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Behavioural Feeding Difficulties amongst Children with Intellectual and Developmental Disabilities: Exploring Experiences, Support, and Interventions for Families

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Thesis submitted in accordance with the requirements of the
University of Kent at Canterbury for the degree of Doctor of
Philosophy in Applied Psychology

November 2022

Word Count: 98,993

Acknowledgements

To say this has taken a village is probably the only way to truly describe the monumental effort of so many people 'behind the scenes' in getting me here. As such, there are many people that I would like to thank for the various roles they have played in my life over the past three years of the PhD (and beyond). Firstly, my PhD supervisors, Dr. Nick Gore, Dr. Ciara Padden, and Dr. Peter Baker. Nick, thank you for pushing me to improve and teaching me so much. Ciara, I wouldn’t have even thought to apply for the PhD scholarship (and other opportunities) if you hadn’t suggested it to me. You have been so inspirational to me on many different levels, and I am very grateful that you set me on this journey. Thank you for your patience and for believing in me and encouraging me. Peter B, thank you for being so willing to step in at key points and provide valuable input. It has been so comforting knowing that I could ask for your support if needed.

There are also some other key people that have inspired me and encouraged me in my journey getting here. Mrs. Hanson and Mr. Sybenga at Wootton High School in Rockville, Maryland – Mrs. Hanson, thank you for admitting me to the H&A Program and quite literally putting me on a path to falling in love with research with my Senior Independent Project. Mr. Sybenga, thank you for taking so much extra time to push me to develop my academic writing skills, these have clearly been instrumental in my academic journey.

During my time at the University of Maryland, College Park there were three key people that I would like to acknowledge. Dr. Margo Gregor, Dr. Ayelet Silberberg, and Dr. Jessie Stern. I haven’t gone down either the counselling psychology or developmental psychology route, but the skills I learned from your lectures, practical classes, and being involved in research with you have been crucial in my clinical and research journeys. Additionally, in the field of behaviour analysis there have been many people that have supported the development of my clinical skills. I would like to acknowledge Dr. Heather Jennett, Dr. Eric Messick, Dr. R. Justin Boyd, Thanos Vostanis, and Athene

Burdge who have all taken the time to train me and encourage me to stay in this profession in one way or another.

Next, I would like to thank all my participants. For the parents that have opened up to me about some very private struggles, thank you for trusting me with your stories and taking the time to speak with me. For the NHS clinicians that even during a pandemic took the time to participate, thank you for helping me understand how difficult the work you do is, and for helping me try to find ways to facilitate this work. For the families that spent three months with me, collecting data, implementing strategies, and working with me – I am humbled that anyone wanted to participate in my interviews, but I am floored that you were willing to work with me closely and collect data daily for so long. Thank you for bringing me into your mealtimes and being so open to working closely with me. I will never forget you and the little ones. I would also like to thank the families and little ones that I have worked with clinically over the years that have brought me into their lives and whom I have learned so much from.

The past three years have been difficult, and there have also been other instrumental people that have encouraged me throughout. To my Tizard Cheerleaders – thank you so much for looking out for me, keeping me going, checking in on me, and for the fun we have had together. Thanos, thank you for believing in me more than I have believed in myself at points. You have been so generous with your time, friendship, guidance, and training. Serena, thank you for taking me under your wing, making me feel like a valued friend and colleague, and for going above and beyond to advocate for me and support me. Josie and Ceridwen, I am so glad we have gone through part of the lecturing and PhD journey together and have been able to support each other through it. Special thanks to Josie for spending an entire Sunday with me, collecting data and doing IOA checks!

I would also like to thank the Directors of the Tizard Centre during my time as a PhD researcher, Professor Peter McGill and Professor Chrissie Rogers. Peter M, thank you for hiring me – I am certain I was given an opportunity that I was probably not qualified for, but which has been life-

changing for me. Chrissie, thank you for advocating for me on EDI issues and learning a lot more about visas and legal issues than you probably thought you would have to in your role as Director! Thank you for leveling the playing field. This has also been life-changing for me. And thank you to the Tizard Centre for my PhD scholarship, without which I would not have been able to do this.

