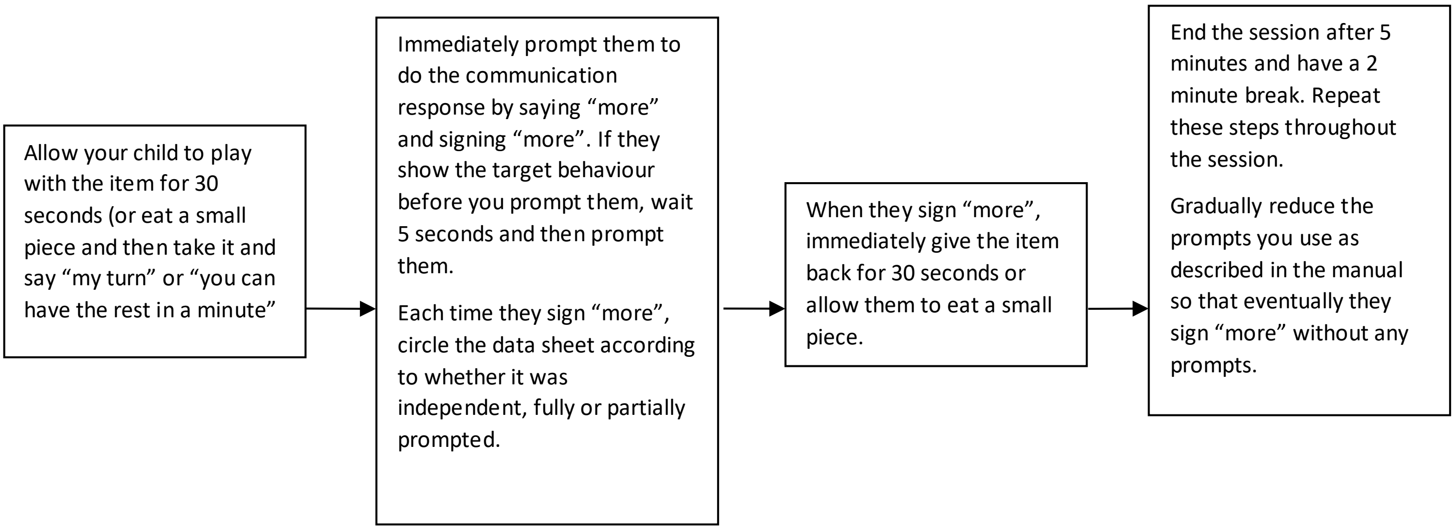
This graph suggests either that the behaviour has **multiple functions**, that it has a **sensory stimulation** function (as it occurred in every session), or that we need to do **more analyses**. If this pattern of data happens, you should seek further support from someone with behavioural expertise.



Appendix 8 – Teaching & FCT procedures for your child in this study

Teaching procedures

These procedures are individualised for the communication response we are focusing on in this study. Teaching procedures for other types of response and function of behaviour are shown in Appendix 9.



Allow your child to play with the item for 30 seconds (or eat a small piece and then take it and say "my turn" or "you can have the rest in a minute"

Immediately prompt them to do the communication response by saying "more" and signing "more". If they show the target behaviour before you prompt them, wait 5 seconds and then prompt them.

Each time they sign "more", circle the data sheet according to whether it was independent, fully or partially prompted.

When they sign "more", immediately give the item back for 30 seconds or allow them to eat a small piece.

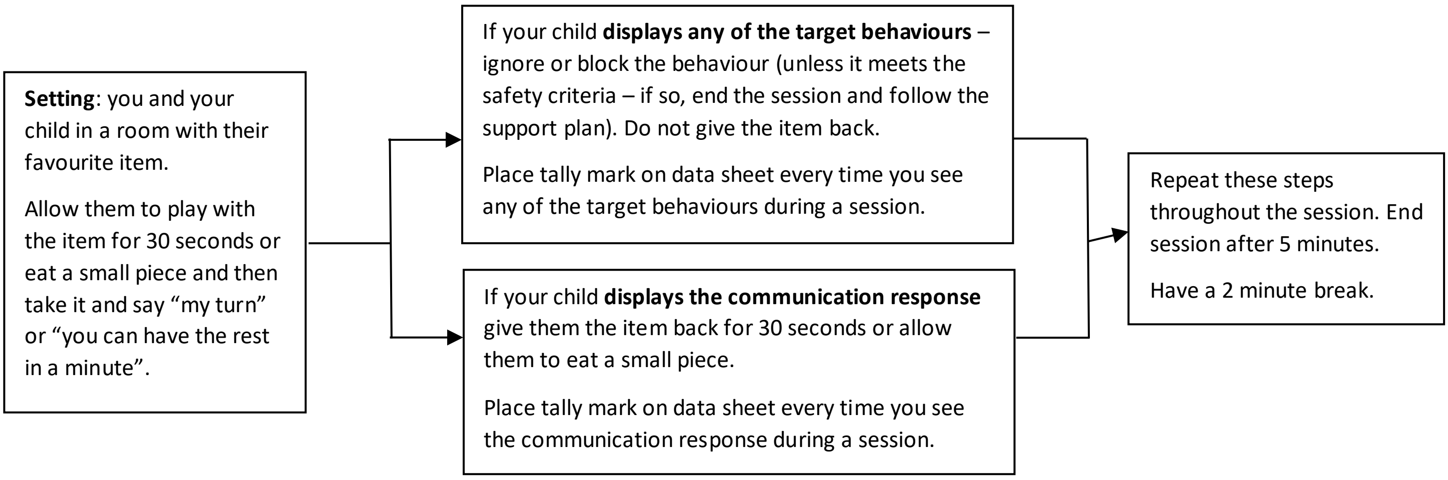
End the session after 5 minutes and have a 2 minute break. Repeat these steps throughout the session.

Gradually reduce the prompts you use as described in the manual so that eventually they sign "more" without any prompts.

FCT procedures

These procedures are individualised for the target behaviours we are focusing on in this study.

If you are doing FCT for different behaviours after the study, the procedures are the same, however run the session in the same way as the functional analysis condition related to the function of the target behaviour you are focusing on.



Setting: you and your child in a room with their favourite item.

Allow them to play with the item for 30 seconds or eat a small piece and then take it and say "my turn" or "you can have the rest in a minute".

If your child **displays any of the target behaviours** – ignore or block the behaviour (unless it meets the safety criteria – if so, end the session and follow the support plan). Do not give the item back.

Place tally mark on data sheet every time you see any of the target behaviours during a session.

If your child **displays the communication response** give them the item back for 30 seconds or allow them to eat a small piece.

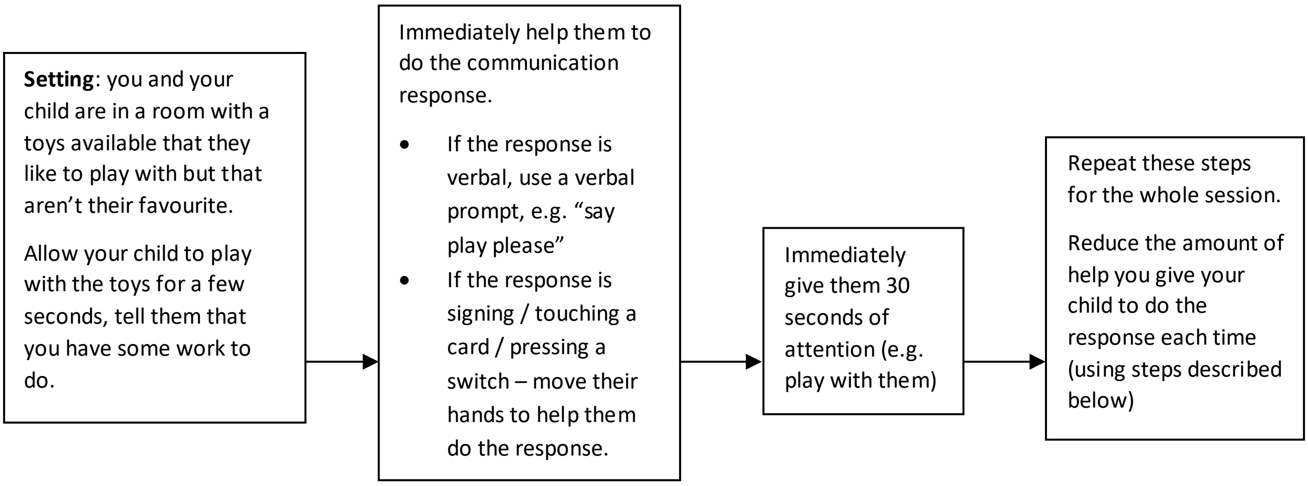
Place tally mark on data sheet every time you see the communication response during a session.

Repeat these steps throughout the session. End session after 5 minutes.

Have a 2 minute break.

Appendix 9 – Teaching procedures for other functions of behaviour

Attention function



Setting: you and your child are in a room with a toys available that they like to play with but that aren't their favourite.

Allow your child to play with the toys for a few seconds, tell them that you have some work to do.

Immediately help them to do the communication response.

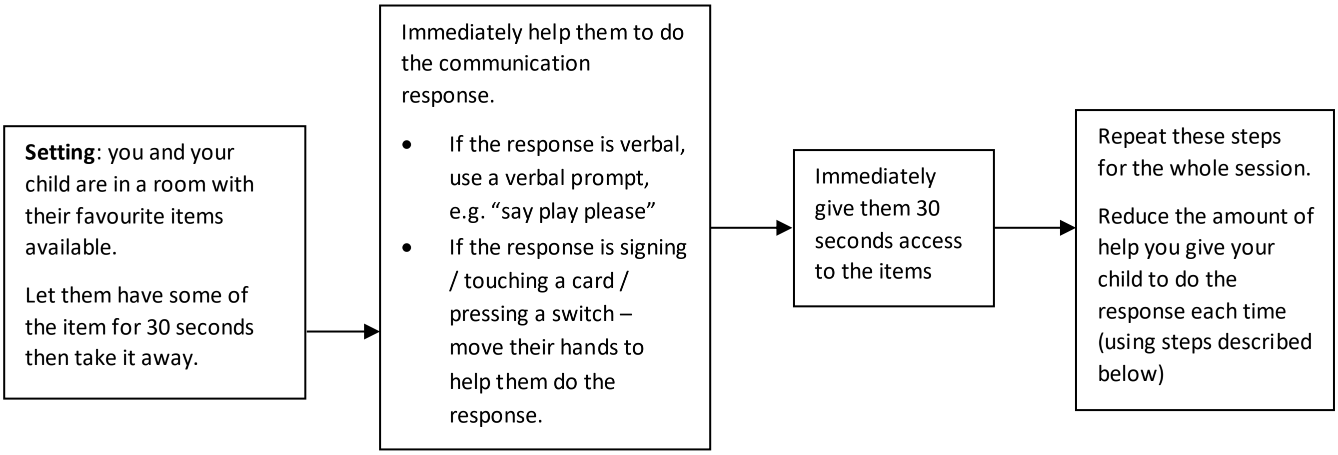
- If the response is verbal, use a verbal prompt, e.g. "say play please"
- If the response is signing / touching a card / pressing a switch – move their hands to help them do the response.

Immediately give them 30 seconds of attention (e.g. play with them)

Repeat these steps for the whole session.

Reduce the amount of help you give your child to do the response each time (using steps described below)

Tangible function



Setting: you and your child are in a room with their favourite items available.

Let them have some of the item for 30 seconds then take it away.

Immediately help them to do the communication response.

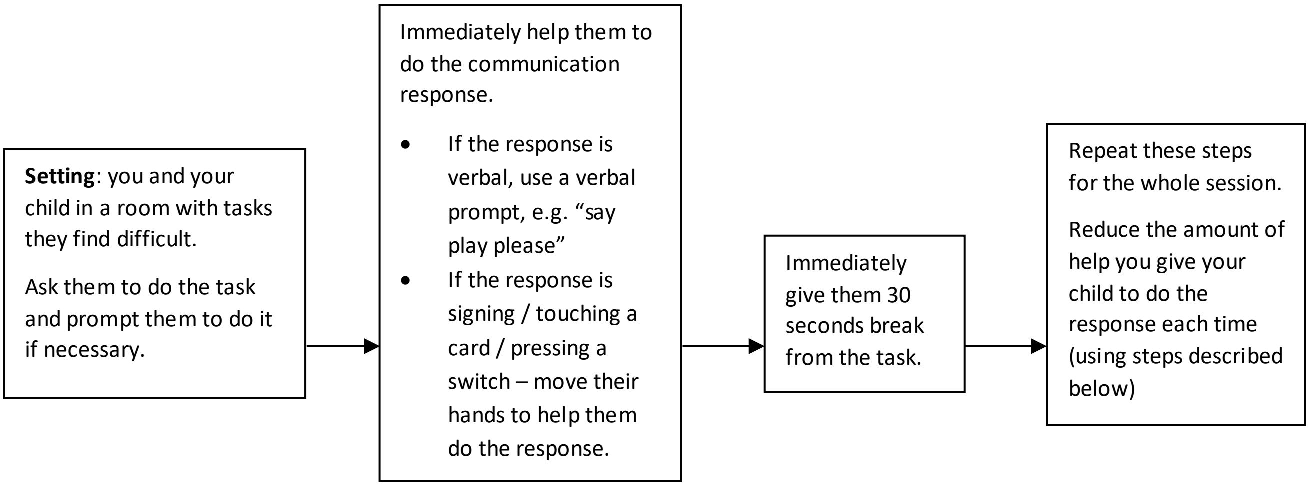
- If the response is verbal, use a verbal prompt, e.g. "say play please"
- If the response is signing / touching a card / pressing a switch – move their hands to help them do the response.

Immediately give them 30 seconds access to the items

Repeat these steps for the whole session.

Reduce the amount of help you give your child to do the response each time (using steps described below)

Escape function



Setting: you and your child in a room with tasks they find difficult.

Ask them to do the task and prompt them to do it if necessary.

Immediately help them to do the communication response.

- If the response is verbal, use a verbal prompt, e.g. "say play please"
- If the response is signing / touching a card / pressing a switch – move their hands to help them do the response.

Immediately give them 30 seconds break from the task.

Repeat these steps for the whole session.

Reduce the amount of help you give your child to do the response each time (using steps described below)

To gradually reduce the amount of help you provide so that your child starts to use the communication response by themselves, follow the steps below for the type of response you are teaching them.

1. If it is a **physical response**, like touching a card or making a sign:
    a. Start by moving their hands to do the whole response, and then moving their hands for the start of the response only and letting them finish the movement. Then just touch their hands so that they move them, then just move your hands near to their hands, and eventually stop moving your hands so that they do the response by themselves.
2. If it is a **spoken response**, like saying a phrase:
    a. Start by saying “say break please” every time. Then reduce how much of the phrase you say, e.g. “say break pl”, then “say break”, then “say br”, then “say”, then “s” until you don’t need to say anything and they say the phrase by themselves.

Appendix 10 – Teaching sessions data sheet

Number each ***5 minute session*** (i.e. 1, 2, 3, 4, 5). Write the session number in the "session" column.

Number each ***communication response*** that happens during the session (i.e. 1, 2, 3, 4, 5) and ***circle*** whether it was:

- **I** - Independent (i.e. you did not help at all)
- **0.25P –** 0.25 partially prompted (i.e. you only prompted them to start the response)
- **0.5P** – 0.5 partially prompted (i.e. you prompted about half of the response)
- **FP** - Fully prompted (i.e. you told them exactly what to say, or had to move their hands to do the whole response).

Date	Session	Response Number	Level of help (circle)
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP
			I 0.25P 0.5P FP

Appendix 11 – Baseline & FCT sessions data sheet

Use the table below to keep a ***tally*** of how many times the target behaviour and communication response occur during each ***5 minute baseline or FCT session***.

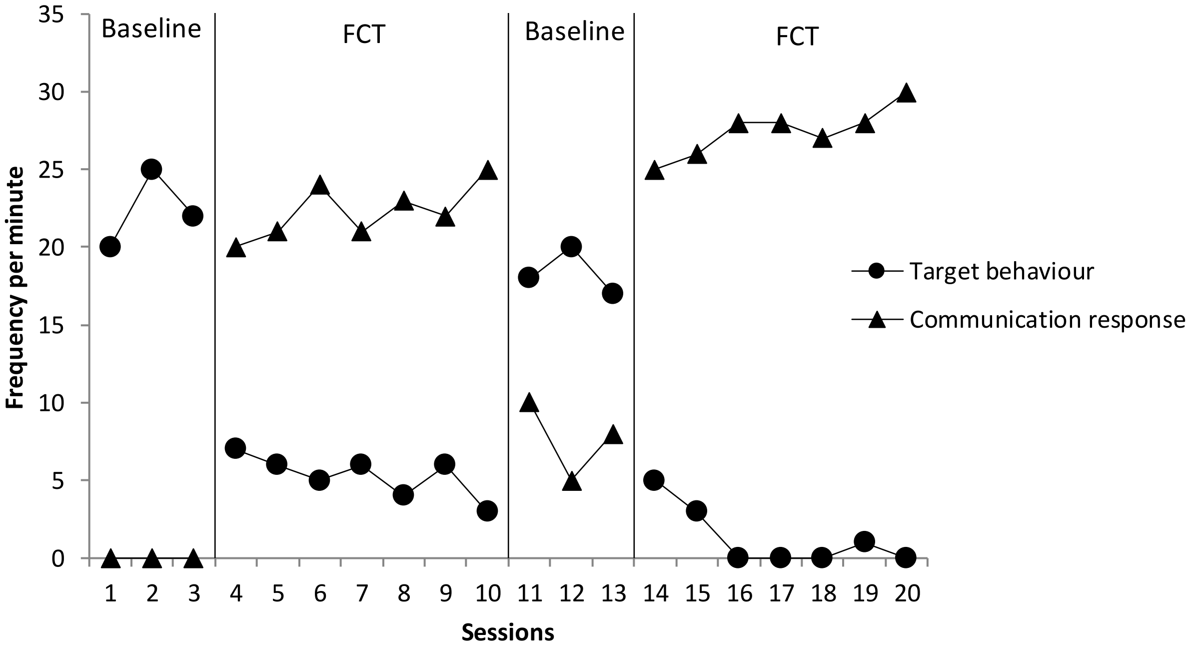
Date	**Session type (circle)**	**Session number**	**Target behaviour**	**Communication response**
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			
	Baseline / FCT			

Appendix 12 – Graphing the FCT results

To graph the results of the baseline and FCT sessions:

1. Convert the number of target behaviours you observed each session to *the frequency per minute* by dividing the number by 5.
2. Use the target behaviour symbol and draw the symbol in line with the session number (along the bottom) and the frequency per minute (along the side).
3. Repeat steps 1 & 2 for the communication responses you observed.
4. When you change session type (i.e. baseline to FCT sessions or vice versa), place a vertical line before the next session (see example below).
5. Join the target behaviour symbols in each session type with a line. Do not join the symbols if the session type changed (see example below).
6. Join the communication response symbols in each session type with a line. Do not join the symbols if the session type changed (see example below).

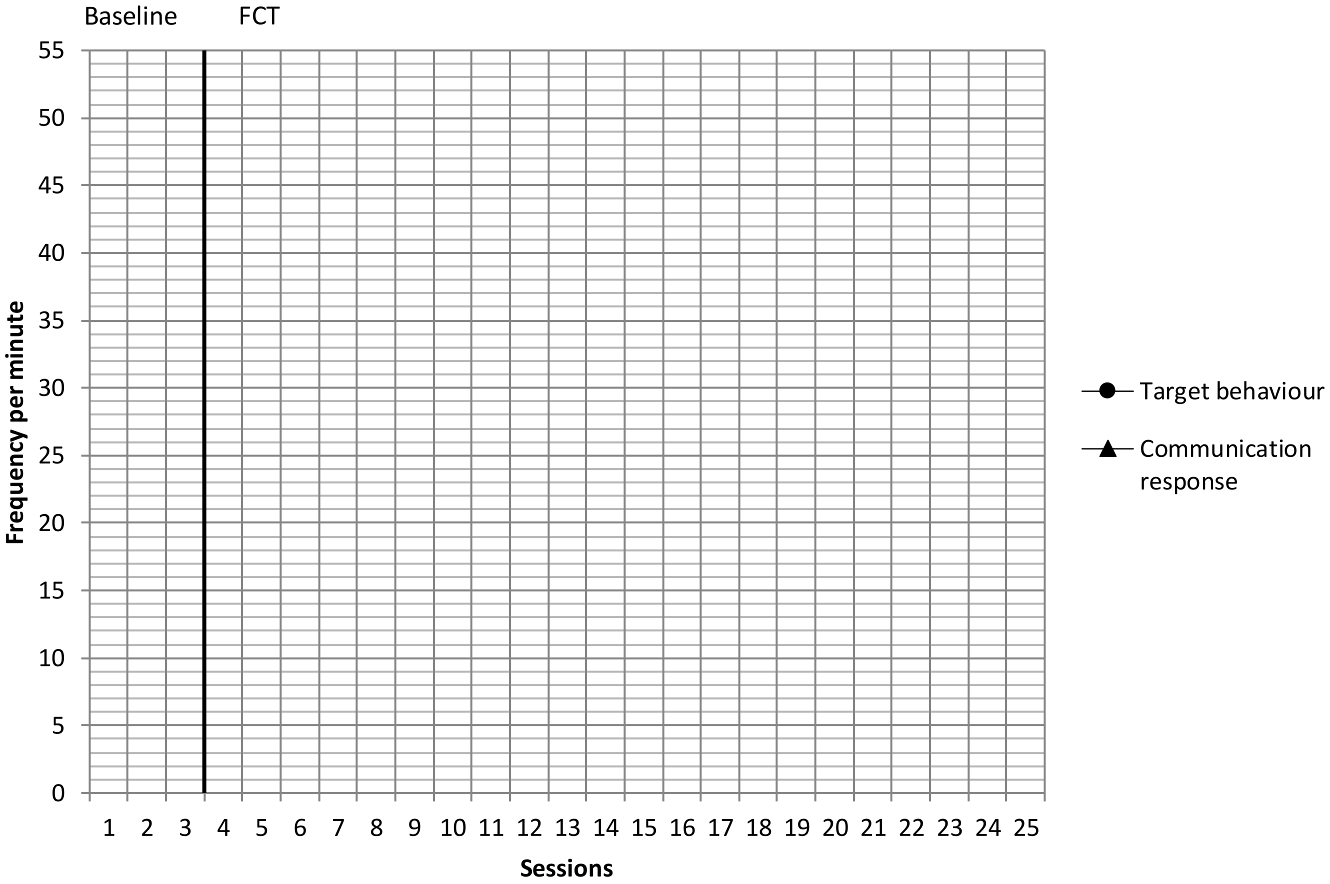
Example FCT graph

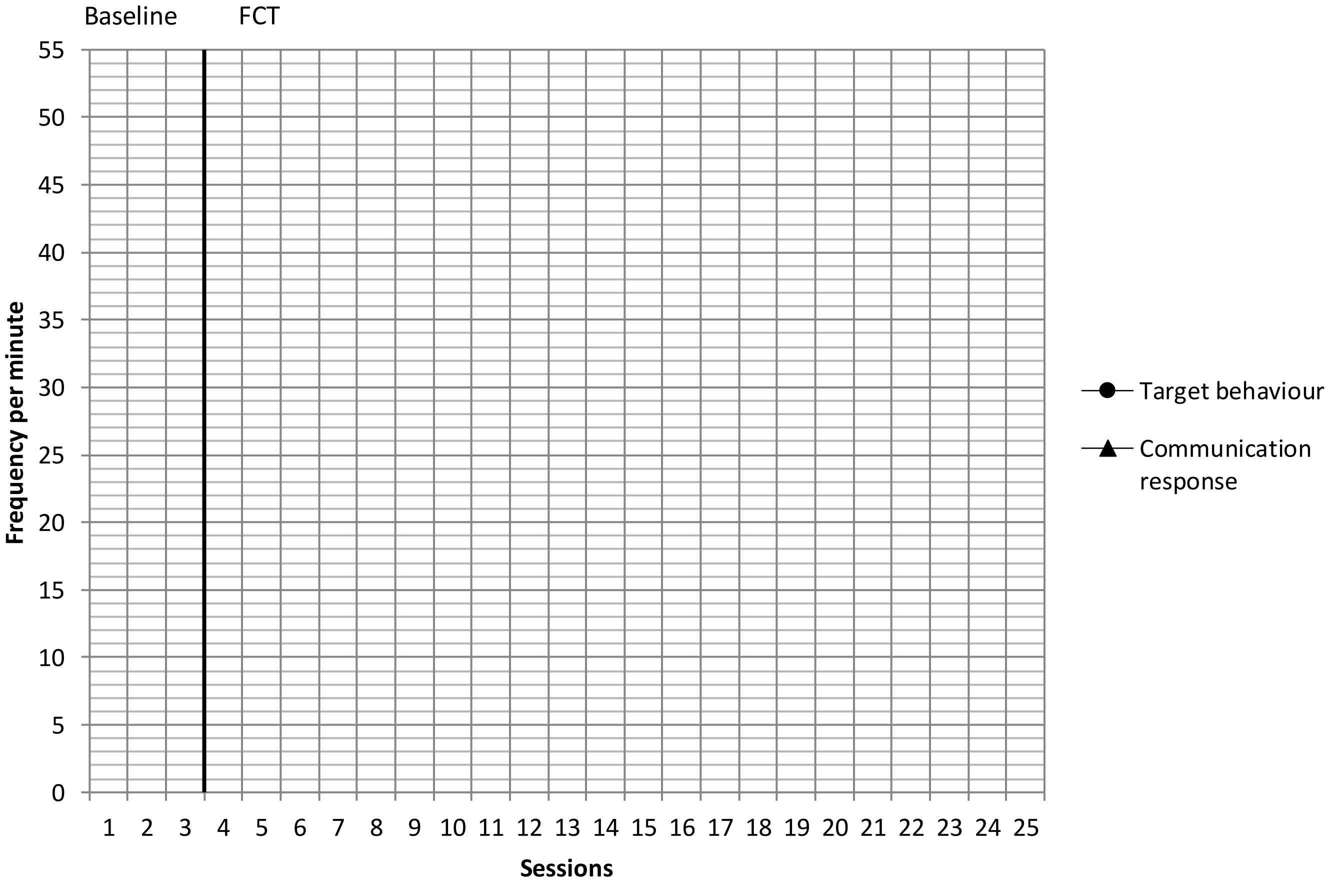


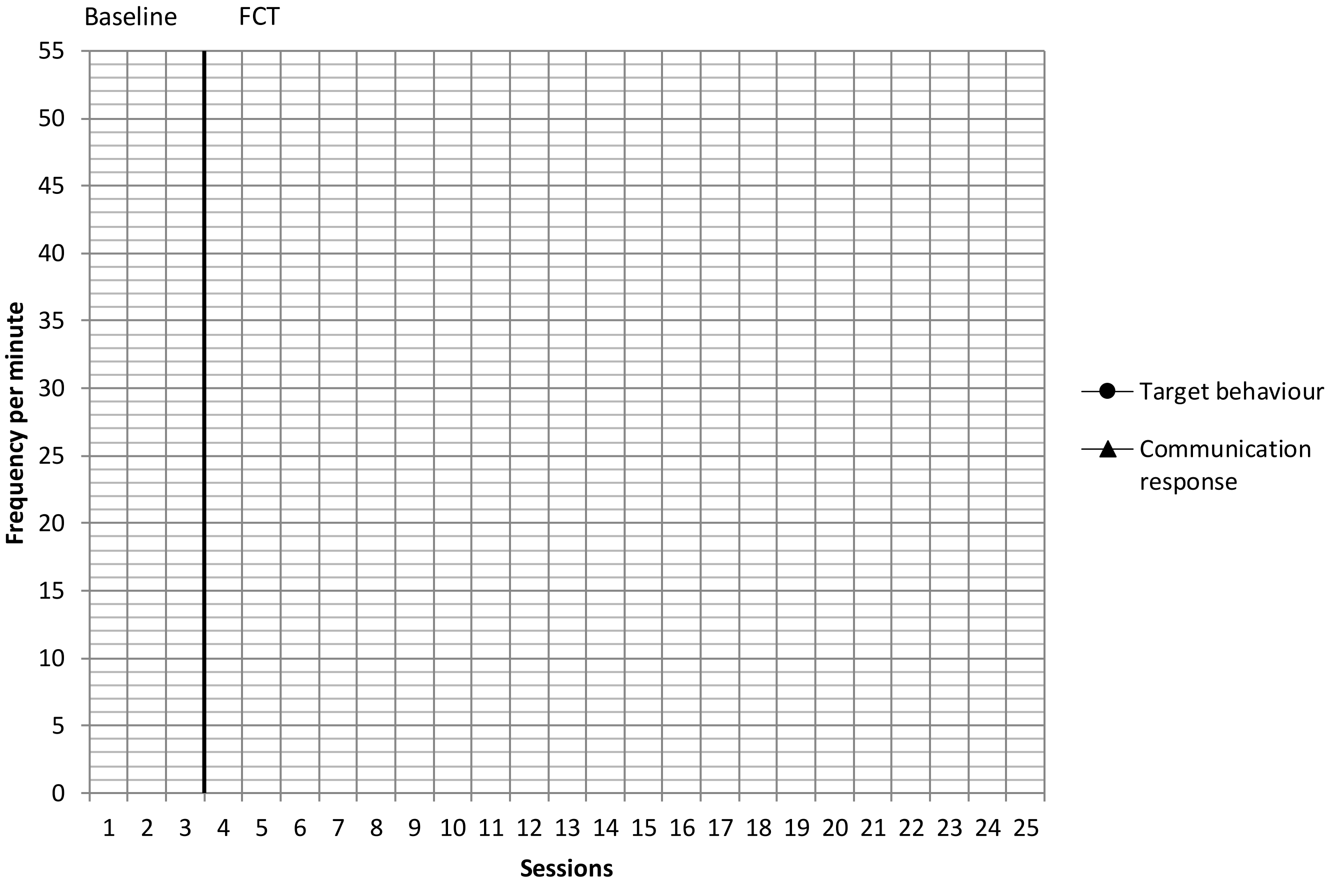
In this graph we can see that:

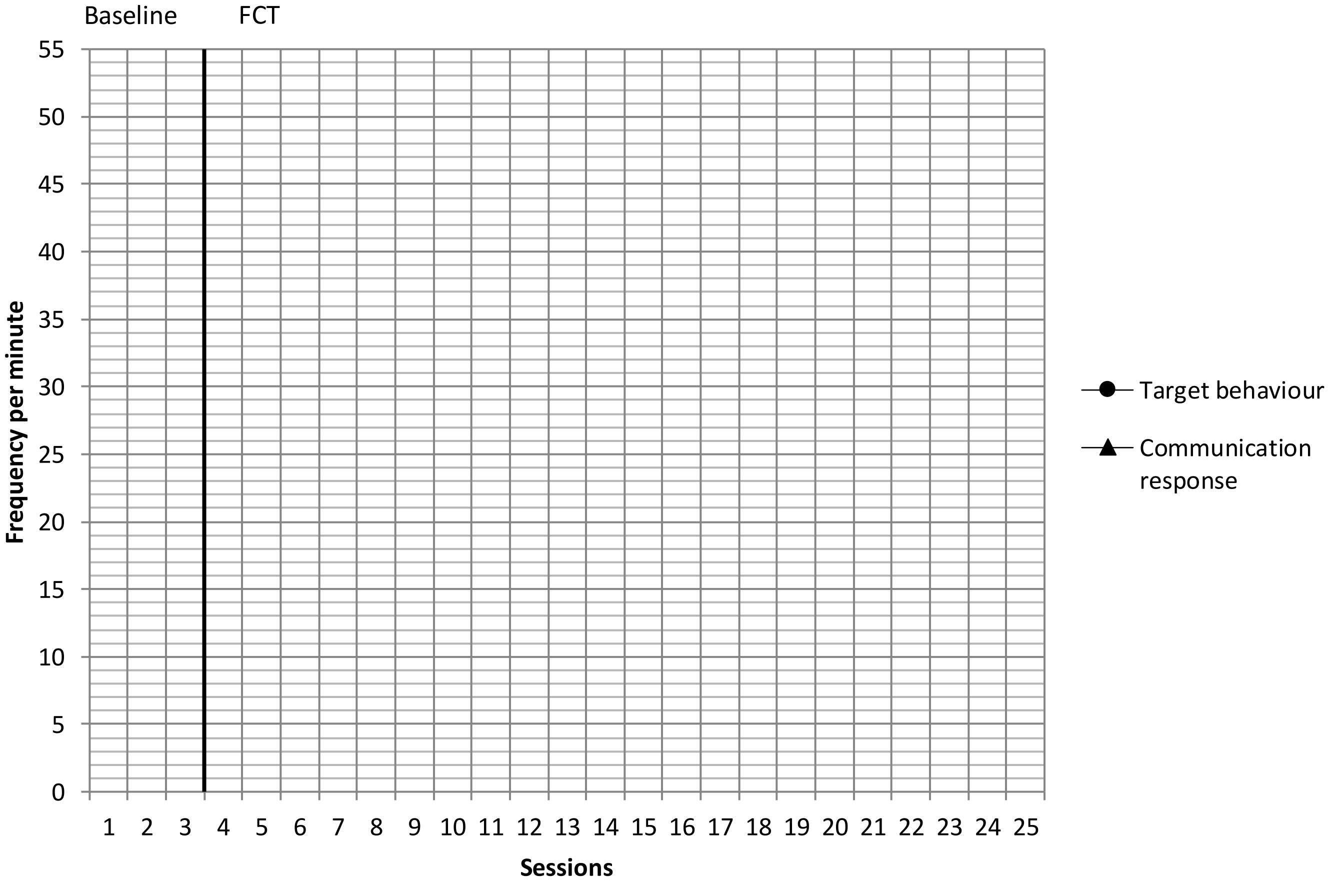
- The target behaviour occurred often during the first baseline phase, and the communication response did not occur.
- When FCT was implemented, the target behaviour reduced to around 5 times per minute, and the communication response increased to around 22 times per minute.
- During the second baseline phase, the target behaviour increased again and the communication response decreased. This gives us confidence that the FCT sessions were resulting in the change in behaviour / communication.
- During the final FCT phase, the target behaviour reduced to 0 and the communication response increased to around 30 times per minute.

Graph paper


Baseline
FCT
55
50
45
40
35
30
25
20
15
10
5
0
Frequency per minute
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25
Sessions
● Target behaviour
▲ Communication response


Baseline
FCT
55
50
45
40
35
30
25
20
15
10
5
0
Frequency per minute
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25
Sessions
● Target behaviour
▲ Communication response


Baseline
FCT
55
50
45
40
35
30
25
20
15
10
5
0
Frequency per minute
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
Sessions
Target behaviour
Communication response


Baseline
FCT
55
50
45
40
35
30
25
20
15
10
5
0
Frequency per minute
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
Sessions
Target behaviour
Communication response

Appendix N

Coaching Task Analyses Examples (Chapter Four)

Coaching Session 2 (Assessments – FA 1)

Time	Task	Done?	Understood?	Notes
15 mins	Review FAO results: Agreement Function			
25 mins	Functional analysis Provide FA manual section Rationale BST for each session (incl. procedure for taking data) Instruct – using manual & task analyses Video model Role play practice Feedback Provide manual sections		Rationale *Role Plays* Play 1 Play 2 Play 3 Attention 1 Attention 2 Attention 3 Tangible 1 Tangible 2 Tangible 3	

			Demand 1 Demand 2 Demand 3 Alone 1 Alone 2 Alone 3	
5 mins	Finish Questions Overview of next coaching session Identify time for coaching session 2			

Appendix O

Study Advertisement (Chapter Five)

[REDACTED]

Appendix P

Coaching Sessions Task Analyses (Chapter Five)

Session 1 (Functional Assessment Observation)

Step	Completed	Notes
Review manual introductory sessions		
☐ Provide overview of study & where we are currently	☐	
☐ Review 'what is behaviour'	☐	
☐ Review 'functional understanding'	☐	
☐ Review 'functions of behaviour'	☐	
☐ Review 'figuring out the function'	☐	
Review FAI		
☐ Provide copy of FAI & briefly review sections	☐	
☐ Discuss summary statements	☐	
○ Check validity, revise if needed	○	
Review behaviour definitions & safety plan		
☐ Provide copy of behavioural definitions & safety criteria	☐	
☐ Check validity of behaviour definitions	☐	
☐ Devise safety criteria & support plan	☐	
FAO		
☐ Provide FAO manual section	☐	
☐ Provide rationale for observation	☐	
☐ Describe procedure	☐	

☐ Describe form and how to set up ☐ Discuss filling in the form ○ Practice for video 1 (setting up & completing) ⌂ Provide positive and corrective feedback ⌂ Compare results and discuss ○ Practice for video 2 (setting up & completing) ⌂ Provide positive and corrective feedback ⌂ Compare results and discuss ☐ Set up form for family carer's child ⌂ Provide positive and corrective feedback ☐ Provide copies of form	☐ ☐ ○ ⌂ ⌂ ○ ⌂ ⌂ ☐ ⌂ ☐	
End ☐ Check if the family carer has questions ☐ Identify suggested time for FAO ☐ Check the family carer has camera or means to record observation ☐ Discuss how to use WeTransfer to send video / form	☐ ☐ ☐ ☐ ☐	

Session 2 (Functional Analysis)

Step	Completed	Notes
Review FAO results		
☐ Discuss agreement between family carer & researcher	☐	
☐ Discuss hypothesised function and any correspondence with summary statements	☐	
Functional analysis		
☐ Provide FA manual section	☐	
☐ Provide rationale for functional analysis & general procedure	☐	
☐ Behaviour skills training (BST) 1 for **PLAY** session	☐	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	○	
☐ BST 2 for **PLAY** session (if needed)	☐	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	○	
☐ BST 3 for **PLAY** session (if needed)	☐	

○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	○	
☐ BST 1 for **TANGIBLE** session	☐	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	○	
☐ BST 2 for **TANGIBLE** session (if needed)	☐	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	○	
☐ BST 3 for **TANGIBLE** session (if needed)	☐	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	○	
☐ BST 1 for **ATTENTION** session	☐	
	○	

○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	☐	
☐ BST 2 for **ATTENTION** session (if needed)	○	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	☐	
☐ BST 3 for **ATTENTION** session (if needed)	○	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	☐	
☐ BST 1 for **DEMAND** session	○	
○ Instruct about procedures for session – using manual & task analyses	○	
○ Video model of session	○	
○ Role play practice	○	
○ Feedback – positive and corrective	☐	
☐ BST 2 for **DEMAND** session (if needed)	○	

○ Instruct about procedures for session – using manual & task analyses ○ Video model of session ○ Role play practice ○ Feedback – positive and corrective ☐ BST 3 for **DEMAND** session (if needed) ○ Instruct about procedures for session – using manual & task analyses ○ Video model of session ○ Role play practice ○ Feedback – positive and corrective	○ ○ ○ ☐ ○ ○ ○ ○	
End ☐ Questions ☐ Identify time for first FA session ☐ Identify items to use in tangible session ☐ Identify items to use for demand session	☐ ☐ ☐ ☐	

Sections highlighted in grey were optional in a given session dependent on family carer performance and reported confidence with procedures.

Appendix Q

Error and Error Correction Definitions for Each Functional Analysis Condition Type (Chapter Five)

Condition	Omission error(s)	Correction	Commission error(s)	Correction
Play	Attention not provided every 30 seconds or when child requests attention [*critical error*]	Family carer instructed to provide attention and reminded to provide attention every 30 seconds or when child requests attention	1) Demand placed (explicit or implicit), e.g. removal of item, verbal instruction, interruption of play [*critical error*] 2) Attention provided following target behaviour [*non-critical error*]	1) Family carer instructed to allow child to play freely with toys without any demands 2) Family carer instructed to neutrally block target behaviour only without providing attention
Tangible	1) Item removed before 30 seconds of access allowed [*critical error*] 2) No signal that access to item will be removed (e.g. family carer did not	1) Family carer interrupted and prevented from removing item too soon, or instructed to return item 2) Family carer instructed to signal removal of item	1) Item returned in the absence of target behaviour [*critical error*] 2) Removal of item signalled whilst child is still consuming item, or only some items removed [*critical error*]	1) Family carer instructed to remove item again and only return it contingent on target behaviour

Condition	Omission error(s)	Correction	Commission error(s)	Correction
	say “finished”, “my turn” or equivalent) [*non-critical error*]			2) Family carer instructed to wait until child has finished item or to remove all items from child
Demand	1) Instruction to complete task (verbal prompt) not delivered [*critical error*] 2) Instruction not redelivered following model / gestural / physical prompt [*critical error*]	1) Family carer instructed to provide verbal prompt 2) Family carer instructed to redeliver verbal prompt after model / gestural / physical prompt	1) Wrong prompt type used following noncompliance with demand [*non-critical error*] 2) Greater than 2 second delay between prompts following noncompliance [*critical error*] 3) Task completed for child or error corrected where task not completed accurately [*critical error*]	1) Family carer reminded of prompt sequence and prompt type that was omitted 2) Family carer instructed to deliver prompt and reminded that they should only wait 2 seconds for compliance before delivering the next prompt 3) Family carer instructed to require child to complete task themselves to prescribed accuracy

Condition	**Omission error(s)**	**Correction**	**Commission error(s)**	**Correction**
			4) Removes items not contingent on target behaviour [*critical error*]	4) Family carer instructed to reinstate demand and only remove items if target behaviour occurs
Attention	Establishing operation not set up by family carer stating that they have work to do and that the child can play [*critical error*]	Family carer instructed to set up establishing operation	Attention provided in the absence of target behaviour [*critical error*]	Family carer instructed to ignore all non-target behaviour and provide attention only following target behaviour

Appendix R

Participant Information Sheet for Study Two (Chapter Five)

Tizard Centre

Cornwallis East

University of Kent

Canterbury

CT1 7NF

Dear Family Carer,

Re: Research project: "Training family carers to do a functional assessment with their children with intellectual / developmental disabilities who display challenging behaviour in the UK"

You are being invited to take part in the above research project conducted by Serena Tomlinson who is a PhD student in Applied Psychology at the Tizard Centre, University of Kent. The project has received ethical approval from the Tizard Centre (University of Kent) ethical review committee on 6th June 2018.

Please read the following information sheet before deciding whether you would like you and your child to take part in the project. If you have any questions or would like further information please do not hesitate to contact me using the details below.

Yours faithfully,

S Tomlinson

Who to contact about the project

Main researcher:	Serena Tomlinson	sb773@kent.ac.uk	01227 827 446
Academic supervisors:	Dr. Nick Gore	n.j.gore@kent.ac.uk	01227 827 755
	Prof. Peter McGill	p.mcgill@kent.ac.uk	01227 823 838
Clinical supervisor:	Dr. Ciara Padden	c.m.padden@kent.ac.uk	01227 824 640

Address: Tizard Centre, Cornwallis North East, University of Kent, Canterbury, CT2 7NF

PARTICIPANT INFORMATION SHEET

Training family carers to do a functional assessment with their children with intellectual / developmental disabilities who display challenging behaviour in the UK

What is the project about?

Children with intellectual / developmental disabilities sometimes display behaviours that challenge (for example, hurting themselves, hurting others, or damaging property). To understand why these behaviours happen and develop a support plan, a functional assessment is usually conducted which involves questionnaires, observations, and experimental analyses about the behaviour. This project aims to identify how best to train family carers to conduct a functional assessment and to develop a behaviour support plan for their child.