Y a mi familia querida. Mami y Papi, solo ahora siento que puedo comenzar a dimensionar el sacrificio que ustedes han hecho por David y por mí. Es muy difícil estar lejos de la familia, y aún más cuando se sienten muchas barreras de por medio. No tengo palabras para expresar cuánto aprecio como me han apoyado en mis estudios, y como han respetado las épocas en las que no he tenido ni fuerzas para llamar por el peso del trabajo que he estado haciendo. Mamita, creo que nunca tendré las palabras para agradecerte el esfuerzo que hiciste conmigo de asegurarte de que hablara inglés. Eso me ha abierto más puertas de las que nos imaginamos. Papi, yo me acuerdo clarito el día en que estábamos almorzando juntos y yo le contaba cuanto quería hacer investigaciones y sacar un doctorado. Yo tenía quince años. No creo que siempre haya sido fácil para usted, pero siempre ha aceptado mis decisiones y me ha apoyado en todo lo que he decidido hacer. Y usted ha sido mi hincha más grande – ese tipo de apoyo y amor no lo sienten todos. Mami y Papi, este título será tanto mío como suyo. David, gracias por todos los videos y memes que he han hecho reír tanto. Esas risas y esos chistes me han sido un gran alivio durante esta época dura. Y gracias por tu apoyo, yo no tengo duda de la confianza que tú tienes en mí, y eso me motiva mucho también.

También tengo que agradecer a mi familia en Ecuador. Aunque haya muchos kilómetros de por medio, se siente el apoyo desde lejos. En particular necesito reconocer a mi abuelita, Mamá Georgina, que por estar lejos intentando avanzar profesionalmente, no he podido visitarle en demasiado tiempo, y a quien siempre estaré agradecida por sacrificarse por mi Mami y abrirnos las puertas a las dos de una manera que estoy segura que nunca se imaginó. Le debo absolutamente todo a usted.

And finally, my family in the UK – my partner and our pets. Millie y Phoebe, mis compañeritas fieles, pacientes, y cariñosas. Ha sido un privilegio tenerlas en nuestra vida y sin la compañía de las dos, creo que este camino se habría sentido mucho más solitario para mí. Millie, te extrañamos bastante. Espero que estes descansando en paz. And my partner, Steve. Every single day I feel grateful for our serendipitous encounter over seven years ago and feel so lucky to have a supportive and understanding partner. Not everyone has somebody that puts themselves second for so long to support their partner in achieving their goals. Thank you for quite literally keeping me alive, cooking for us, keeping the house in a presentable state, getting me out of the house, getting me to the gym, having fun with me, listening to me talk about my research, keeping me going, motivating me, cheering me on, celebrating all the milestones and achievements along the way with me, reading my thesis (!), and everything else in between. Thank you for supporting me to have the space I needed to complete this PhD and thesis. Thank you for encouraging me to shine and putting the spotlight on me. You are an exemplary partner, and you are the reason we have gotten through this chapter in our lives. I am so excited to see what adventures life has in store for us next, and I can't wait to continue growing with you and having fun with you for the rest of our lives.

Para la próxima generación de mujeres latinas que seguirán este camino - completar un doctorado es quizás lo más difícil que he hecho en mi vida, y se siente aún más difícil cuando parece que no hay muchas personas como nosotras en estas posiciones y que no pertenecemos aquí. Ojalá que mi esfuerzo sirva como inspiración y ejemplo de que, sí se puede, y nosotras también pertenecemos en estos espacios. Mi puerta siempre estará abierta.

Contextualising this Thesis

Thank you for taking the time to reading my work. I completed my PhD research and this thesis as a full-time international PhD researcher from September 2019 to September 2022, and part-time from September 2022 to October 2022. In that time, I undertook a number of additional projects and work that supported my development as a lecturer, researcher and clinician. This was all carried out in the context of the ongoing COVID-19 pandemic and ongoing physical and mental health challenges. It has been a challenging time and I hope this provides some context for all I have accomplished in this time, in addition to my PhD research and thesis.

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- Associate Fellowship Scheme, September 2021-July 2022

Conference Presentations

- International Pediatric Feeding Disorders Conference, April 2022 – Virtual Lightening Talk: Families' experiences of pediatric feeding disorder in their children with intellectual and developmental disabilities in England. Attended by 595 people.

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Abstract

Introduction

Behavioural feeding difficulties amongst children with intellectual and developmental disabilities (IDD) are common and there are often many impacts that children exhibiting these, and their families experience when a child exhibits a behavioural feeding difficulty. Children with IDD have many risk factors that makes it more likely for them to develop and continue to exhibit behavioural feeding difficulties, including the complexities that come alongside having an IDD itself. The theoretical literature on behavioural feeding difficulties is complex and often overlaps, resulting in lack of clarity in a theory that clearly encapsulates all the relevant factors to consider and target in an intervention for behavioural feeding difficulties amongst children with IDD. This thesis seeks to explore the experiences of behavioural feeding difficulties, related supports and interventions for families.