What will the project involve?

1. ***Questions*** about your child's behaviour and communication, and your family quality of life *(One appointment lasting approximately 1.5 hours)*
2. ***Training*** you to conduct an observation of your child's behaviour *(One appointment lasting approximately 1 hour)*
3. An ***observation*** of your child's behaviour at home *(30 minutes)* which you will do
4. ***Training*** you to conduct a functional analysis *(One appointment lasting approximately 1 hour)*
6. A ***functional analysis*** which involves setting up conditions to see if they are related to the behaviour *(Two-four 1 hour appointments)*
7. The development of a ***behaviour support plan*** and completion of final questionnaires *(One appointment lasting approximately 2 hours)*

Depending on your location, I will support you either in person, or via videoconferencing. If you are supported via videoconferencing, an additional person (called a 'family carer assistant') will also help you in person. I will work with you to identify someone who can be a family carer assistant if this is needed.

What are the potential benefits of taking part?

1. ***Learning about why your child displays challenging behaviour*** and how to assess this
2. ***Receiving a manual and resources tailored to your child*** about how to conduct the assessment which you can use during the study and in the future
3. ***Developing a comprehensive behaviour support plan*** tailored for your child which can be used by you and others who support your child to help them manage their behaviour and develop skills

What are the potential risks of taking part?

The project has been carefully designed to minimise any risks and burdens to taking part. There is a risk to you/your child from their behaviour (for example if their behaviour involves hurting themselves or others) as we will need to see the behaviour occur to identify when / why it happens. However, the study procedures will be conducted in a highly controlled environment in order to minimise risks. I will also work with you to develop a plan for how to keep everyone safe during the study.

Your option to take part

You do not have to take part in the project. The support you or your child receives will not be affected by whether you choose to take part. If you choose to take part and later change your mind then that's ok. If you do decide that you want to take part you and your child will remain anonymous. I will give you a unique number to use in place of your name on any questionnaires and all of the data will be safely stored in locked filing cabinets and only accessed by me and my supervisory team. Anything that you say to me will also be confidential, however if any concern is raised regarding the safety of you or your child, confidentiality would be broken and the relevant authorities would be notified.

I hope to present the results of the research at conferences and publish them in academic journals, however you and your child will not be identified in any publications, presentations, or reports relating to the project.

Video recordings

I will need to take video recordings of the sessions and, if applicable, record the videoconferencing meetings in order to help me collect data on your child's behaviour, on my teaching, and how you use the procedures. These recordings will be safely stored on encrypted hard drives and only seen by me and my supervisory team. Recordings will be kept for up to 10 years after the end of the project and then destroyed.

You will also be asked if you are happy for the videos to be used when training other family carers to do functional assessments. If the videos are used for this you and your child would not be named, however your faces would be visible. You do not have to agree to this in order to take part in the project, and if you don't want these videos to be used to train others then that's ok.

The next steps

If you are interested in taking part then please contact me by returning the reply slip below using the pre-paid envelope, or via telephone or email (details above). I will then discuss the study with you, complete a screening questionnaire, and answer any questions you may have.

Thank you for taking the time to read this information.

REPLY SLIP

If you would like the researcher to contact you in order to discuss the study further, please fill in this slip and return it to the researcher using the pre-paid envelope provided.

Name:

Address:

Home phone number:

Mobile number:

Email address:

Appendix S
Family Carer Manual for Study Two (Chapter Five)

Training family carers to do a functional assessment with their children with intellectual / developmental disabilities who display challenging behaviour in the UK

FAMILY CARER MANUAL

Researcher contact details: sb773@kent.ac.uk, 01227 827 446

Using this manual

This manual is to be used alongside the researcher's support during the study. It gives you more detail about each part of the project and can help to remind you about how to do each technique.

The manual contains lots of sections about the different stages of the project. The researcher will give you each section of the manual when you need it during the study. The manual is yours to keep so that you can go back over it if you need to, or write notes on it to help you remember.

The researcher will go through each section with you to teach you how to do the things in the manual. There is a glossary at the back which explains some of the terms used throughout the manual. Any terms that are in **bold** are listed in the glossary. You can also ask the researcher questions by email (sb773@kent.ac.uk) or telephone (+447943 555 427, 9am-7pm) if you have any questions or need help with any of the techniques.

Table of Contents

The Family Carer Assistant

During the study, the researcher will support you either in person or via videoconferencing at each stage. If you are supported via videoconferencing, the researcher will work with you to identify someone who can also support you in person, called a 'Family Carer Assistant' (FCA). This could be another member of your family, someone else who supports your child, or someone who works at a charity that supports you. The FCA will:

- Set up the videoconferencing calls with the researcher
- Send the videos and any paperwork to the researcher using WeTransfer or via post, or help you to do this
- Relay messages between you and the researcher during the sessions
- Help with your child's behaviour during the sessions if needed

Information about how the Family Carer Assistant will support your during each stage of the study can be found in the **blue circles** in each section of this manual. If the researcher is supporting you in person you can ignore these boxes, as the researcher will provide this support.

1. Understanding Behaviour

What is behaviour?

Behaviour is everything we do or say. This includes things like walking, running, talking, using the telephone, eating, drinking etc.

We learn different behaviours as we are growing up because of the effect that our behaviour has on other people, or on the world around us (also called the environment). The examples in Box 1 below explain this in a bit more detail.

Box 1 – Examples of how behaviour is learnt

Example 1 – Communication

At first, a young baby can only communicate with those around them by crying when they need something. People respond by trying to figure out why the baby is crying (e.g. are they hungry, tired, do they need a hug or their nappy changed?). Over time, the baby's parents learn what the different cries or movements mean because the baby stops crying when the parents have provided what they need. At the same time, because of their parent's reactions, the baby learns that people respond differently to certain cries or movements. As a result, they are more likely to use specific movements / sounds for different things because they help them to get what they need.

The same process happens when they start to babble and this eventually leads to them learning to talk because people respond differently to sounds that are similar to words (e.g. "da-da", "ma-ma" etc.). You can see here how the baby has learnt to make certain sounds or movements because of the *way other people react to them*.

Example 2 – Avoiding danger

To begin with, a young child does not understand when something might be dangerous, like a hot oven. Over time, they learn not to touch a hot oven either because those around them react negatively if they go near it ("No, don't touch that, it's hot!"), or because they touch it one day and it hurts. In this example, *other people's reactions and / or the natural outcomes of behaviour* help the child to learn that the oven could be dangerous and to avoid touching it.

A functional understanding of behaviour

All behaviours are learnt in this way – because of the effect that they have on the world around us (the environment), or because of how other people react to them. We learn to use the behaviours that result in us getting things we want or need (either from other people, or the environment), or to escape / avoid things that are unpleasant.

We call this the role or **function** of behaviour. We *all* need to have our needs met, to access things we like, and to escape / avoid things we don't like – we use our behaviour to do this. In the examples above, one child cries or babbles to have their needs met, and another avoids a painful experience or other people's negative reactions by not going near the oven. This is called the **functional understanding of behaviour.**

Understanding difficult behaviours

Children with disabilities sometimes find it harder to learn things. This can include communication or other types of behaviour. For many reasons, they sometimes display difficult behaviours like hurting themselves, hurting others, or damaging things around them. Because they have difficulty learning to communicate, they might be more likely to use these difficult behaviours to meet their needs.

> For example, if a child does not know how to ask for a drink they might get upset and hit their head. When trying to comfort them someone might give the child a drink, which meets the function of the child's behaviour. In future, the child will be more likely to hit their head when they need a drink because this has led to them getting a drink in the past.

These sorts of interactions happen all the time and are completely normal – remember, we *all* need to be able to have our needs met, have access to things we like and to escape / avoid things that we don't like. As we learn more ways to communicate, we become less likely to use other behaviours (like crying) because communication is quicker and easier. However, if children find it difficult to learn ways to communicate they might continue to use other types of behaviours instead. This can sometimes include the difficult behaviours described above.

The functional understanding of behaviour means that we should look at these difficult behaviours in the same way as other behaviours – they serve important functions for the child. Our job is to figure out what that function is so that we can support the child in the most effective way to develop skills to replace these difficult behaviours, and to prevent the behaviour from happening.

Functions of behaviour

There are four main functions of behaviour. We can think of these as communication messages because the function tells us about what the child needs. The common functions are;

- To gain **attention** from others (this can be *any* type of attention, not just positive).
- To gain access to something that they want or need, called a **tangible** – e.g. food, drinks, toys, activities etc.
- To **escape** something difficult – e.g. difficult tasks, requests from others, a room that's too hot/noisy/bright etc.
- To get **sensory** stimulation

The function of a behaviour is not usually linked to what the behaviour looks like. Any behaviour can have one or more of the functions above. Sometimes the same behaviour will have different functions depending on the situation, and different behaviours can serve the same function. This is why it is so important to use a range of different ways to try and work out the function of the behaviour so that we are sure we have it right. Box 2 (below) tells you more about the functions of behaviour.

Box 2 - about the functions of behaviour

Lots of different behaviours can sometimes serve the *same function*. For example, instead of pouring ourselves a glass of water, we could make a cup of tea, buy a drink from a shop, or ask someone to make us a drink. These behaviours all help us to get a drink.

The same behaviours can sometimes serve a *different function*. For example, we might pour a drink because we are thirsty, or because someone has asked us to pour a drink for them.

Figuring out the function

We can work out the function of behaviour by using a range of tools to look at what happens before and after the behaviour – this is called a **functional assessment**. Once we know the function, we can use this information to develop a detailed **behaviour support plan** for the child which includes ways to teach them alternative skills, prevent the behaviour from happening, and manage it safely if it does happen..

Functional assessment in this study

In this study, we will use three main tools to do a functional assessment;

4. A **Functional Assessment Interview**, to get information about what the behaviour is, when it happens, as well as about your child's skills and abilities
5. An **Observation**, so that we can see the behaviour in real life and check what we learnt during the interview
6. A **Functional Analysis**, which is a way for us test out specific situations to see if they are related to the behaviour.

These three tools together will help us to work out the function of your child's behaviour.

2. The Functional Assessment Interview

The first stage of working out the function of your child's behaviour is to complete the Functional Assessment Interview.

The interview has 9 parts and will take about an hour to complete. The researcher will complete the interview with you during the study, but it is also in Appendix 1 of this manual in case you need to go back to it after the end of the study. You can use it in the future if you need to, and you can complete it with other people who interact with your child to get more information about the behaviour.

Why do we need to do the interview?

The interview helps us to work together to understand your child's skills and abilities, their behaviour and the difficult behaviours that you want to focus on (called the **target behaviours**). It also helps us to think of what might be the function of those behaviours.

SECTION A – this section focuses on describing the behaviour. It asks about how often the behaviour happens. It will also ask about how hard it is to manage the behaviour safely.

SECTION B – this section focuses on identifying all the things that your child does throughout the day. We will make a note of which of these your child likes or dislikes.

SECTION C – this section focuses on when the behaviour is most likely and least likely to happen. This helps us to identify the things that often happen before the target behaviour. We call things that happened a while before the target behaviour (like a poor night's sleep, being hungry etc.) the **setting events.** The things that happen immediately before the target behaviour are called the **antecedents**.

SECTION D – this section focuses on the things that often happen after the target behaviour. We call these things the **consequences**.

SECTION E – this section focuses on the things your child can already do that might have the same consequences as the target behaviour.

SECTION F – this section focuses on the ways that your child communicates things that they want or need.

SECTION G – this section focuses on important things to know about when working with your child.

SECTION H – this section focuses on things that your child likes, e.g. food items, toys

SECTION I – this section helps us to summarise what we found out during the interview into one statement. This is called a **summary statement**. It tells us when the behaviour is likely to happen and what happens afterwards (see Box 2).

Box 2: Examples of summary statements related to each function of behaviour

Attention function

"When Sarah is alone she will start to hit herself to gain adult attention."

"When his mum is on the phone, Jack begins to throw his toys at his brother to get his mum's attention."

Tangible function

"When Caleb doesn't eat much breakfast and he sees his friends eating something he will hit other children to get their food."

"When Emily can't reach her favourite toy she will bang her head on something until someone gives her the toy."

Escape function

"When Danny is doing mathematics and is given a question to do he will bite others to avoid having to do the question."

"When Tom has had a bad night's sleep and is asked to do a task such as put his shoes away, he begins throwing and breaking things around him; others ignore this behaviour meaning he avoids having to do the task."

Sensory function

"When Ellie is alone, she will pick her skin to gain sensory input."

Summary statement:

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Using the results

We will use the results of this interview in different stages of the study.

6. We will use section A to clearly ***define*** the target behaviour. This is important so that we know exactly what we are looking for when we observe the behaviour during the rest of the study. The researcher will help you to define the behaviour(s) during the study, and there is space for you to write the definition(s) below.
7. We will use section C to identify the best time to ***observe*** the behaviour. The best time is when the behaviour is most likely to occur.
8. We will use the summary statement and the information about your child's favourite items to think about what the ***function*** of the behaviour might be. See Box 1 above for examples of summary statements for different functions. We will check the statement during the observation and test it in the functional analysis.
9. We will use information about your child's favourite items in the ***functional analysis***.
10. We will use the information about your child's skills, reinforcers, and communication when we ***develop their behaviour support plan***.

Defining behaviour

It is really important that we define the behaviour in a very detailed and specific way. This is because we will often need to count or time the behaviour, so it will be really helpful to know what we count as the behaviour and what we don't count as the behaviour. We might identify more than one target behaviour if we think that some behaviours always happen together.

The researcher will help you to define the target behaviour(s) during the study. You can write the definition below to remind yourself and to refer back to later as an example of how you might define a behaviour.

Definition of behaviour(s): (e.g., slapping their head with an open hand hard enough to be heard or to leave a visible mark.)

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Family Carer Assistant's Role During the FAI

The Family Carer Assistant will be at the appointment where we complete the FAI so that they know what we said during the interview, i.e. what the target behaviours are, when they are likely to happen etc.

3. Safety Criteria & Support Plan

Like with most things, we will need to see your child's behaviour in order to assess and understand it. This means that we will sometimes be trying to make the behaviour happen. This is common when supporting children who display difficult behaviours, and is the same as when a doctor needs to see/hear something (e.g. a cough) to be able to say what is wrong.

However, it is important to consider how to keep your child and yourself safe during the study when the behaviour happens. We have carefully designed the procedures to minimise any risks. We will also make sure that you and your child are safe by making criteria to end a session if your child's behaviour reaches a certain point where it is a risk to them or others.

The researcher will work with you to make these criteria and you can write them here to remind yourself of them throughout the study. You can also use this in the future to remind you of the type of criteria you could use.

A session / observation will be stopped if: (e.g. "Sarah hits herself hard enough to leave a mark, or hits herself more than 5 times in 2 minutes")

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Support plan

If a session/observation is stopped because your child's behaviour meets the criteria above, it is important that we support them to become calmer. The researcher will work with you to identify the best ways to do this for your child. You can write these here:

Support plan: (e.g. give Danny a drink, give him some space, remove all demands etc.)

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Remember, you can always contact the researcher using the details on the first page of this manual to discuss what happened, but don't do this until your child has calmed down and everyone is safe.

4. Functional Assessment Observation

After we have completed the Functional Assessment Interview, the next step is to observe the behaviour in a structured way.

We will do one 30 minute observation of the behaviour and we will videotape this observation so that we can go back over it later if we need to.

Why do we need to do the observation?

The observation helps us to clearly define the behaviour so that we know what we are looking for and how to collect data on it throughout the study. It also helps us to confirm our summary statement about the behaviour by looking at what happens before and after the behaviour. It is a way for us to check what we found during the interview before we try and test it out in the functional analysis

When to observe?

The best time to observe is the time that the target behaviour (i.e. the behaviours we have decided to focus on) is most likely to happen. We identified this in section C of the Functional Assessment Interview.

How to observe?

During the observation just let your child do what they would normally do, try not to get involved if possible. If you need to get involved because the behaviour only happens with you, that's ok as we'll also be filming the observation.

We will use a form called the Functional Assessment Observation Form to help us keep track of what happens when we observe. The form is described in detail below. It is best to fill out the form during the observation, however if you can't do this (for example, because the behaviour only happens when you are interacting with your child) you can fill out the form from the video afterwards.

SAFETY FIRST!

Remember to always think about the safety criteria whenever you are working with your child during the study. If your child's behaviour meets these criteria, or you feel that you or your child are unsafe, you **must** stop the observation and do the things we identified that can help your child calm down. We can always redo the observation another time if we need to – the safety or your child, yourself, and anyone else around is the most important thing. Remember that you can always contact the researcher afterwards if you need to talk about what happened, but make sure that your child has calmed down and everyone is safe before you do this.

The form

The form is in Appendix 2 and the researcher will give you a copy of the form.

The next page shows you what the form looks like. It also has arrows to show the different parts of the form. After this, instructions are given for how to fill in the form. The researcher will go through this with you during the study, but the information in this section will help to remind you about what to do.

[REDACTED]

Filling out the form

7. On the top of the form write:
    a. Your child’s name
    b. Your name
    c. The date
    d. The observation start time
    e. The observation end time
    f. The activity your child was doing
8. Write the target behaviours we are looking for in the behaviour section.
9. Begin watching your child and what they are doing.
10. When you see any of the behaviours we are looking for, write ‘1’ in the event box, and put a tick in every column that applies to the behaviour (i.e. behaviours observed, antecedents, and consequences) that applies to that event. Remember, you can add antecedents/consequences to the form if you need to.
    a. An event is an instance of the target behaviour(s) happening.
    b. More than one target behaviour/antecedent/consequence might happen during an event – put a tick in all of boxes that apply.
    c. Only consider something a new event if it is more than 10 seconds since the last target behaviour happened.
11. Repeat for each new event.
12. Add up how many events are listed in each column and write this under the columns.

Example form

Below is an example of Danny's functional assessment observation form. We can see that across a 30 minute observation during maths, Danny displayed 7 instances of behaviour.

- The most common **behaviours** were biting and pinching.
- The most common **antecedent** was a demand or request presented to him.
- The most common **consequence** was escaping the demand.

[REDACTED]

This observation confirms our summary statement that Danny's biting functioned to escape demands because the behaviour often happened during difficult tasks, and often resulted in Danny being given a break.

Using the results

The researcher will discuss the results of the observation with you and help you to interpret them. You can use the results in a number of ways;

- To identify the **target behaviours** that happened most often, and which ones happened together.
- To identify the most common thing that happened before a behaviour (the **antecedents**).
- To identify the most common thing that happened after the behaviour (the **consequences**).

It might be helpful to look at each type of behaviour individually if you observed lots of types of behaviour. For Danny's form, it might be useful for us to also look at the other behaviours he displayed, such as when he hit himself or others. We could look at what happened before and after these specific behaviours, rather than just looking at the most common antecedents and consequences overall.

You can use this to identify what you think the function is. Look back over the summary statement and see if the observation results agree with this. If they don't, that's ok – the researcher will discuss this with you and we can still test out what we think the function is in the next step (see below).

Family Carer Assistant’s Role During the Observation

The Family Carer Assistant will help you to send the video and form to the researcher, and they may watch the video so that they know what happened during the observation.

5. Functional Analysis

What is a functional analysis?

A functional analysis is a way to test what the function of your child's behaviour is. We do this by setting up carefully controlled **conditions** to see when the behaviour happens.

Why do we need to do a functional analysis?

A functional analysis allows us to systematically test what the function of your child's behaviour is. It gives us more confidence that we know what the function is. This is important because if we get the function wrong, we might include strategies in the behaviour support plan which aren't likely to be effective for your child and might be inappropriate.

Functional analysis conditions

There are usually four or five types of condition in a functional analysis, and each condition is done four times. The conditions set up situations that are related to one of the functions of behaviour. This is to see if the behaviour happens more in one type of condition than another. The conditions are;

Play
The child has access to the adult's attention and their favourite toys / items. They are not asked to do anything. This condition serves as a control condition to see how much the target behaviour occurs when the child has access to all the things they like. We use this condition to compare to other conditions.

Attention
The child is given some toys (not their favourites) and is told that the adult needs to do some work and they will be with them in a minute. If they display the behaviour, the adult gives them attention. This tests the attention function as the child can get attention from others by displaying the behaviour.

Alone (only if we think the target behaviour might function to access sensory stimulation)
The child is alone in a room (with an adult watching from another room) to see whether they display the behaviour when they are by themselves. This tests the sensory stimulation function as the behaviour happens when the child is alone or not receiving interaction without anything else to do.

Demand
The child is asked to do something they find difficult (called a **demand**). If they display the behaviour, they are given a break from the demand. This tests the escape function as the child can escape from demands by displaying the behaviour.

Tangible
The child is allowed to play with a toy for 30 seconds or eat some of their favourite food at the beginning of the session. The item is then taken and they are told they can have it back in a minute. If they display the target behaviour, they are given the item. This tests the tangible function as the child can get something they like by displaying the behaviour.

How we use the results of a functional analysis

After conducting a functional analysis, the results can be used to identify the function of the behaviour. For the analysis in this study, we collect data on how long after the start of the condition the behaviour happens (see below for more detail). We can then identify the function by looking at how quickly the behaviour usually happens in each type of condition. We can also compare this to the play condition which acts as a control to show us how quickly the behaviour happens when all the things that might be related to the function of the behaviour are already available to your child.

If the behaviour occurs more quickly in one type of condition than the other conditions, this shows us that the function is related to what happens in that condition. For example, if the function of a behaviour was to gain attention we would expect to see the behaviour happen quickly in the attention condition because the child is told that the adult has to do some work and cannot give them attention.

Danny's functional analysis results are shown in Box 3 to give you an example of how we identify the function from the results of the functional analysis.

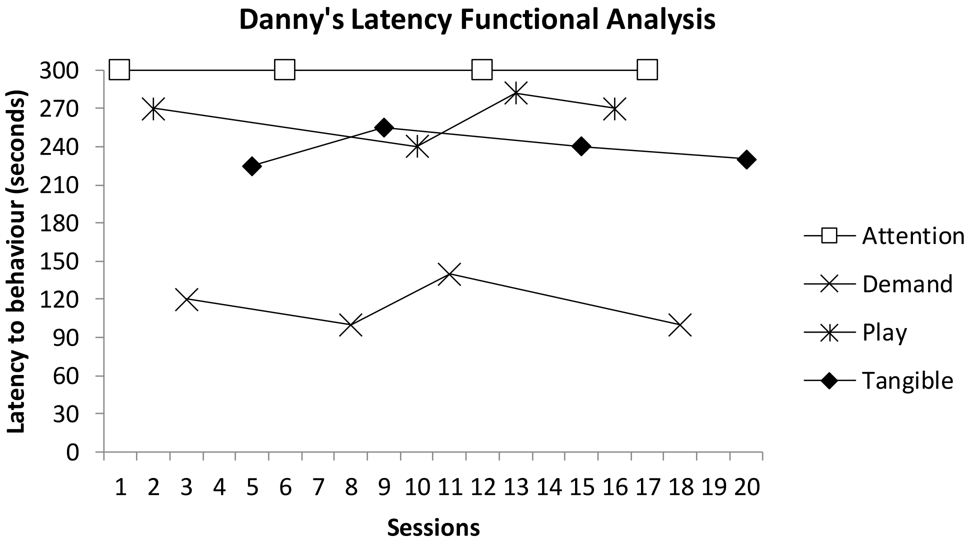
Box 3: Danny's functional analysis

Remember that we thought Danny's biting functioned to escape from demands (difficult maths questions). His summary statement was: **"When Danny is doing mathematics and is given a question to do he will bite others to avoid having to do the question."**

We did a functional analysis with Danny and found that he tried to bite the adult after;

- Around 2 minutes in the demand condition.
- Around 4 minutes and 30 seconds in the play (control) condition.
- Around 4 minutes in the tangible condition.

Biting did not occur in the attention condition. We drew a graph of these results which you can see below.



The graph really makes it clear that Danny displayed biting much more quickly in the demand conditions than in any of the other conditions. This confirms our theory that his biting functions to allow him to escape from demands. We can now use this information to include strategies in his behaviour support plan the are relevant to this, e.g. providing him with extra help during difficult tasks or teaching him to ask for a break.

Conducting the analysis

This section will explain how to do the analysis during the study. You can also use this section in case you need to do an analysis again in the future.

SAFETY FIRST!

Remember to always think about the safety criteria whenever you are working with your child during the study. If your child's behaviour meets these criteria, or you feel that you or your child are unsafe, you **must** stop the session and do the things we identified that can help your child calm down. We can always redo the session another time if we need to – the safety or your child, yourself, and anyone else around is the most important thing. Remember that you can always contact the researcher afterwards if you need to talk about what happened, but make sure that your child has calmed down and everyone is safe before you do this.

What you will need

The table below lists the items you will need to do the analysis and which items the researcher will supply during study. The researcher will supply many of the items however you will need to provide the toys/items your child likes, and the activity that they find difficult because these should be the same as the ones they use at home. The researcher/family carer assistant will help to make sure that we have all of the items we need for each session.

Item	**Supplied by researcher**	**Possibly supplied by you**
8. A room that is quiet and doesn't have a lot of distractions (i.e. without lots of toys around).	✓ **(If not doing the analysis at home)**	✓ **(If doing the analysis at home)**
9. Your child's favourite items for the tangible condition (i.e. those we identified during the Functional Assessment Interview)		✓
10. Items that your child likes but that aren't their favourite for the attention condition		✓
11. Activities that your child finds a bit difficult to do for the demand condition		✓
12. Papers/magazine that you can pretend to be using to work in the attention condition	●	

If you are doing the analysis after the study, you will also need a stopwatch to collect data (see below) and a datasheet to record the data (Appendix 4), but the researcher will have these for the study.

How to do the conditions

The conditions should be done in a random order. The researcher will tell you what order to conduct the conditions in. You only need to do the alone condition if we think that the target behaviours function to access sensory stimulation.

Each condition will last 5 minutes if the target behaviour doesn't happen and less than this if the behaviour does happen as we will stop the condition as soon as the behaviour happens. There will be a short break between each condition where your child can play with some toys (but not their favourites).

The analysis will be conducted in two to four appointments during the study (depending on how many conditions we are able to complete in each session). The researcher will provide support during these appointments either in person or via videoconferencing, and if applicable the Family Carer Assistant will be there to provide support in person (see below).

Detailed instructions for how to do each type of condition are written below. Appendix 3 gives you an easy to use breakdown of the steps for doing each type of condition – you can use this during the analysis to remind yourself of what to do.

Play

- Make sure there are lots of toys that your child likes to play with in the room, including their favourites
- Allow your child to play with the toys. You can play with them if they want you to.
- Roughly every 30 seconds give your child some attention – e.g. play with them, comment on what they are doing, or praise them if they're playing appropriately
- Ignore any target behaviours (unless they meet the safety criteria, if they do – end the condition). If you need to, block the behaviour so that you or your child don't get hurt. 1 minute after a target behaviour or 5 minutes after the start of the session (whichever comes first), end the session and start the next condition after a short break
- If they don't display the target behaviour within 5 minutes, have a short break and then start the next session

Tangible

- Have your child's favourite item (e.g. a toy, food etc.) in the room
- Allow your child to play with the item for 30 seconds or to eat a small piece. After 30 seconds (or when they have finished the food), take the item away and tell them they can have it in a minute.
- If the target behaviour happens – say "ok you can have it back" and give them the item. If this is a toy, allow them to play with it for 30 seconds. If it is a food item, allow them to eat it. After a short break, start the next condition
- If the target behaviour doesn't happen, end the condition after 5 minutes. Have a short break before the next condition

Demand

- Have activities that your child finds difficult to do (e.g. putting blocks into a shape sorter). Make sure these can be done for 5 minutes.
- Ask them to do the activity, e.g. "Danny, please put these blocks in here". If they don't do the activity within 2 seconds, show them how to. If they still don't do the activity within 2 seconds, help them to do it by moving their hands. Repeat these steps for the 5 minute condition or until the target behaviour occurs (whichever comes first).
- If the target behaviour happens, say "ok you don't have to", stop asking your child to do the task and remove the items. Turn away from your child for 30 seconds. End the condition and allow them to have a short break. Start the next condition.
- If the target behaviour doesn't happen, end the condition after 5 minutes. Have a short break before the next condition.

Attention

- Have some items that your child likes to play with but are not their favourite items.
- Tell them that they can play with the toys and that you need to do some work for a minute.
- Pretend that you are doing some work, e.g. writing or reading.
- If the target behaviour happens, say “no don’t do that, it’ll hurt you / me” and physically comfort them, e.g. by touching their shoulder. Start the next condition after a short break.
- If the target behaviour doesn’t happen, end the condition after 5 minutes. Have a short break before the next condition.

Alone (only if we think the behaviour might function to access sensory stimulation)

- Your child should sit in a room by themselves, without any toys or distractions. Make sure you can still see them (e.g. through a window or door).
- If the target behaviour happens ignore it. End the condition 1 minute after the behaviour or 5 minutes after the start of the condition (whichever comes first). Have a short break and then start the next condition.
- If the target behaviour doesn’t happen, end the condition after 5 minutes. Have a short break before the next condition.

Collecting data

We need to collect data during the analysis so we can see which condition the behaviour happens quickest in. The researcher will collect the data during the study, but this section will tell you how to do this in case you need to do another functional analysis in the future. An example data sheet is in Appendix 4.

We will use a stopwatch to collect the data. The stopwatch will be started at the beginning of each session and stopped when the target behaviour occurs or after 5 minutes if the target behaviour does not occur. The time on the stopwatch will be written on the data sheet next to the condition.

Graphing the results

As we saw in Danny’s example, the easiest way to look at the results is in a graph.

Appendix 5 includes some graph paper with pre-drawn graph outlines on. The researcher will graph the results for you during the study, however there are some instructions on how to do this in Appendix 5 if you need to do it after the study.

Interpreting the results

The researcher will help you to interpret the results during the study. You can interpret the results by looking at the graph to see if the behaviour usually happens more quickly in one condition than the others, like in Danny’s graph above. Appendix 6 shows some examples of the types of graphs you might see and how we would interpret the results.

You might find that the behaviour seems to have more than one function – that's ok and is quite common. We can include strategies for all of the functions in your child's behaviour support plan.

You might find that the behaviour doesn't seem to have a clear function and happens quickly in many of the sessions. This might suggest that it has a sensory stimulation function (as the behaviour happens all the time), or it might suggest that we need to do some more assessments. If this happens, the researcher will discuss this with you and help you. If you are conducting the analysis after the study it is advised that you seek additional support from someone with expertise in behavioural analysis to interpret this. You can find someone by contacting the UK Society for Behaviour Analysis.

Family Carer Assistant's Role during the Functional Analysis

The Family Carer Assistant will be at each of the appointments where we conduct the functional analysis. They will make sure that the room is set up properly, and also set up the videoconferencing call with the researcher. During the analysis, they will help to relay any messages from the researcher to you and vice versa, but they won't get involved in the analysis conditions. They will also help you by giving you any items you need, reminding you when to start and finish each condition and helping with your child's behaviour if needed.

6. Developing the Behaviour Support Plan

Once we know the function of your child's behaviour, we can develop a behaviour support plan for them. This is a detailed plan which identifies skills that we can teach your child, ways that we can change how we support them to minimise the likelihood of the difficult behaviours happening, and what we should do if the behaviours do happen to keep everyone safe.

The researcher will work with you to develop your child's behaviour support plan during the study. Behaviour support plans usually have five main sections:

Why do we need a Behaviour Support Plan?

A Behaviour Support Plan is useful so that everyone knows how best to support your child. The plan can help identify things we can do to prevent the behaviour happening or make it less likely to happen, as well as how to keep everyone safe if it does happen. The plan helps to make sure that everyone supports your child in the same way using strategies that are most likely to be effective and are based on your child's specific needs and the function of their behaviour.

1. **Background:** Information about your child and their needs, their behaviour, what the behaviour looks like, when it typically happens, and the behaviour's function
2. **Environmental adaptations:** Ways to change how your child is supported to prevent the behaviour from happening. This might include changing things in their environment like light, sound, available toys, how predictable the activities are, or changing how people communicate with them, the tasks they are asked to do, their daily schedule etc.
3. **Skills teaching:** Skills that might be useful to teach your child and might reduce the likelihood that they use difficult behaviours to get their needs met. These will often be related to the function we identified and might include communication or independence skills, as well as general skills such as coping with changes to their routine.
4. **Focused support:** Specific strategies to reduce how often the behaviour happens. This might include rewarding your child for periods when the behaviour doesn't happen or changing the outcomes of the behaviour (e.g., making sure that it no longer meets the function and the function is met in other ways).
5. **Reactive strategies:** Things we should do if the behaviour does happen. These strategies focus on helping your child to calm down and keeping them and others safe.

You can see an example of some of the strategies for each section of Danny's behaviour support plan in the box 4. These are just an example, and your child's plan will be more detailed than this.

Box 4: Example of strategies included in Danny's Behaviour Support Plan

Background: Danny is 8 years old and is autistic. He loves swimming and playing with Lego. He displays aggressive behaviours which include biting, pinching, and hitting people. These behaviours function to escape difficult tasks.

Environmental adaptations: Give Danny help with difficult tasks and build lots of breaks into his day.

Skills teaching: Prompt Danny to sign for a break regularly when he is doing difficult tasks.

Focused support: Let Danny have a short break for every 2 minutes of work he does without hitting/pinching/biting.

Reactive strategies: Block Danny's attempts to hit/pinch/bite and move others away to keep them safe.

Reviewing the plan

You and the people who support your child should review the plan regularly and modify it if needed. It might be helpful to consult someone with behavioural expertise if your child's behaviour continues to be difficult even after implementing the plan and reviewing it. You can find someone to help by contacting the UK Society for Behaviour Analysis.

Family Carer Assistant's Role when we develop the BSP

The Family Carer Assistant will be at the meeting when we develop the Behaviour Support Plan so that they can provide input and advice, and so they know which strategies we included in the plan. If they are someone who usually supports your child they can be sent a copy of the Behaviour Support Plan too.

Glossary

Antecedents: the things that happen immediately before a target behaviour.

Baseline sessions: sessions during FCT where we ignore the target behaviour *and* communication response to see how often the target behaviour normally happens. This is so we can compare the results during FCT sessions to the baseline sessions to check that FCT is working.

Behaviour support plan: a detailed plan for supporting your child's behaviour based on the results of the functional assessment.

Condition: the name given to a specific type of session during a functional analysis, for example, attention, tangible, play, alone, demand etc. The sessions of a particular condition are always conducted in the same way.

Consequences: the things that happen immediately after a target behaviour.

Demand: a request or instruction that the individual does not like or finds a bit difficult to do.

Function: the name given to the outcome that a target behaviour achieves for the person. For example, if the behaviour results in the person getting a drink, we call this a tangible function.

Functional analysis: an experimental procedure which uses carefully controlled conditions to identify the function of a target behaviour.

Functional assessment: the name given to a range of assessments used to identify the function of a behaviour. For example, an observation, interviews with those who know the person etc.

Functional understanding of behaviour: the understanding that all behaviours serve a purpose for the individual displaying them, even difficult behaviours.

Latency: for this study this means how long after the start of the functional analysis condition the target behaviour happens.

Observation: watching to see when the behaviour happens and what happens before / after it.

Setting events: the things that happen before a target behaviour, but not necessarily immediately before, that may make the target behaviour more likely. For example, getting a poor night's sleep, being hungry, being in pain, having a busy day etc.

Summary statement: a sentence that states the target behaviours, setting events, antecedents, consequences.

Tangible: the name given to an item (e.g. food, drink, activity, toy) that the individual likes.

Target behaviour: the specific behaviour or behaviours that we are looking for. In this study, this is a specific type of difficult behaviour, e.g. hitting/kicking.

Appendix 1 – Functional Assessment Interview

[REDACTED]

Adapted from the Functional Assessment Interview (O’Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

[REDACTED]

Adapted from the Functional Assessment Interview (O’Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

[REDACTED]

Adapted from the Functional Assessment Interview (O’Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

[REDACTED]

Adapted from the Functional Assessment Interview (O’Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

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Adapted from the Functional Assessment Interview (O’Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

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Adapted from the Functional Assessment Interview (O'Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

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Adapted from the Functional Assessment Interview (O’Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

[REDACTED]

Adapted from the Functional Assessment Interview (O'Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

[REDACTED]

Adapted from the Functional Assessment Interview (O’Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

[REDACTED]

Adapted from the Functional Assessment Interview (O'Neill et al., 2014) and the Challenging Behaviour Checklist (Harris, Humphreys, & Thomson, 1994)

Appendix 2 – Functional Assessment Observation Form

[REDACTED]

Appendix 3 – Functional Analysis Conditions

Attention condition

Setting: you and your child are in a room with a range of toys that they like (but not their favourites) freely available

1. Tell your child to play with the toys and that you have some work to do.
2. Start the stopwatch.
3. Pretend to work, e.g. by reading a magazine.

If your child **displays any of the target behaviours** – stop the stopwatch and say something like “no don’t do that, you’ll hurt yourself!” and touch them to comfort them, e.g. on the shoulder. Write the time from the stopwatch on the data sheet.

End the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.

Demand condition

Setting: you and your child are in a room with some activities your child finds a bit difficult, e.g. putting shapes in a shape sorter

1. Tell your child to do the activity.
2. Start the stopwatch.
3. If they don’t do the activity within 2 seconds, show them how to.
4. If they still don’t do it after another 2 seconds – repeat the instruction and help them to do it by physically guiding them.
5. Praise them when they do the activity.
6. Repeat steps 1-5 until the end of the session.

If your child **displays any of the target behaviours** – stop the stopwatch and say “ok you don’t have to”. Turn away from your child for 30 seconds and remove items. Do not ask them to keep doing the activity. Write the time from the stopwatch on the data sheet.

End the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.

Alone (only if we suspect a sensory stimulation function)

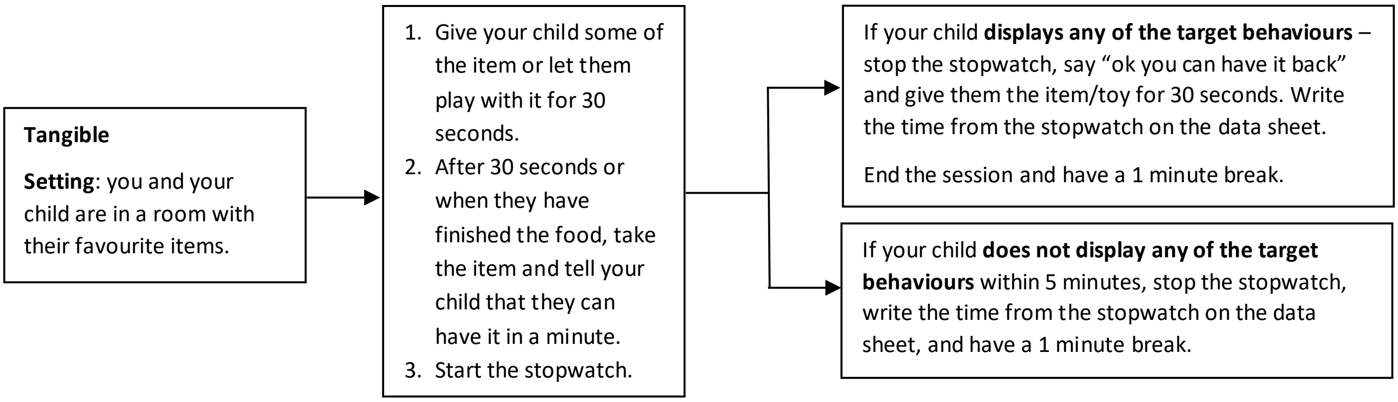
Setting: your child is in a room alone without any toys or other people. This should be somewhere where you can still see your child (e.g. through a door or window)

1. Start the stopwatch.
2. Observe your child.

If your child **displays any of the target behaviours** – stop the stopwatch and ignore / block the behaviour. Write the time on the data sheet.

Continue the session for 1 minute after the behaviour or until 5 minutes after the start of the session (whichever comes first), then end the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.



Tangible

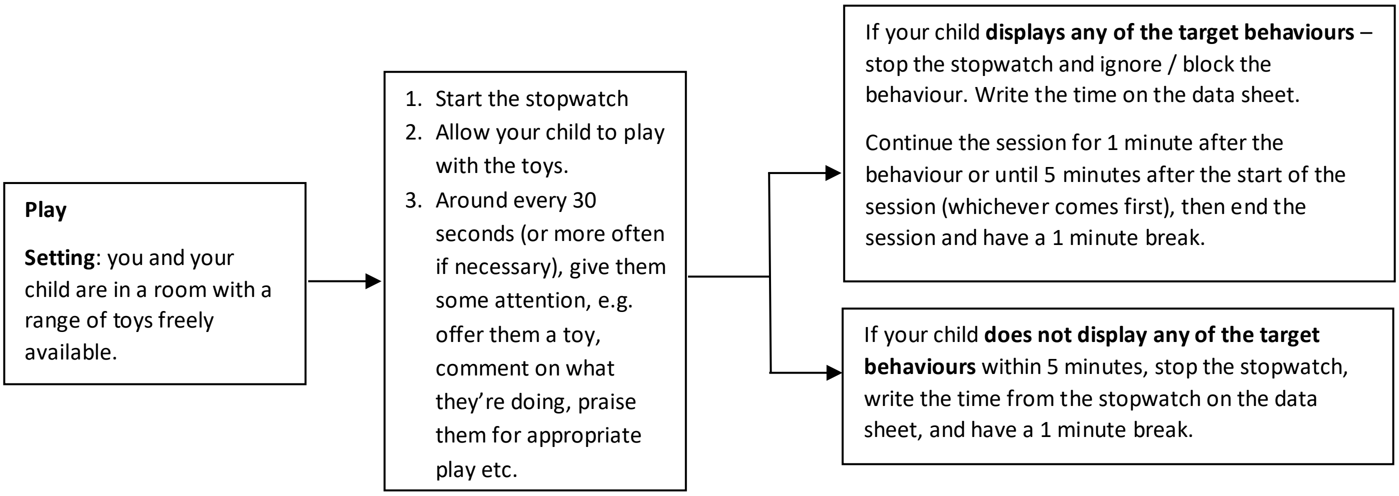
Setting: you and your child are in a room with their favourite items.

1. Give your child some of the item or let them play with it for 30 seconds.
2. After 30 seconds or when they have finished the food, take the item and tell your child that they can have it in a minute.
3. Start the stopwatch.

If your child **displays any of the target behaviours** – stop the stopwatch, say "ok you can have it back" and give them the item/toy for 30 seconds. Write the time from the stopwatch on the data sheet.

End the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.



Play

Setting: you and your child are in a room with a range of toys freely available.

1. Start the stopwatch
2. Allow your child to play with the toys.
3. Around every 30 seconds (or more often if necessary), give them some attention, e.g. offer them a toy, comment on what they're doing, praise them for appropriate play etc.

If your child **displays any of the target behaviours** – stop the stopwatch and ignore / block the behaviour. Write the time on the data sheet.

Continue the session for 1 minute after the behaviour or until 5 minutes after the start of the session (whichever comes first), then end the session and have a 1 minute break.

If your child **does not display any of the target behaviours** within 5 minutes, stop the stopwatch, write the time from the stopwatch on the data sheet, and have a 1 minute break.

Appendix 4 – Functional Analysis Data Sheet

The table below can be used to record how long after the start of a session (the **latency**) the behaviour happens during the functional analysis. You can change the order of the conditions if you need to, but remember they should be in a **random** order and each condition must be done **four** times.

***only do the alone sessions if we suspect the target behaviours function to access sensory stimulation**

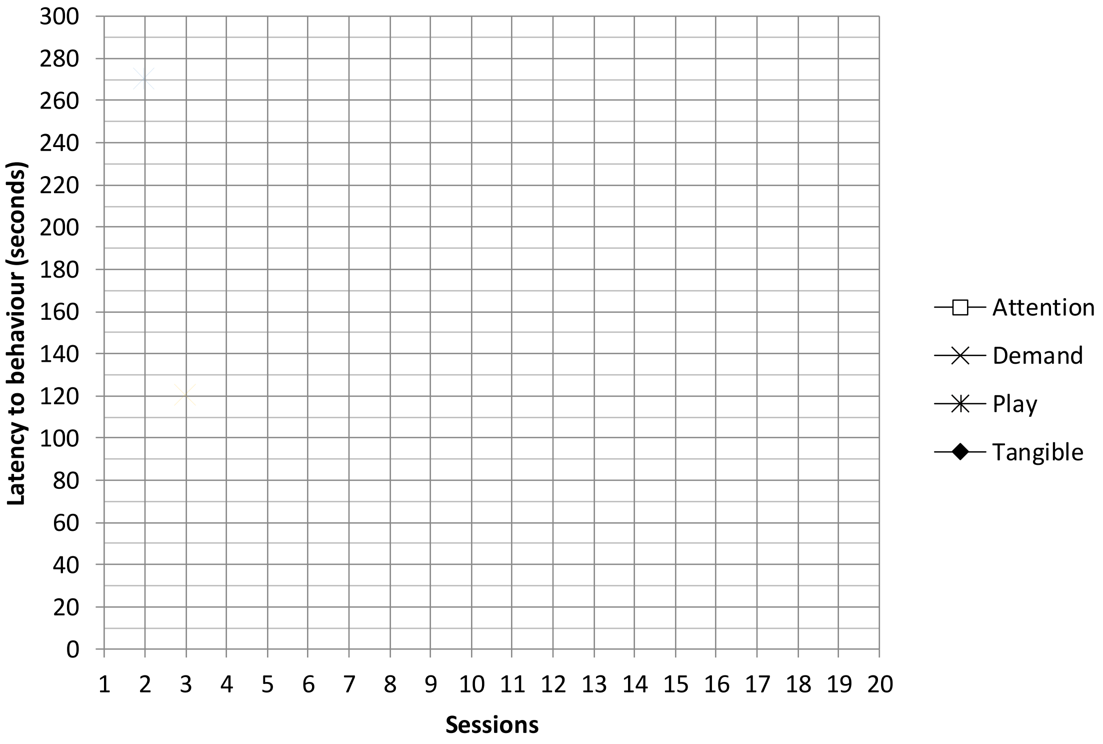
.

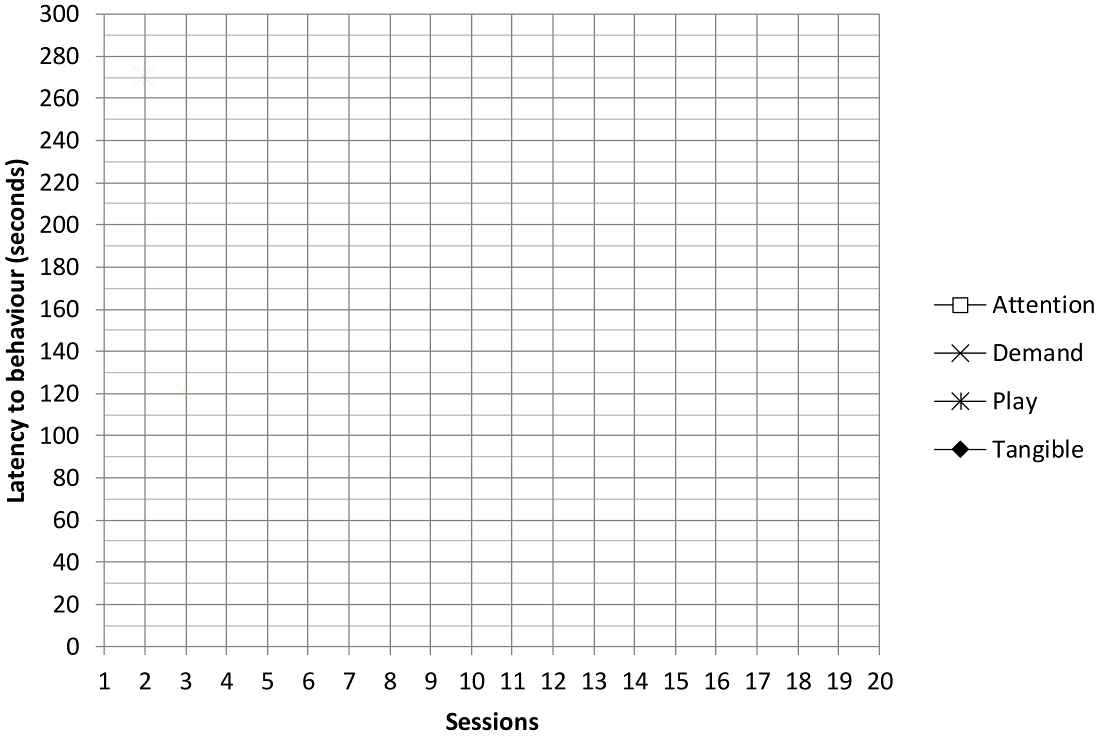
Session	Condition type	Latency to behaviour (minutes & seconds)
1	Play	
2	Demand	
3	Tangible	
4	Attention	
5	Alone*	
6	Demand	
7	Attention	
8	Play	
9	Tangible	
10	Alone*	
11	Attention	
12	Tangible	
13	Demand	
14	Alone*	
15	Play	
16	Tangible	
17	Demand	
18	Play	
19	Alone*	
20	Attention	

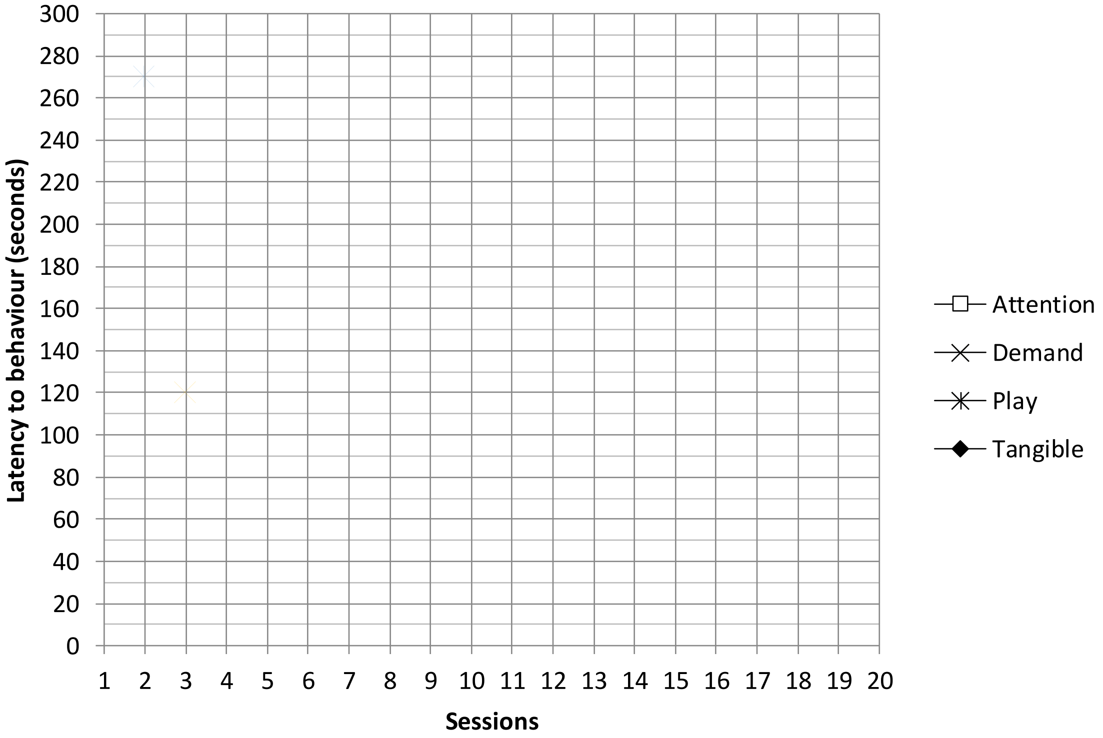
Appendix 5 – Graphing the Results of a Functional Analysis

To graph the results of the functional analysis;

4. Convert the time to seconds by multiplying the number of minutes by 60 and adding on the number of seconds. E.g. for 4 minutes 22 seconds you would do 4 x 60 = 240 + 22 = 262.
5. Do one condition at a time.
    a. Use the correct symbol for that condition (listed on the graph templates) and draw the symbol at the relevant point on the graph for that session. E.g. if the data above was for session 3, you would draw the symbol in line with 3 on the bottom axis and 262 on the side axis. If the target behaviour did not occur during the session, draw the symbol at 300 seconds.
    b. Do this for each session of that condition (there will be 4 per condition).
    c. Connect the points for sessions of the same condition type with a line.
6. Do this for every condition type, i.e. demand, alone, play, tangible, attention.

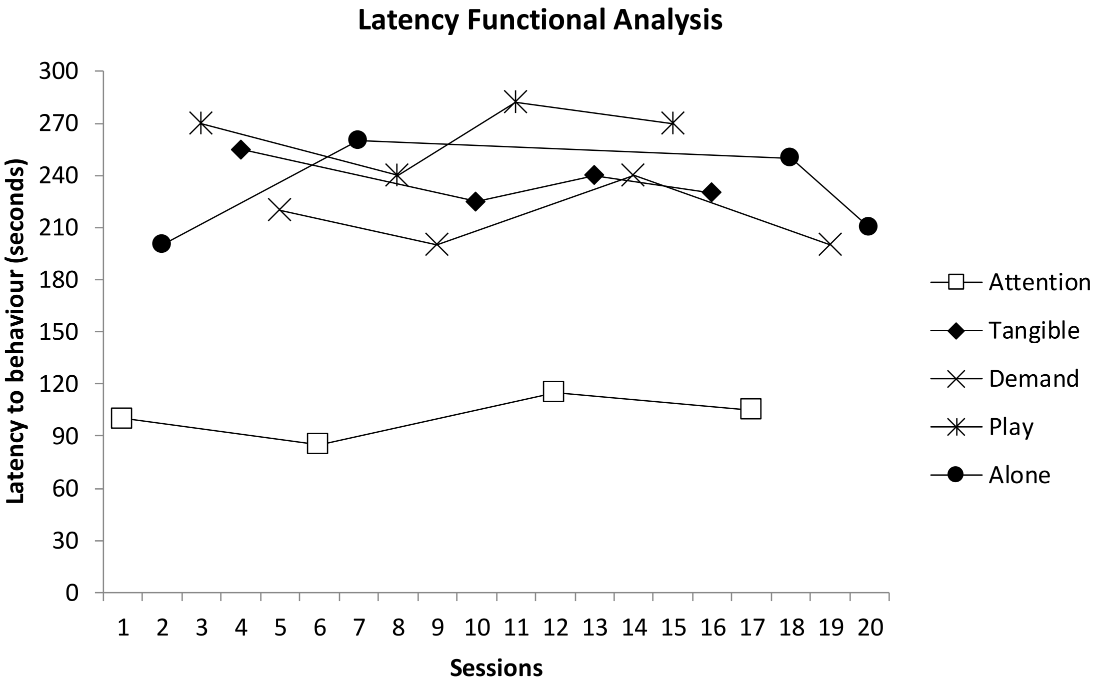



Latency to behaviour (seconds)
300
280
260
240
220
200
180
160
140
120
100
80
60
40
20
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Sessions
Attention
Demand
Play
Tangible

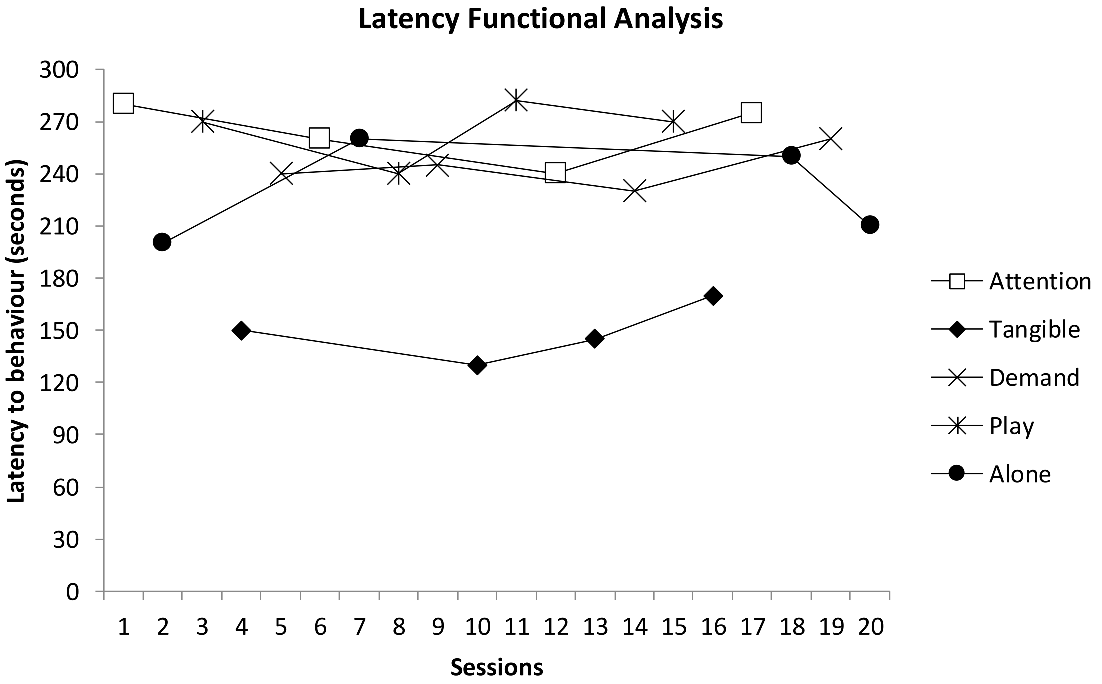

Latency to behaviour (seconds)
300
280
260
240
220
200
180
160
140
120
100
80
60
40
20
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Sessions
Attention
Demand
Play
Tangible

Appendix 6 – Functional Analysis Graph Examples

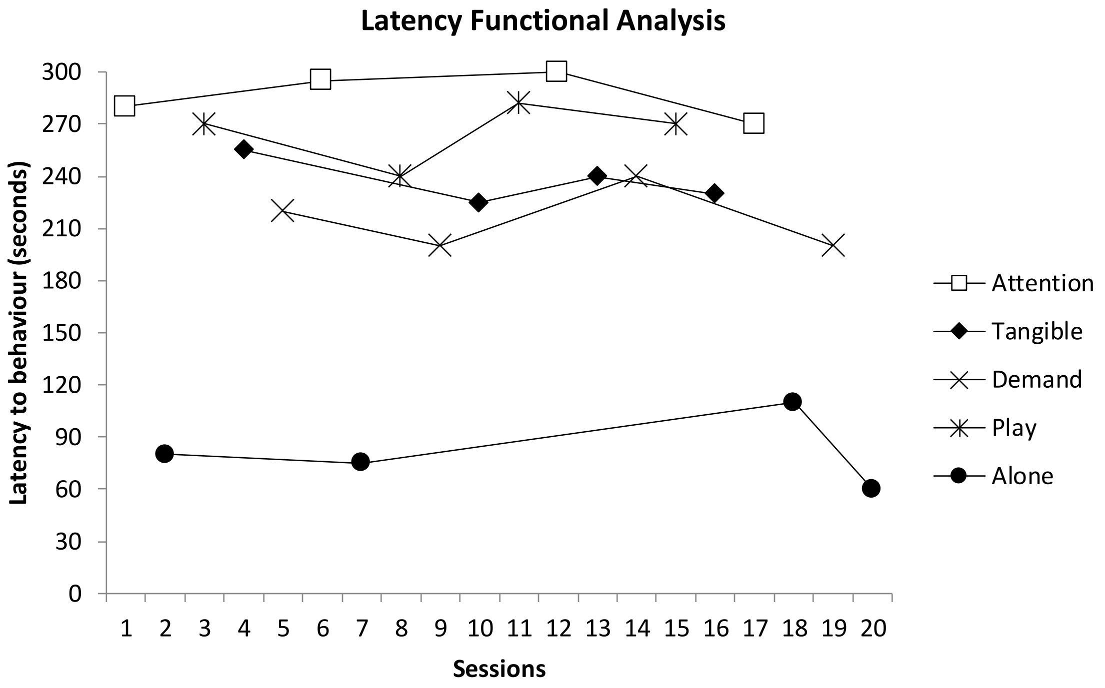
This graph indicates that the behaviour functions to gain **attention**, as it occurred more quickly in the attention conditions than in any other condition.



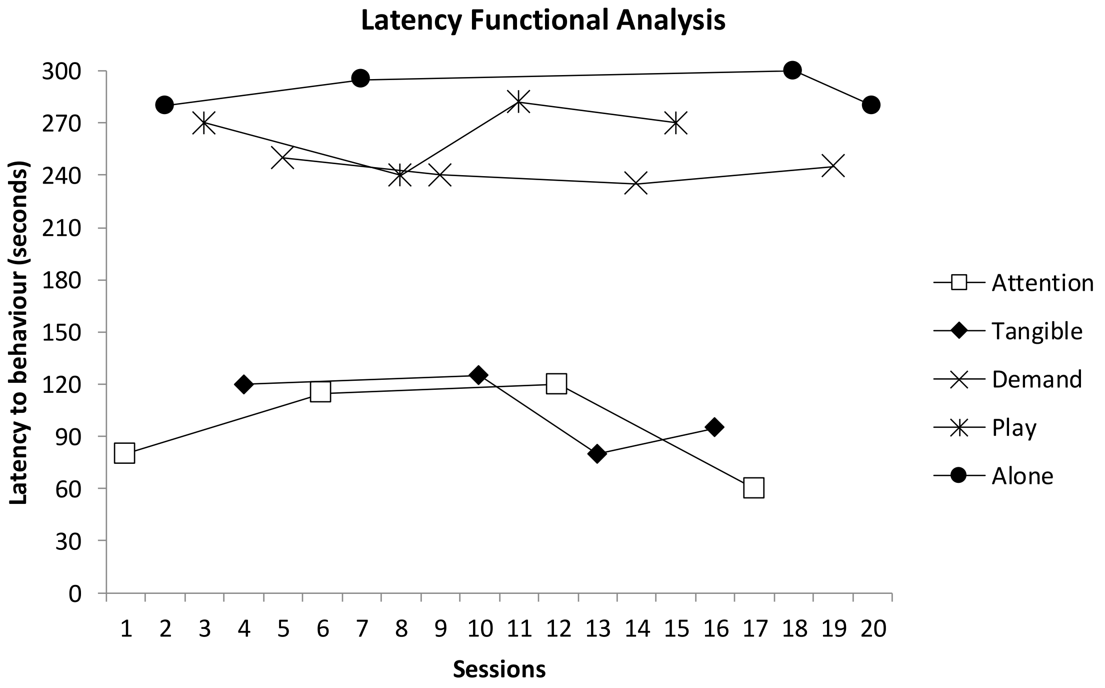
This graph indicates that the behaviour functions to gain access to an item the child likes, as it occurred more quickly in the **tangible** conditions than in other conditions.



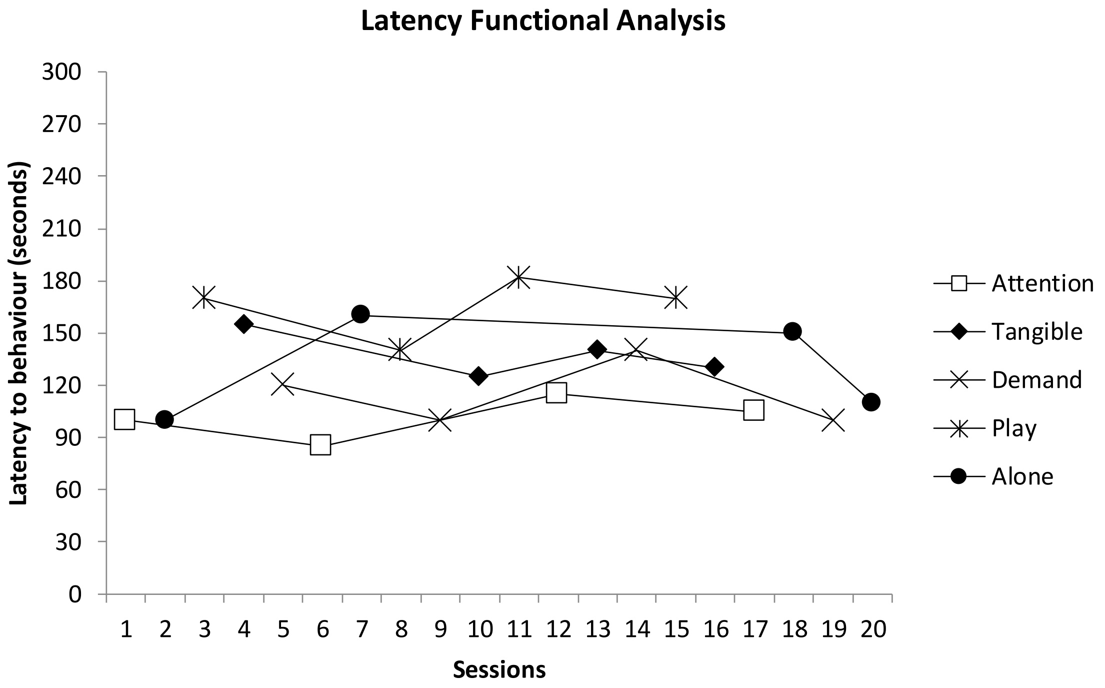
This graph indicates that the behaviour functioned to gain **sensory stimulation**, as it occurred more quickly when the child was alone than in other conditions.



This graph indicates that the behaviour has **multiple functions** (access to items the individual likes and attention) as behaviour occurred more quickly in attention and tangible conditions than in other conditions.



This graph suggests either that the behaviour has **multiple functions**, that it has a **sensory stimulation** function (as it occurred in every session), or that we need to do **more analyses**. If this pattern of data happens, you should seek further support from someone with behavioural expertise.



Appendix T

Five-Minute Speech Sample Instructions and Scoring (Chapter Five)

"I'd like to hear your thoughts about why your child displays challenging behaviour, in your own words without my interrupting with any questions or comments. When I ask you to begin I'd like you to speak for 5 minutes, telling me what kind of behaviour [child's name] displays and why you think this is. In this period, I will not speak or ask further questions so that you can talk in an uninterrupted manner, but I will be listening carefully. Sometimes people like to talk all of the time and sometimes to take pauses, and both are fine to do. After you begin to speak, I prefer not to answer any questions until after the 5 minutes are over. Do you have any questions before we begin?

Ok, so tell me, why do you think your child displays challenging behaviour?"

If there are still a couple of minutes to go and the family carer is quiet for 30 seconds and appears unable to continue, make one comment: "Tell me anything you can about why you think [child] displays challenging behaviour for a few more minutes".

If family carer finishes speaking after prompt and seems unable to continue, stop recording and note time recording was made for.

Scoring:

Behavioural function (count) ☐

Tick

Function (attention)? ☐

Function (tangible)? ☐

Function (escape)? ☐

Function (sensory)? ☐

Function (pain)? ☐

Emotional cause (count) ☐

Diagnostic / biological cause (count) ☐

Environmental cause (count) ☐

Cognitive cause (count) ☐

Unable to predict / no cause (count) ☐

Family carer attributions about their ability to manage behaviour:

Positive statements (count) ☐

Negative statements (count) ☐

With all – specify in order to justify coding.

Consider discrete statements, but if explanation of an issue is ongoing (e.g. describing a particular situation) count only once.

Appendix U

First Advertisement Used to Recruit Participants for Both Panels (Chapter Six)

[REDACTED]

Appendix V

Redesigned Advertisement for Recruiting Family Carers for Panel Two (Chapter Six)

[REDACTED]

Appendix W

Participant Information Sheet for Study Three (Chapter Six)

PARTICIPANT INFORMATION SHEET

Family carer and professional perceptions of the delivery and adoption of telehealth methodology for behavioural support for people with intellectual / developmental disabilities in the UK: A Delphi consultation

You are being invited to take part in a research project conducted by Serena Tomlinson who is a PhD student in Intellectual and Developmental Disabilities at the Tizard Centre, University of Kent. Her academic supervisors are Dr. Nick Gore and Prof. Peter McGill (contact details below). Please read the following information before deciding whether you would to take part in the project, and please contact Serena using the details below if you have any questions. The project received ethical approval from the Tizard Centre (University of Kent) Research Ethics Committee on 13th April 2017.

What is the project about?

This project relates to the use of telecommunications and IT (called 'telehealth') to provide support / advice / training to family carers of people with learning or developmental disabilities relating to their relative's behaviour. We want to find out how family carers would feel about being offered support via telehealth rather than face to face, and any advantages or barriers they perceive to this. We also want to know how professionals would feel about using telehealth for this purpose within their own clinical practice. You do not need to have received or provided support via telehealth to take part.

What will the project involve?

The project uses the Delphi method of consultation, which means that participants on two expert panels will be consulted about the use or delivery of telehealth. One panel will consist of 10-15 family carers of people with learning or developmental disabilities who have experience of receiving support from a professional about their relative's behaviour. The other panel will consist of 10-15 professionals who have experience of providing support to family carers of people with learning or developmental disabilities about their relative's behaviour.

If you choose to take part, you will be sent a link to complete questionnaires electronically in up to four rounds. These questionnaires will ask about your thoughts on different aspects receiving or delivering support via telehealth, and any advantages or barriers you think there might be in relation to this. The questionnaires should take no more than 30 minutes to fill out in each round. You will be given two weeks to complete the questionnaires in each round, and can complete them whenever is most convenient to you during this period.

After every round, the researcher will look at the responses and try to draw together or summarise the answers and feed this back to the panel. Your individual answers will only be seen by the researcher and her academic supervisors, and no one else on the panel will know what you've said or who you are.

What are the potential benefits of taking part?

The study will provide information about ways to improve support delivered via telehealth for family carers, and how to overcome any barriers or difficulties in providing support via telehealth. This will make it easier for family carers to receive support via telehealth in the future and for professionals to deliver support to family carers via telehealth.

What are the potential risks if I take part?

The project requires use of your time in relation to completing the questionnaire for each round, however the questionnaires have been designed to be as brief and easy to complete as possible. You will be asked to complete the questionnaires electronically and you can complete them whenever is most convenient for you within a two week period.

Your option to take part in the project

You do not have to take part in the project. If you choose to take part and later change your mind then that's ok and you can withdraw your data at any time. If you do decide that you want to take part you will remain anonymous. The researcher will give you a unique number to use in place of your name on any questionnaires and all of the data will be safely stored and only accessed by the researcher and her supervisory team. You will be asked to provide the researcher with contact details (e.g. name, telephone number, and email address) to enable them to contact you throughout the study but these will be stored in a locked filing cabinet and only accessed by the researcher. This information will be destroyed after the end of the study.

We hope to present the results of the research at conferences and publish them in an academic journal, however you will not be identified in any publications, presentations, or reports relating to the project. We might use quotations from what you have said, but we won't identify you by name if we do this.

The next steps

If you are interested in taking part as a panel member for this study then please complete and return the consent form via email to the researcher. If you would like to know more before deciding, please don't hesitate to contact the researcher using the details below.

Main researcher:	Serena Tomlinson	sb773@kent.ac.uk	01227 827 446
Academic supervisors:	Dr. Nick Gore	n.j.gore@kent.ac.uk	01227 827 755
	Prof. Peter McGill	p.mcgill@kent.ac.uk	01227 823 838

Address: Tizard Centre, Cornwallis East, University of Kent, Canterbury, CT2 7NF

Thank you for taking the time to read this information.

Appendix X

Round One Questionnaire for Panel One (Chapter Six)

Round 1 Questionnaire - Professionals

Thank you for taking part in round 1! The following questionnaire has 3 parts including a section about you, a section about the people you support, and a section about the use of telehealth. Please answer all questions and feel free to contact me if anything isn't clear. Your answers are completely confidential and no one will know who has said what during the questionnaire.

* Required

1. **Please create a unique code so that you can find your answers in the next rounds. The code should consist of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).** *

____

About you

This section asks some brief questions about you and your role as a professional.

2. **Gender** * *Mark only one oval.*

○ Male
○ Female

3. **Age:** *
Mark only one oval.

○ 18-25
○ 26-35
○ 36-45
○ 46-55
○ 56-65
○ 66+

4 **Professional background: (tick all that apply)** * *Check all that apply.*

☐ Psychologist e.g. clinical, educational
☐ Behaviour analyst
☐ Speech & language therapist
☐ Occupational therapist
☐ Teacher / educational staff
☐ Learning disability nurse
☐ Psychiatrist
☐ GP
☐ Other: ____________________

About the people you support

This section asks some brief details about who you typically support and the type of support you provide. Please think specifically about the needs and characteristics of the person with learning / developmental disabilities, even if you only support family carers.

5. **Age range of individuals with a learning / developmental disability: (tick all that apply)** * *Check all that apply.*

☐ Early years, i.e. 0-7
☐ Children - i.e. 8-12
☐ Adolescents- i.e.13-18
☐ Young people - i.e. 19-26
☐ Adults - i.e. 27+

6. **Please describe the needs of the people with learning / developmental disabilities: (tick all that apply)** * *Check all that apply.*

☐ Learning disability - mild/moderate
☐ Learning disability - severe/profound
☐ Global developmental delay
☐ Autism spectrum conditions
☐ Down syndrome
☐ Other: ____________________

7. **How many years experience do you have providing support to family carers about their relative's behaviour?** * *Mark only one oval.*

○ Less than one year
○ 1-5 years
○ 6-10 years
○ More than 10 years

8 **Where do you typically provide support to family carers: (tick all that apply)** * *Check all that apply.*

☐ In schools / educational contexts
☐ In their home
☐ At an NHS site
☐ Within a charitable organisation
☐ Other: ____________________

9. **What type of support do you typically provide to family carers about their relative's behaviour? (tick all that apply)** * *Check all that apply.*

☐ Advice
☐ Written information / signposting to other services
☐ Training
☐ Other: ____________________

10. **How do you typically provide this support? (tick all that apply)** * *Check all that apply.*

☐ In person, e.g. meetings
☐ In writing, e.g. reports, letters, information leaflets
☐ Via videoconferencing, e.g. Skype, google hangouts, video calling
☐ Via email
☐ Over the telephone
☐ Text message or other messaging platform, e.g. WhatsApp, viber
☐ Social media, e.g. Facebook, twitter
☐ Online forums, groups, or chatrooms
☐ Other: ____________________

About using telehealth to provide behavioural support

A new way of delivering support to family carers about their relative's behaviour is through the use of telehealth. Telehealth involves using technology to deliver support across distance, and not via traditional meetings in person.

The definition of telehealth is "the use of telecommunications and information technology to provide access to health [or behavioral health] assessment, diagnosis, intervention, consultation, supervision, education, and information across distance" (Nickelson, 1998, p. 527). This could include videoconferencing, email, text messages or other messaging applications, social media or online forums, telephone consultations or any other way that technology might be used by a professional to communicate with a family carer about their relative's behaviour.

For the rest of the questions, please think of telehealth in this context.

The questions will first ask about your perceptions / opinions relating to the support you provide to family carers, and then about how you think other professionals (including those from a different background or who might work in a different way to you) might feel. Please answer each question and give as much detail as you can.

11 **Have you ever used telehealth in your professional practice? This does not need to be in relation to your work with families, but can be in any area of your professional work.** * *Mark only one oval.*

○ Yes
○ No

12. **If you answered yes, how have you used telehealth in the past?**

13. **Are there circumstances when you would be willing to use telehealth to provide support to family carers about their relative's behaviour?** * *Mark only one oval.*

○ Yes
○ No

14. **If you answered yes, please describe the circumstances when you would be willing to use telehealth for this purpose.**

15. **If you answered yes, which methods would you be most willing to use? (tick all that apply)**
Check all that apply.

☐ Videoconferencing, e.g. skype, google hangouts, video calling etc.
☐ Email
☐ Telephone
☐ Text messaging
☐ Social media
☐ Online forums, groups or chatrooms
☐ Other: ______________________

16. **If you answered no, please tell us a little bit about why you wouldn't be willing to use telehealth.**

____
____
____
____
____

17 **Do you think there would be circumstances when other professionals would be willing to use telehealth to provide support to family carers about their relative's behaviour?** * *Mark only one oval.*

○ Yes
○ No

18. **If you answered yes, please describe the circumstances when you think other professionals would be willing to use telehealth for this purpose.**

____
____
____
____
____

19. **If you answered yes, which methods do you think other professionals might be most willing to use? (tick all that apply)** *Check all that apply.*

☐ Videoconferencing, e.g. skype, google hangouts, video calling etc.
☐ Email
☐ Telephone
☐ Text messaging
☐ Social media
☐ Online forums, groups or chatrooms
☐ Other: ____________________

20. **If you answered no, please tell us a little bit about why you think other professionals wouldn't be willing to use telehealth.**

____
____
____
____
____

Advantages

Please think about any advantages there might be to using telehealth to provide support to family carers about their relative's behaviour.

You might want to think about the following areas: your relationship and interactions with the family carer; understanding the behaviours of concern and planning support; the type and quality of support you can provide; the practical aspects of the appointment (e.g. time, travel, resources); the technology itself.

21 **Advantages for you as a professional:** *

____
____
____
____
____

22. **Advantages for the family carer:** *

23. **Advantages for others:** *

24. **Are there additional advantages in any of these areas for other professionals (including those from a different background or who work in a different way to you)?** *

Barriers

Please think about any disadvantages or barriers there might be to using telehealth to provide support to family carers about their relative's behaviour.

You might want to think about the following areas: your relationship and interactions with the family carer; understanding the behaviours of concern and planning support; the type and quality of support you can provide; the practical aspects of the appointment (e.g. time, travel, resources); the technology itself.

25. **Disadvantages / barriers for you as a professional:** *

26 **Disadvantages / barriers for the family carer:** *

27. **Disadvantages / barriers for others:** *

28. **Are there additional barriers / disadvantages in any of these areas for other professionals (including those from a different background or who work in a different way to you)?** *

Appendix Y

Round One Questionnaire for Panel Two (Chapter Six)

Round 1 Questionnaire - Family Carers

Thank you for taking part in round 1! The following questionnaire has 3 parts including a section about you, a section about your relative with a learning / developmental disability, and finally a section about the use of telehealth. Please answer all questions and feel free to contact me if anything isn't clear. Your answers are completely confidential and no one will know who has said what during the questionnaire.

* Required

1. **Please create a unique code so that you can find your answers in the next rounds. The code should consist of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).**

About you

This section asks some brief questions about you.

2. **Gender:** * *Mark only one oval.*

   ○ Male
   ○ Female

3. **Age:** *

   Mark only one oval.

   ○ 18-25
   ○ 26-35
   ○ 36-45
   ○ 46-55
   ○ 56-65
   ○ 65+

4. **How are you related to someone with a learning or developmental disability?** * *Mark only one oval.*

○ Parent
○ Sibling
○ Grandparent
○ Aunt / Uncle
○ Cousin
○ Other: ______________________

About your relative

These questions are about your relative who has a learning / developmental disability and who you have previously received behavioural support for.

5. **How old is your relative?** * *Mark only one oval.*

○ 0-5
○ 6-10
○ 11-15
○ 16-18
○ 19-25
○ 26-35
○ 36-45
○ 46-55
○ 56-65
○ 65+

6. **Please describe their needs: (tick all that apply)** * *Check all that apply.*

☐ Learning disability - mild / moderate
☐ Learning disability - severe / profound
☐ Global developmental delay
☐ Autism spectrum condition
☐ Down Syndrome
☐ Other: ______________________

7. **When was the last time you received support (advice, training, information etc.) from a professional about your relative's behaviour?** * *Mark only one oval.*

○ Less than a year ago
○ 1-5 years ago
○ 6-10 years ago
○ More than 10 years ago

8. **In the past, what type of support have you received from professionals about your relative's behaviour? (tick all that apply)** * *Check all that apply.*

☐ Advice
☐ Information / signposting to other services
☐ Training
☐ Other: ____________________

9 **In the past, which professionals have provided you with support about your relative's behaviour? (tick all that apply)** * *Check all that apply.*

☐ Psychologist, e.g. clinical, educational
☐ Behaviour analyst
☐ Speech and language therapist
☐ Occupational therapist
☐ Psychiatrist
☐ Learning disability nurse
☐ Teacher / educational staff
☐ GP
☐ Other: ____________________

10. **In the past, how has support been provided about your relative's behaviour? (tick all that apply)** *

Check all that apply.

☐ In person, e.g. meetings
☐ In writing, e.g. reports, letters, information leaflets
☐ Via videoconferencing, e.g. Skype, Google hangouts, video calling
☐ Via email
☐ Over the telephone
☐ Text message or other messaging platform, e.g. WhatsApp, viber
☐ Social media, e.g. Facebook, twitter
☐ Online forums, groups or chatrooms
☐ Other: ____________________

About using telehealth to receive behavioural support

A new way of delivering support to family carers about their relative's behaviour is through the use of telehealth. Telehealth involves using technology to deliver support across distance, and not via traditional meetings in person.

The definition of telehealth is "the use of telecommunications and information technology to provide access to health [or behavioral health] assessment, diagnosis, intervention, consultation, supervision, education, and information across distance" (Nickelson, 1998, p. 527). This could include videoconferencing, email, text messages or other messaging applications, social media or online forums, telephone consultations or any other way that technology might be used by a professional to communicate with a family carer about their relative's behaviour.

For the rest of the questions, please think of telehealth in this context.

The questions will ask you to think about your perceptions or opinions about telehealth and any advantages / barriers there might be to receiving support in this way. Please answer each question as fully as possible giving as much detail as you can.

11. **Have you ever received support using telehealth methodology? This can be in any area, and does not need to be in relation to your relative or their support.** * *Mark only one oval.*

○ Yes
○ No

12 **If you answered yes, what type of support have you received via telehealth and using which telehealth methods?**

13. **Would you be willing to receive support from a professional about your relative's behaviour via telehealth instead of in person?** * *Mark only one oval.*

○ Yes
○ No

14. **If you answered yes, which methods would you be most willing to use? (tick all that apply)** *Check all that apply.*

☐ Videoconferencing, e.g. skype, google hangouts, video calling
☐ Email
☐ Telephone
☐ Text messaging
☐ Social media
☐ Online forums, groups or chatrooms
☐ Other: __________

15. **If you answered no, please tell us a little bit about why you wouldn't be willing to use telehealth.**

16. **Do you think other families would be willing to receive support from a professional about their relative's behaviour via telehealth instead of in person?** * *Mark only one oval.*

○ Yes
○ No

17 **If you answered yes, which methods do you think other families would be most willing to use? (tick all that apply)** *Check all that apply.*

☐ Videoconferencing, e.g. skype, google hangouts, video calling
☐ Email
☐ Telephone
☐ Text messaging
☐ Social media
☐ Online forums, groups or chatrooms
☐ Other: ____________________

18. **If you answered no, please tell us a little bit about why you think other families wouldn't be willing to use telehealth.**

Advantages

Please think about the advantages of using telehealth rather than in person methods for you and your family. For each question, please give as much detail as you can about each advantage.

19. **Advantages for you:** *

20. **Advantages for your relative:** *

21 **Are there additional advantages for other families and their relatives (including those from a different background to you) relating to the use of telehealth rather than in person support?** *

Barriers

Please think about the barriers or disadvantages there might be to using telehealth rather than in person methods for you and your family. For each question, please give as much detail as you can about each barrier/disadvantage.

22. **Barriers for you:** *

23. **Barriers for your relative:** *

24. **Are there additional barriers for other families and their relatives (including those from a different background to you) relating to the use of telehealth rather than in person support?** *

Appendix Z

Round Two Questionnaire for Panel One (Chapter Six)

Round 2 Questionnaire - Professionals

Thank you for taking part in the Round 2 questionnaire!

In round 1, panellists identified a range of advantages and disadvantages / barriers to the use of telehealth for providing support to family carers about their relative's behaviour. This questionnaire lists these items and asks you to think about how influential the item is in relation to the likelihood that you would adopt telehealth methodology in your professional work.

* Required

1. **Please rewrite the unique code you produced in round 1 so that you can find your answers in the next rounds. As a reminder, the code consisted of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).** *

Advantages

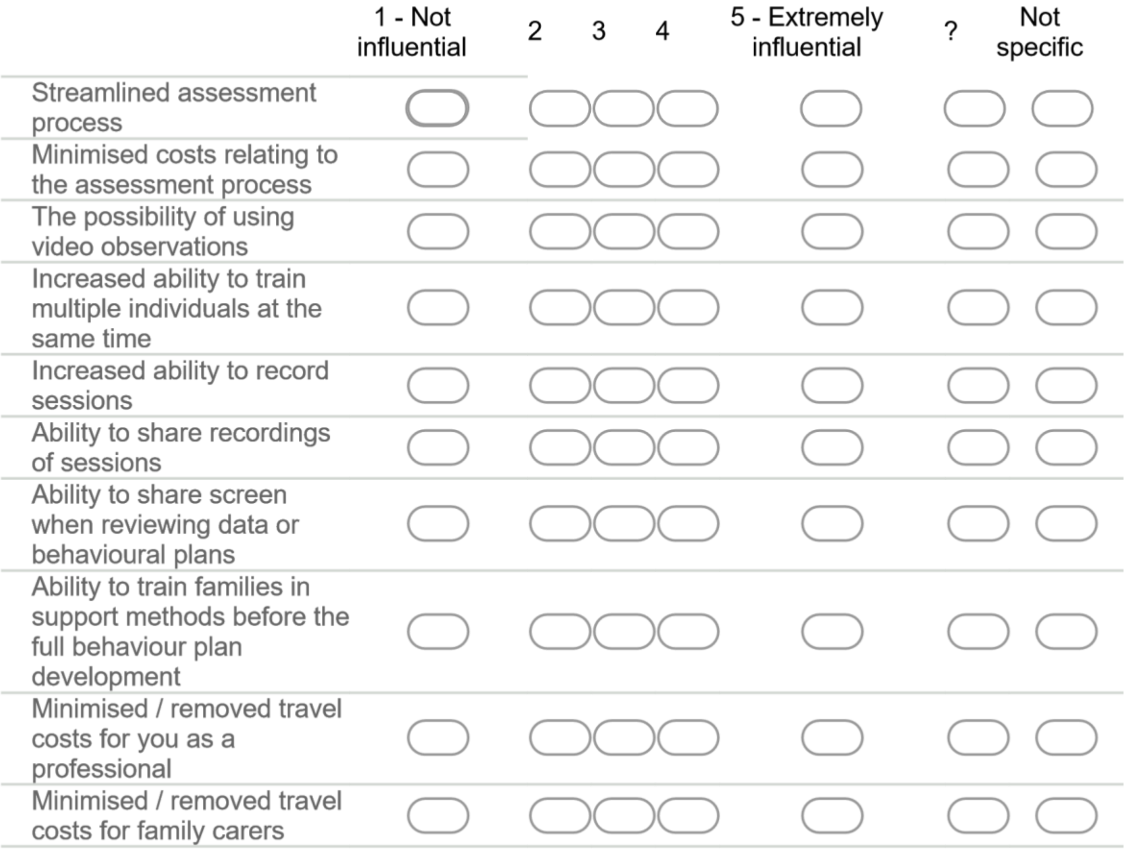
The items below relate to advantages that panellists identified in relation to the use of telehealth for providing support to family carers about their relative's behaviour.

Please rate each item according to how influential you think this advantage is in relation to your likelihood of adopting telehealth in your professional work.

- You should rate the item on a 5 point scale from 1 - not influential, to 5 - extremely influential.
- If you are unsure about what an item means please select '?' for this item.
- Please think about each item in relation to the use of telehealth methodology. If you think that this item is a more general advantage for many types of support (i.e. not specific to support provided via telehealth methodology) please select 'Not specific'

2 **Advantages 1** *

Mark only one oval per row.



	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Streamlined assessment process	○	○	○	○	○	○	○
Minimised costs relating to the assessment process	○	○	○	○	○	○	○
The possibility of using video observations	○	○	○	○	○	○	○
Increased ability to train multiple individuals at the same time	○	○	○	○	○	○	○
Increased ability to record sessions	○	○	○	○	○	○	○
Ability to share recordings of sessions	○	○	○	○	○	○	○
Ability to share screen when reviewing data or behavioural plans	○	○	○	○	○	○	○
Ability to train families in support methods before the full behaviour plan development	○	○	○	○	○	○	○
Minimised / removed travel costs for you as a professional	○	○	○	○	○	○	○
Minimised / removed travel costs for family carers	○	○	○	○	○	○	○

3. **Advantages 2** *

Mark only one oval per row.

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Minimised / removed room hire costs, clinic space costs or office overheads	○	○	○	○	○	○	○
Reduced costs as a result of missed appointments	○	○	○	○	○	○	○
Increased ability for professionals to work from home	○	○	○	○	○	○	○
Ability for family carers to join sessions from their own home	○	○	○	○	○	○	○
Ability for others to be in situ (e.g. in the service setting) with all necessary resources during sessions	○	○	○	○	○	○	○
Ability for family carers to contact professionals quickly using email	○	○	○	○	○	○	○
Increased ability to provide support to family carers during times of crisis	○	○	○	○	○	○	○
Ability to offer appointments more quickly	○	○	○	○	○	○	○
Ability to offer more appointments overall	○	○	○	○	○	○	○
Increased ability to gather information from family carers without waiting for in person clinic appointment	○	○	○	○	○	○	○

4. **Advantages 3** *

Mark only one oval per row.

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Ability to share emails and other permanent products with others	○	○	○	○	○	○	○
Ability to carefully consider response when communicating using email / text messaging	○	○	○	○	○	○	○
Reduced observer effects on client's presentation by using video observations	○	○	○	○	○	○	○
Increased ability to monitor procedural fidelity via video recordings	○	○	○	○	○	○	○
Flexibility for family carers in relation to fitting appointments around their other commitments	○	○	○	○	○	○	○
Reduced time needed by family carers for support received	○	○	○	○	○	○	○
Increased ability to quickly rearrange missed appointments	○	○	○	○	○	○	○
Ability to communicate with wide range of people more quickly, e.g. using email	○	○	○	○	○	○	○
Ability to arrange multi-disciplinary meetings more easily	○	○	○	○	○	○	○
Reduced waiting times for support	○	○	○	○	○	○	○

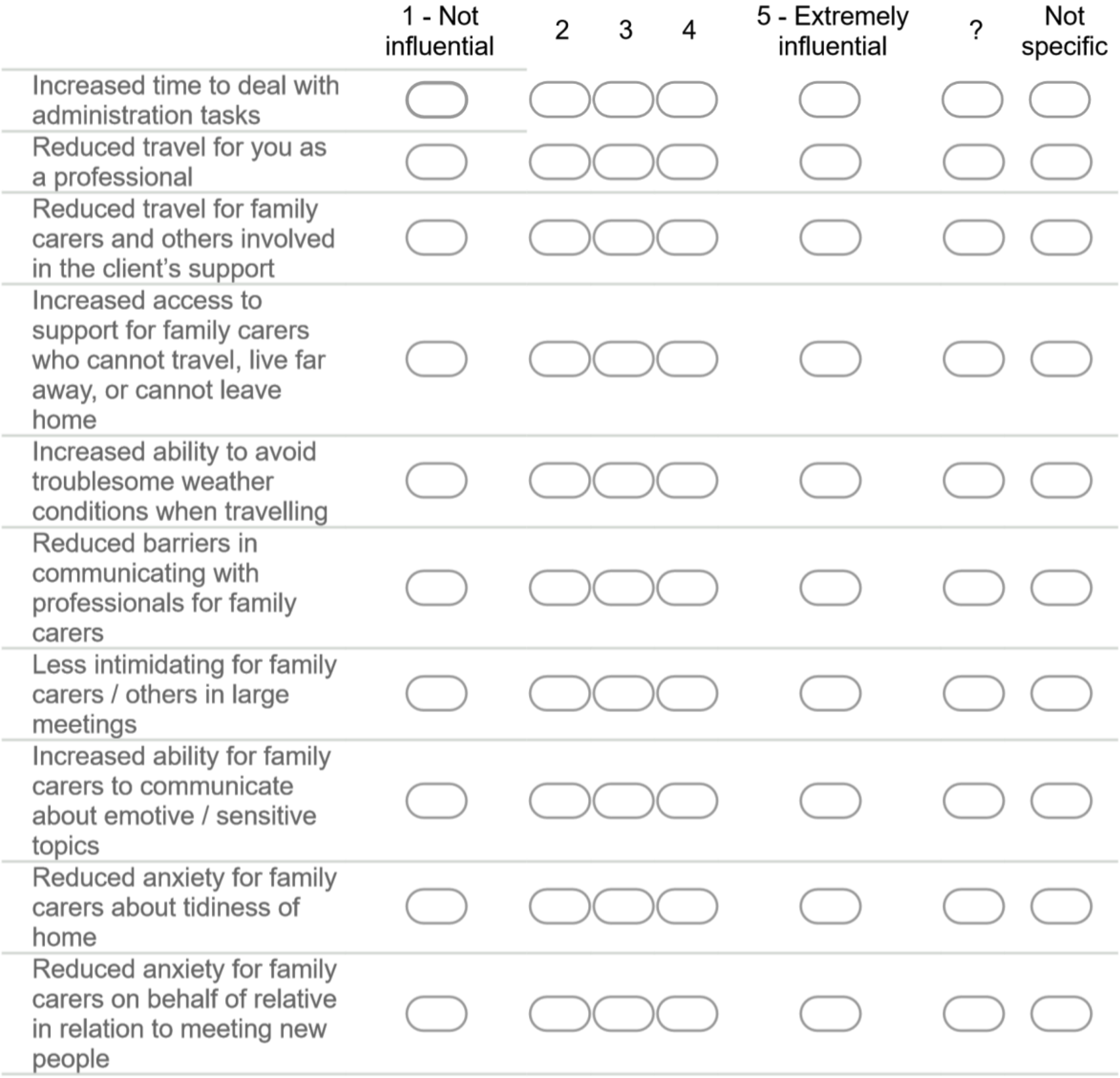
5 **Advantages 4 ***

Mark only one oval per row.

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Increased choice for family carers about how they communicate with professionals	○	○	○	○	○	○	○
Increased choice for family carers about what information they are given and how	○	○	○	○	○	○	○
Increased convenience for family carers	○	○	○	○	○	○	○
Ability to involve more people in the client's support	○	○	○	○	○	○	○
Ability for family carers to access group or peer support	○	○	○	○	○	○	○
Increased ability to involve interpreters during sessions	○	○	○	○	○	○	○
Increased access for you to a wider network of professionals	○	○	○	○	○	○	○

6. **Advantages 5***

Mark only one oval per row



	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Increased time to deal with administration tasks	○	○	○	○	○	○	○
Reduced travel for you as a professional	○	○	○	○	○	○	○
Reduced travel for family carers and others involved in the client's support	○	○	○	○	○	○	○
Increased access to support for family carers who cannot travel, live far away, or cannot leave home	○	○	○	○	○	○	○
Increased ability to avoid troublesome weather conditions when travelling	○	○	○	○	○	○	○
Reduced barriers in communicating with professionals for family carers	○	○	○	○	○	○	○
Less intimidating for family carers / others in large meetings	○	○	○	○	○	○	○
Increased ability for family carers to communicate about emotive / sensitive topics	○	○	○	○	○	○	○
Reduced anxiety for family carers about tidiness of home	○	○	○	○	○	○	○
Reduced anxiety for family carers on behalf of relative in relation to meeting new people	○	○	○	○	○	○	○

7 **Are there any other advantages related to the use of telehealth to provide support to family carers about their relative's behaviour that aren't listed in the items above?** *

Disadvantages / barriers

The items below relate to disadvantages / barriers that panellists identified in relation to the use of telehealth for providing support to family carers about their relative's behaviour.

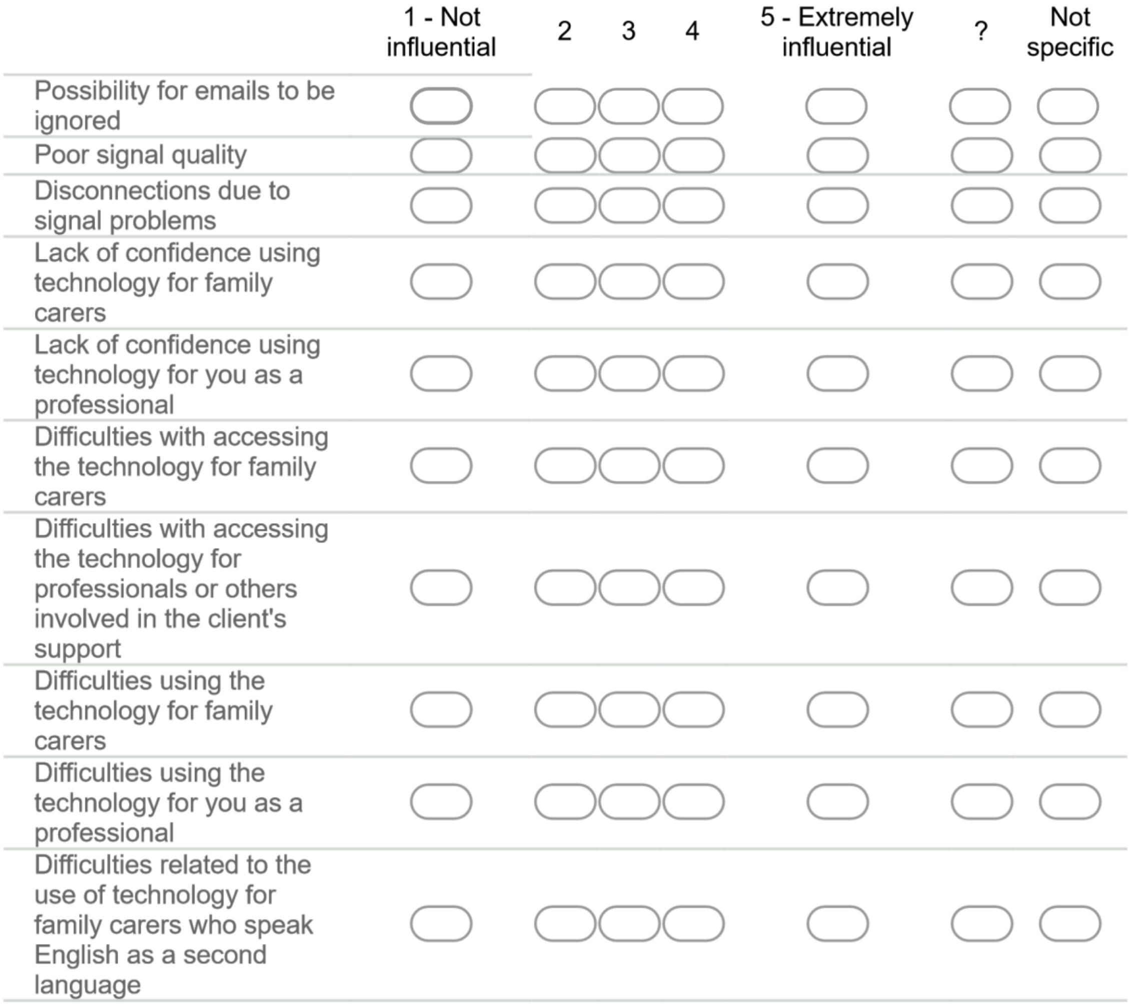
Please rate each item according to how influential you think this disadvantage / barrier is in relation to your likelihood of adopting telehealth in your professional work.

- You should rate the item on a 5 point scale from 1 - not influential, to 5 - extremely influential.
- If you are unsure about what an item means please select '?' for this item.
- Please think about each item in relation to the use of telehealth methodology. If you think that this item is a more general disadvantage / barrier for many types of support (i.e. not specific to support provided via telehealth methodology) please select 'Not specific'

8. **Disadvantages / Barriers 1** * *Mark only one oval per row.*

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Potential for mistakes to be made in assessment / advice given	○	○	○	○	○	○	○
Negative perceptions of others about quality of assessment / intervention	○	○	○	○	○	○	○
Negative perceptions of others about quality of data provided by family carers	○	○	○	○	○	○	○
Difficulty with modelling specific intervention strategies via telehealth	○	○	○	○	○	○	○
Potential that family carers might not know which information to share	○	○	○	○	○	○	○
Difficulty with delivering specific intervention strategies via telehealth, e.g. ABA therapy	○	○	○	○	○	○	○
Increased costs associated with technology for family carers	○	○	○	○	○	○	○
The need for access to a quiet room for videoconferencing	○	○	○	○	○	○	○
Difficulty for family carers to protect appointment time	○	○	○	○	○	○	○
Possibility of sessions being interrupted if family carers are at home	○	○	○	○	○	○	○

9 **Disadvantages / Barriers 2** * *Mark only one oval per row.*



	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Possibility for emails to be ignored	○	○	○	○	○	○	○
Poor signal quality	○	○	○	○	○	○	○
Disconnections due to signal problems	○	○	○	○	○	○	○
Lack of confidence using technology for family carers	○	○	○	○	○	○	○
Lack of confidence using technology for you as a professional	○	○	○	○	○	○	○
Difficulties with accessing the technology for family carers	○	○	○	○	○	○	○
Difficulties with accessing the technology for professionals or others involved in the client's support	○	○	○	○	○	○	○
Difficulties using the technology for family carers	○	○	○	○	○	○	○
Difficulties using the technology for you as a professional	○	○	○	○	○	○	○
Difficulties related to the use of technology for family carers who speak English as a second language	○	○	○	○	○	○	○

10 **Disadvantages / Barriers 3** * *Mark only one oval per row.*

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Difficulty involving interpreters in sessions via telephone	○	○	○	○	○	○	○
Possibility of misinterpreting communication e.g. via email	○	○	○	○	○	○	○
Increased difficulty for the client in relation to social interaction via technology	○	○	○	○	○	○	○
Family carer preference for meeting in person	○	○	○	○	○	○	○
Your preference for meeting in person	○	○	○	○	○	○	○
Other people's preference for meeting in person	○	○	○	○	○	○	○
Difficulty for family carers to get point across via technology	○	○	○	○	○	○	○
Possibility of missing subtlety of communication when not in person	○	○	○	○	○	○	○
Difficulty related to checking misunderstandings	○	○	○	○	○	○	○
Lack of face to face / in person contact	○	○	○	○	○	○	○

11. **Disadvantages / Barriers 4** *

Mark only one oval per row.

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Difficulty developing rapport with family carers via telehealth	○	○	○	○	○	○	○
Family carer's difficulty with developing rapport and trust with you via telehealth	○	○	○	○	○	○	○
Difficulty in understanding family carer's reactions to suggestions	○	○	○	○	○	○	○
Confidentiality / privacy issues	○	○	○	○	○	○	○
Data protection / security issues	○	○	○	○	○	○	○
Ethical issue of offering support / advice without seeing situation in person	○	○	○	○	○	○	○
Suggestion that you are 'ever available' to family carers	○	○	○	○	○	○	○

12 **Are there any other disadvantages / barriers related to the use of telehealth to provide support to family carers about their relative's behaviour that aren't listed in the items above?** *

Appendix AA

Round Two Questionnaire for Panel Two (Chapter Six)

Round 2 Questionnaire - Family Carers

Thank you for taking part in round 2!

In round 1, you identified a range of advantages and disadvantages / barriers to the use of telehealth for receiving support about your relative's behaviour. This questionnaire lists these items and asks you to think about how influential the item is in relation to your willingness to accept support delivered via telehealth rather than in person.

* Required

1. **Please rewrite the unique code that you created in round 1. As a reminder, the code consisted of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).** *

About you

This section asks some brief questions about you.

2. **Gender:** *

3. **Age:** *

Mark only one oval.

○ 18-25
○ 26-35
○ 36-45
○ 46-55
○ 56-65
○ 65+

4. **How are you related to someone with a learning or developmental disability?** * *Mark only one oval.*

- ○ Parent
- ○ Sibling
- ○ Grandparent
- ○ Aunt / Uncle
- ○ Cousin
- ○ Other: ______________________

Advantages

The items below relate to advantages that you identified in relation to receiving support for your relative's behaviour via telehealth.

Please rate each item according to how influential you think this advantage is in relation to your willingness to accept support for your relative's behaviour delivered via telehealth rather than in person.

- You should rate the item on a 5 point scale from 1 - not influential, to 5 - extremely influential.
- If you are unsure about what an item means please select '?' for this item.
- Please think about each item in relation to the use of telehealth methodology. If you think that this item is a more general advantage for many types of support (i.e. not specific to support provided via telehealth methodology) please select 'Not specific'

5. **Advantages 1** *

Mark only one oval per row.

	1 - Not Influential	2	3	4	5 - Extremely Influential	?	Not Specific
Removed triggers / barriers to attendance for individuals with ASD who find social interaction aversive	○	○	○	○	○	○	○
Your relative finding it easier to communicate due to being in their own home	○	○	○	○	○	○	○
Increased ability for your relative to have a choice about whether to join or leave the discussion if they are at their own home	○	○	○	○	○	○	○
Your relative feeling more comfortable due to being in their own home	○	○	○	○	○	○	○
Increased ability for support to be provided in your home	○	○	○	○	○	○	○
Reduced need to travel and find parking for appointments	○	○	○	○	○	○	○
Increased ability to fit appointments around other commitments, e.g. childcare, work	○	○	○	○	○	○	○
Ability to save emails as records of contact with services	○	○	○	○	○	○	○
Increased ability to revisit any advice that was provided	○	○	○	○	○	○	○
Reduced referral waiting times	○	○	○	○	○	○	○

6 **Advantages 2** *

Mark only one oval per row.

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Ability for support to be provided more quickly as issues arise	○	○	○	○	○	○	○
Ability to arrange appointments more easily	○	○	○	○	○	○	○
Reduced disruption to your relative's routine	○	○	○	○	○	○	○
Increased time to consider something before responding	○	○	○	○	○	○	○
Less time wasted due to attending lengthy or ill-informed meetings	○	○	○	○	○	○	○

7. **Are there any other advantages related to the use of telehealth to receive support about your relative's behaviour that aren't listed in the items above?** *

Disadvantages / Barriers

The items below relate to disadvantages / barriers that your identified in relation to the use of telehealth to receive support about your relative's behaviour.

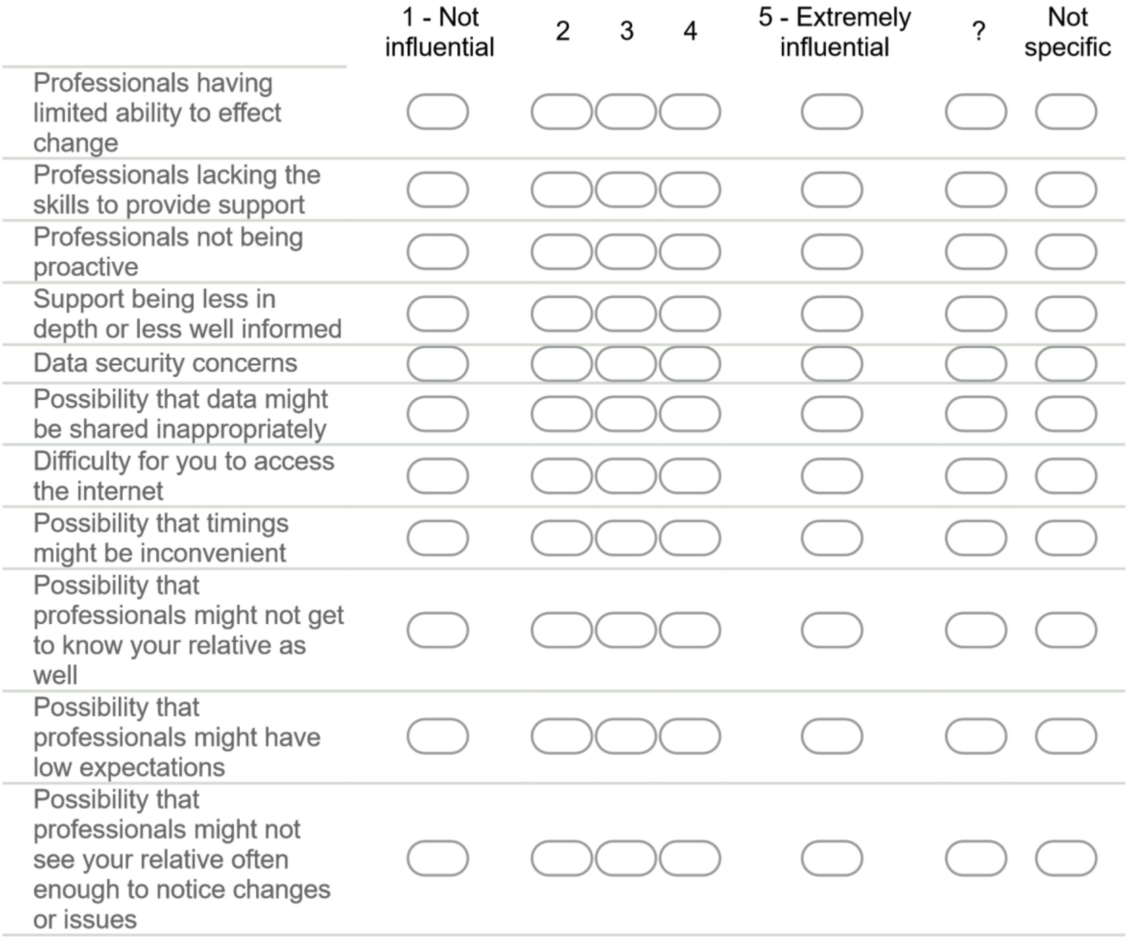
Please rate each item according to how influential you think this disadvantage / barrier is in relation to your willingness to accept support for your relative's behaviour delivered via telehealth rather than in person.

- You should rate the item on a 5 point scale from 1 - not influential, to 5 - extremely influential.
- If you are unsure about what an item means please select '?' for this item.
- Please think about each item in relation to the use of telehealth methodology. If you think that this item is a more general disadvantage / barrier for many types of support (i.e. not specific to support provided via telehealth methodology) please select 'Not specific'

8 **Disadvantages / Barriers 1** * *Mark only one oval per row.*

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Potential for things to be misunderstood or social signals to be missed when communicating via telehealth	○	○	○	○	○	○	○
The possibility that professionals might be unwilling to commit something to writing when using telehealth	○	○	○	○	○	○	○
The possibility that professionals might provide generic or inappropriate advice when providing support via telehealth	○	○	○	○	○	○	○
Your relative being less likely to engage with support provided via telehealth	○	○	○	○	○	○	○
The potential that support provided via telehealth might mean you have to oversee and manage this more than support provided in person	○	○	○	○	○	○	○
Difficulty for you to find time or a quiet location for appointments when receiving support at home	○	○	○	○	○	○	○
Increased difficulty for your relative to engage due to support being provided at home (which is not traditionally associated with this support)	○	○	○	○	○	○	○
Professionals not meeting your relative in person	○	○	○	○	○	○	○
Professionals being unable to directly observe your relative	○	○	○	○	○	○	○
Professionals being unable to influence other people who support your relative	○	○	○	○	○	○	○
Your understanding of the technology used for telehealth	○	○	○	○	○	○	○

9 **Disadvantages / Barriers 2** * *Mark only one oval per row.*



	1 - Not influential	2	3	4	5 - Extremely influential	?	Not specific
Professionals having limited ability to effect change	○	○	○	○	○	○	○
Professionals lacking the skills to provide support	○	○	○	○	○	○	○
Professionals not being proactive	○	○	○	○	○	○	○
Support being less in depth or less well informed	○	○	○	○	○	○	○
Data security concerns	○	○	○	○	○	○	○
Possibility that data might be shared inappropriately	○	○	○	○	○	○	○
Difficulty for you to access the internet	○	○	○	○	○	○	○
Possibility that timings might be inconvenient	○	○	○	○	○	○	○
Possibility that professionals might not get to know your relative as well	○	○	○	○	○	○	○
Possibility that professionals might have low expectations	○	○	○	○	○	○	○
Possibility that professionals might not see your relative often enough to notice changes or issues	○	○	○	○	○	○	○

10. **Are there any other disadvantages / barriers related to the use of telehealth to receive support about your relative's behaviour that aren't listed in the items above?** *

Appendix BB

Round Three Questionnaire for Panel One (Chapter Six)

Delphi Round 3 - Professionals

PLEASE ONLY COMPLETE THIS QUESTIONNAIRE IF YOUR UNIQUE CODE IS .

As a reminder, the code consisted of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).

IF YOUR CODE IS NOT , PLEASE CLOSE THIS FORM AND RETURN TO THE EMAIL TO CLICK THE LINK FOR THE QUESTIONNAIRE FOR YOUR CODE

* Required

1. **Please tick to confirm that your unique code is...** * *Mark only one oval.*

   ○ My code is ....

Thank you for taking part in the Round 3 questionnaire!

In round 2, panelists rated a list of advantages and disadvantages / barriers relating to the use of telehealth that had been identified in round 1. Ratings were based on how influential panelists felts these items were in relation to the likelihood that they would adopt telehealth methodology in their professional work.

For some of these items, more than 80% of panelists agreed that the item was influential to the likelihood of adopting telehealth (i.e. consensus was reached). For some items, a majority (over 60%, consensus almost reached) of panelists agreed that the item was influential to their likelihood of adopting telehealth, and for others, less than 60% agreed (i.e. no consensus was reached).

The items where the majority of panelists agreed that the item is influential to their likelihood of adopting telehealth are represented below, along with 3 new items that were identified last round. Your score and the group median score is also listed for each item. Please use this information to reconsider the item and rate how influential the item is in relation to the likelihood that you would adopt telehealth methodology in your professional work. You can choose to keep you score the same as it was in the last round, or to change your score for this round.

2. **Advantages 1** *

   Mark only one oval per row.

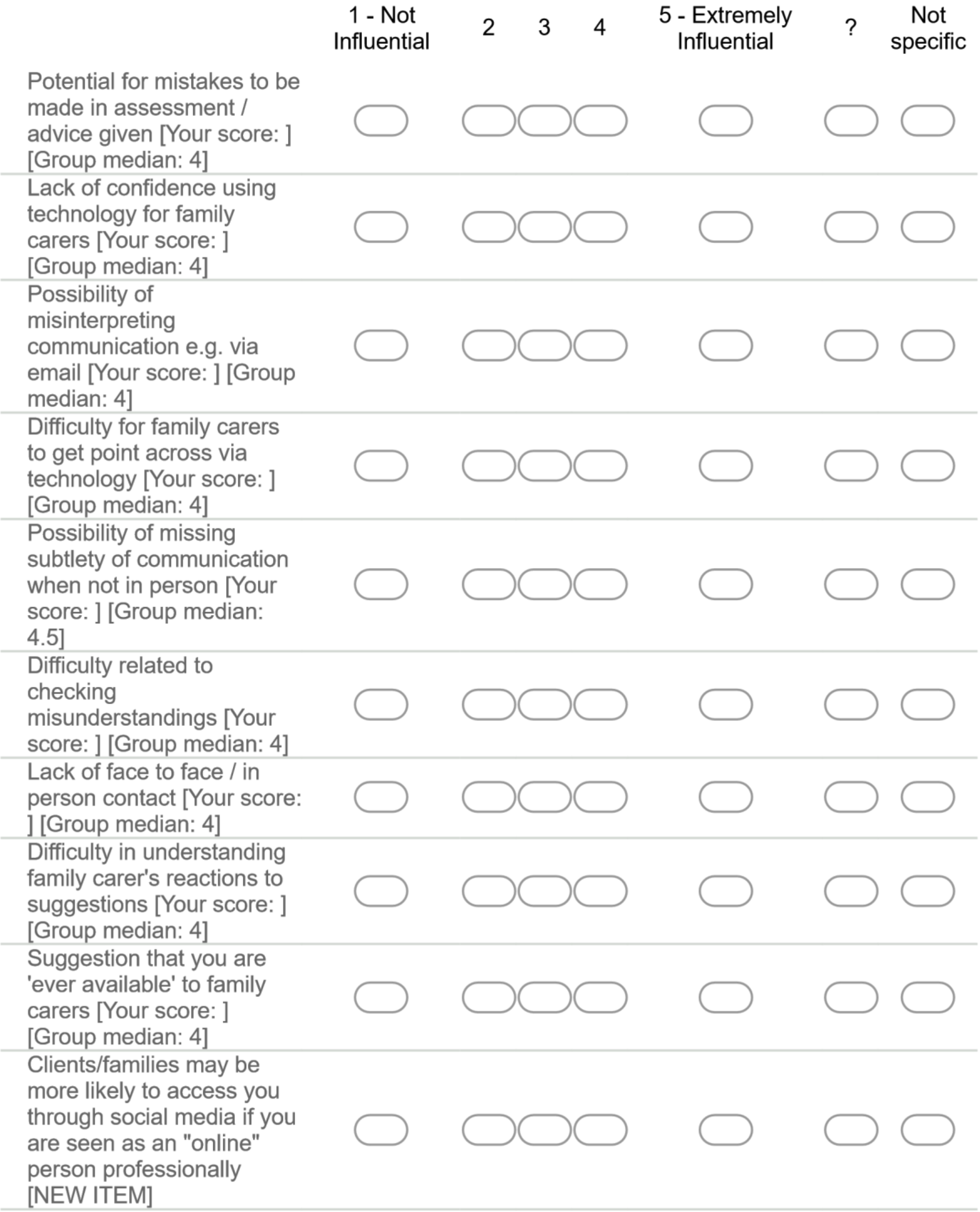
	1 - Not influential	2	3	4	5 - Extremely influential	?	Not Specific
Minimised costs relating to the assessment process [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased ability to record sessions [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Ability to share recordings of sessions [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Ability to share screen when reviewing data or behavioural plans [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Ability for family carers to contact professionals quickly using email [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Ability to share emails and other permanent products with others [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Reduced observer effects on client's presentation by using video observations [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Reduced time needed by family carers for support received [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased ability to quickly rearrange missed appointments [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Ability to communicate with wide range of people more quickly, e.g. using email [Your score:] [Group median: 4]	○	○	○	○	○	○	○

3. **Advantages 2** *

Mark only one oval per row.

	1 - Not influential	2	3	4	5 - Extremely influential	?	Not Specific
Ability to arrange multi-disciplinary meetings more easily [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Reduced waiting times for support [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased time to deal with administration tasks [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased ability to avoid troublesome weather conditions when travelling [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Less intimidating for family carers / others in large meetings [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased choice for family carers about how they communicate with professionals [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased choice for family carers about what information they are given and how [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased convenience for family carers [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Ability for family carers to access group or peer support [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Increased access for you to a wider network of professionals [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Email can be sent 24 hours a day [NEW ITEM]	○	○	○	○	○	○	○
Clients/families have a known point of contact to develop rapport with [NEW ITEM]	○	○	○	○	○	○	○

4. **Disadvantages / Barriers** * *Mark only one oval per row.*



	1 - Not Influential	2	3	4	5 - Extremely Influential	?	Not specific
Potential for mistakes to be made in assessment / advice given [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Lack of confidence using technology for family carers [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Possibility of misinterpreting communication e.g. via email [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Difficulty for family carers to get point across via technology [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Possibility of missing subtlety of communication when not in person [Your score:] [Group median: 4.5]	○	○	○	○	○	○	○
Difficulty related to checking misunderstandings [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Lack of face to face / in person contact [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Difficulty in understanding family carer's reactions to suggestions [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Suggestion that you are 'ever available' to family carers [Your score:] [Group median: 4]	○	○	○	○	○	○	○
Clients/families may be more likely to access you through social media if you are seen as an "online" person professionally [NEW ITEM]	○	○	○	○	○	○	○

Appendix CC

Round Three Questionnaire for Panel Two (Chapter Six)

Round 3 Questionnaire - Family Carers

PLEASE ONLY COMPLETE THIS QUESTIONNAIRE IF YOUR UNIQUE CODE IS .

As a reminder, the code consisted of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).

IF YOUR CODE IS NOT , PLEASE CLOSE THIS FORM AND RETURN TO THE EMAIL TO CLICK THE LINK FOR THE QUESTIONNAIRE FOR YOUR CODE

* Required

1. **Please rewrite the unique code that you created in round 1. As a reminder, the code consisted of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).** *

Thank you for taking part in the Round 3 questionnaire!

In round 2, you rated a list of advantages and disadvantages / barriers relating to the use of telehealth that had been identified in round 1. Ratings were based on how influential you felt these items are in relation to the likelihood that you would be willing to receive support for your relative's behaviour via telehealth, rather than in-person.

For some of these items, more than 80% of you agreed that the item was influential to your likelihood of using telehealth (i.e. consensus was reached). For some items, a majority (over 60%, consensus almost reached) of you agreed that the item was influential to your likelihood of using telehealth, and for others, less than 60% agreed (i.e. no consensus was reached).

The items where the majority of you agreed that the item is influential to your likelihood of using telehealth are re-presented below, along with a some new items that were identified last round. Your score and the group median score is also listed for each item. Please use this information to reconsider the item and rate how influential the item is in relation to the likelihood that you would be willing to receive support for your relative's behaviour via telehealth, rather than in-person. You can choose to keep you score the same as it was in the last round, or to change your score for this round.

2. **Advantages** *

Mark only one oval per row.

	1 - Not Influential	2	3	4	5 - Extremely Influential	?	Not Specific
Increased ability to fit appointments around other commitments, e.g. childcare, work [Your score:] [Group Median: 5]	○	○	○	○	○	○	○
Reduced referral waiting times [Your score:] [Group Median: 5]	○	○	○	○	○	○	○
Increased time to consider something before responding [Your score:] [Group Median: 5]	○	○	○	○	○	○	○
Reduced costs [NEW ITEM]	○	○	○	○	○	○	○
Quicker response times [NEW ITEM]	○	○	○	○	○	○	○
Easier access to information [NEW ITEM]	○	○	○	○	○	○	○
No need to attend appointments to deal with admin [NEW ITEM]	○	○	○	○	○	○	○
Increased ability to plan ahead, e.g. preparing an email or document to be sent in advance [NEW ITEM]	○	○	○	○	○	○	○
Useful to have distance as meetings at home can be invasive, but meetings in new places can be problematic [NEW ITEM]	○	○	○	○	○	○	○

3. **Disadvantages / Barriers** * *Mark only one oval per row.*

	1 - Not Influential	2	3	4	5 - Extremely Influential	?	Not Specific
Potential for things to be misunderstood or social signals to be missed when communicating via telehealth [Your score:] [Group Median: 4]	○	○	○	○	○	○	○
Difficulty for you to find time or a quiet location for appointments when receiving support at home [Your score:] [Group Median: 4]	○	○	○	○	○	○	○
Lack of focus from professional as they may be dealing with multiple clients and might mix people up or not go into much depth [NEW ITEM]	○	○	○	○	○	○	○
Technology issues, e.g. poor infrastructure, connectivity [NEW ITEM]	○	○	○	○	○	○	○
Concerns about trusting whether professionals know your relative well, are complying with legislation (e.g. the Mental Capacity Act, Equality Act) and are not diagnostically overshadowing due to your relative's disability [NEW ITEM]	○	○	○	○	○	○	○
Additional work for families who are already tired [NEW ITEM]	○	○	○	○	○	○	○

Appendix DD

Round Four Questionnaire for Panel One (Chapter Six)

Delphi Round 4 - Professionals

Thank you for taking part in the Round 4 questionnaire!

In rounds 2 & 3, panelists rated how influential a range of advantages and disadvantages/barriers (which had previously been identified by panelists) were to their likelihood of adopting telehealth in their professional practice.

This round asks you to select the five advantages (from those that had reached consensus in previous rounds as being influential or highly influential) which you feel would be the most influential to your own likelihood of adopting telehealth. It also asks you to suggest some possible solutions to the disadvantages / barriers that reached consensus in previous rounds as being influential or highly influential.

* Required

1. **Please rewrite the unique code you produced in round 1. As a reminder, the code consisted of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).** *

2. **Please read each of the advantages listed below and select the 5 advantages which you feel would be most influential to the likelihood of adopting telehealth in your professional practice.** * *Check all that apply.*

- ☐ Increased ability to record sessions
- ☐ Ability to share recordings of sessions
- ☐ Ability for family carers to contact professionals quickly using email
- ☐ Ability to share emails and other permanent products with others
- ☐ Ability to arrange multi-disciplinary meetings more easily
- ☐ Reduced waiting times for support
- ☐ Increased time to deal with administration tasks
- ☐ Increased choice for family carers about what information they are given and how
- ☐ Increased convenience for family carers
- ☐ Ability for family carers to access group or peer support
- ☐ Clients/families have a known point of contact to develop rapport with
- ☐ The possibility of using video observations
- ☐ Ability to train families in support methods before the full behaviour plan development
- ☐ Minimised / removed travel costs for you as a professional
- ☐ Minimised / removed travel costs for family carers
- ☐ Ability for family carers to join sessions from their own home
- ☐ Ability for others to be in situ (e.g. in the service setting) with all necessary resources during sessions
- ☐ Ability to offer appointments more quickly
- ☐ Ability to offer more appointments overall
- ☐ Increased ability to gather information from family carers without waiting for in person clinic appointment
- ☐ Increased ability to monitor procedural fidelity via video recordings
- ☐ Flexibility for family carers in relation to fitting appointments around their other commitments
- ☐ Reduced travel for you as a professional
- ☐ Reduced travel for family carers and others involved in the client's support
- ☐ Increased access to support for family carers who cannot travel, live far away, or cannot leave home
- ☐ Ability to involve more people in the client's support

3. **Of the 5 advantages you selected above, which are the TWO most influential to your likelihood of adopting telehealth?** *

For each of the groups of disadvantages / barriers listed in this section, please think about whether there are any potential solutions or ways that these barriers could be overcome in order to improve your likelihood of adopting telehealth and improve the utility of telehealth for your professional work. Please suggest as many solutions as you can for each group of disadvantages / barriers.

4. **Disadvantages / barriers: (1) Potential for mistakes to be made in assessment / advice given; (2) Ethical issue of offering support / advice without seeing situation in person** *

5. **Disadvantages / barriers: (1) Difficulty with modelling specific intervention strategies via telehealth; (2) Difficulty with delivering specific intervention strategies via telehealth, e.g. ABA therapy** *

6. **Disadvantages / barriers: (1) Possibility of misinterpreting communication e.g. via email; (2) Difficulty related to checking misunderstandings; (3) Difficulty in understanding family carer's reactions to suggestions; (4) Difficulty for family carers to get point across via technology** *

7. **Disadvantage / barrier: Lack of confidence using technology for family carers** *

8. **Disadvantage / barrier: Family carer preference for meeting in person** *

Appendix EE

Round Four Questionnaire for Panel Two (Chapter Six)

Delphi Round 4 - Family Carers

Thank you for taking part in the Round 4 questionnaire!

In rounds 2 & 3, you rated how influential a range of advantages and disadvantages/barriers (which had previously been identified by you) were to your likelihood of being willing to receive support about your relative's behaviour via telehealth.

This round asks you to select the five advantages (from those that had reached consensus in previous rounds as being influential or highly influential) which you feel would be the most influential to your own likelihood of being willing to receive support about your relative's behaviour via telehealth. It also asks you to suggest some possible solutions to the disadvantages / barriers that reached consensus in previous rounds as being influential or highly influential.

* Required

1. **Please rewrite the unique code you produced in round 1. As a reminder, the code consisted of three characters in the following order: 1) the third letter of your first name (i.e. John would be H), 2) the last digit of the year you were born (i.e. 1987 would be 7), and 3) the first letter of the month you were born (i.e. January would be J).** *

    ____

2. **Please read each of the advantages listed below and select the 5 advantages which you feel would be most influential to your likelihood of being willing to receive support about your relative's behaviour via telehealth.,** * *Check all that apply.*

    ☐ Increased ability to revisit any advice that was provided
    ☐ Ability for support to be provided more quickly as issues arise
    ☐ Ability to arrange appointments more easily
    ☐ Reduced disruption to your relative's routine
    ☐ Less time wasted due to attending lengthy or ill-informed meetings
    ☐ Quicker response times
    ☐ No need to attend appointments to deal with admin
    ☐ Increased ability to plan ahead, e.g. preparing an email or document to be sent in advance

3. **Of the 5 advantages you selected above, which are the TWO most influential to your likelihood of being willing to use telehealth?** *

For each of the groups of disadvantages / barriers listed in this section, please think about whether there are any potential solutions or ways that these barriers could be overcome in order to improve your likelihood of being willing to receive support about your relative's behaviour via telehealth. Please suggest as many solutions as you can for each group of disadvantages / barriers.

4. **Disadvantages / barriers: (1) Additional work for families who are already tired; (2) The potential that support provided via telehealth might mean you have to oversee and manage this more than support provided in person** *

5. **Disadvantages / barriers: (1) The possibility that professionals might provide generic or inappropriate advice when providing support via telehealth; (2) Support being less in depth or less well informed; (3) Lack of focus from professional as they may be dealing with multiple clients and might mix people up or not go into much depth** *

6. **Disadvantages / barriers: (1) Concerns about trusting whether professionals know your relative well, are complying with legislation (e.g. the Mental Capacity Act, Equality Act) and are not diagnostically overshadowing due to your relative's disability; (2) Professionals being unable to influence other people who support your relative; (3) Professionals having limited ability to effect change; (4) Professionals lacking the skills to provide support; (5) Professionals not being proactive** *

7. **Disadvantages / barriers: (1) Professionals not meeting your relative in person; (2) Professionals being unable to directly observe your relative; (3) Possibility that professionals might not get to know your relative as well; (4) Possibility that professionals might not see your relative often enough to notice changes or issues** *