Methodology

Parents of children with IDD exhibiting behavioural feeding difficulties were interviewed to understand their lived experience of their child's behavioural feeding difficulty and any related supports they had received (Chapter Two). The existing qualitative literature was also explored, and family experiences of their child's behavioural feeding difficulties were reviewed and data re-analysed using meta-ethnographic methods, resulting in a meta-synthesis of the qualitative research on this topic (Chapter Three). Following this, National Health Service (NHS) Clinicians were interviewed about their experiences of supporting children with IDD exhibiting behavioural feeding difficulties (Chapter Four). The data from these chapters (Chapter Two, Chapter Three, and Chapter Four) provided important information related to stakeholder perspectives of behavioural feeding difficulties and the support that are available for these. This information, along with the wider literature was explored and synthesised into a logic model for an intervention approach for behavioural feeding difficulties amongst children with IDD (Chapter Five). Finally, this logic model,

informed by stakeholder perspectives and the wider literature, was used to inform the development of an intervention for behavioural feeding difficulties in this population, and a final empirical study (Chapter Six) used single-case design methodology to test the effectiveness of this intervention approach (i.e., were changes in the dependent variables – food refusal, other challenging mealtime behaviours – seen when the independent variable – the intervention – was implemented?).

Results

Twenty-two parents of children with IDD exhibiting behavioural feeding difficulties were interviewed in Chapter Two. Parents reported a wide range of impacts experienced to their children, themselves, their wider family, and the results yielded a grounded theory of the impact of behavioural feeding difficulties on families and the role of understanding. It was clear that understanding was very powerful for families, and this was reported to mitigate some of the impacts parents experienced. Families also reported experiencing significant difficulties obtaining appropriate supports for their child in England. Chapter Three reviewed 16 studies and found that the experience of families and their reported difficulties were largely congruent experiences, including difficulties related to receiving support for their child's behavioural feeding difficulty.

Ten clinicians supporting children with behavioural feeding difficulties and IDD in NHS Trusts in England were also interviewed (Chapter Four). Participants described three key factors to delivering effective support or intervention for this population, and barriers or challenges that they encountered when delivering this support. There was an interesting juxtaposition whereby clinicians reported the critical role of parents but appeared to describe the nature of family work as a challenge. Clinicians also reported multiple systemic barriers related to the NHS system that made it challenging for them to support this population.

An intervention was developed, guided by the logic model developed (Chapter Five), which had several main components: carrying out a functional assessment, undergoing a formulation process, parent training, intervention development, and parent coaching. The intervention was a contextual, values-based approach to behavioural feeding difficulties that was influenced by many factors (described in Chapter Five) like a guiding values-base, collaborative working, and a behavioural approach, among others. Two families participated in this study (Chapter Six) and a multiple-baseline design showed that there were no changes in the children's behavioural feeding difficulties. Interestingly, parents appeared to describe having experienced changes in their mealtimes from pre- to post-intervention, and described reappraising the goals of the intervention itself, describing how it would have been more meaningful to target creating a positive mealtime environment. Social validity was mixed, with the intervention and outcomes being acceptable and appropriate, and the suggestion was that the goal of the intervention could have been enhanced by focusing less on decreasing food refusal and increasing food acceptance and focusing more on creating a positive mealtime environment.

Discussion

It is clear from this thesis that parents experience significant impacts when their children exhibit behavioural feeding difficulties. It is important for families to feel validated in their feeding struggle and have access to appropriate and relevant support, as difficulties with feeding are challenging for parents to manage on their own, despite their abilities to adapt to their child's feeding situation. This support may consider supporting families with understanding why their child is exhibiting a behavioural feeding difficulty as this may result in families feeling a reduced impact from the behavioural feeding difficulty. It may also be important for families to understand why it is happening as this may support families with accepting their children and finding new ways to support them with feeding. Clearly, there are some difficulties with providing support for behavioural feeding difficulties in the NHS in England (e.g., lack of commissioning, no specific service for these feeding difficulties, lack of clarity around service provision), which means families in England may be likely to struggle receiving support in this area. Clinicians sometimes experience a conflicting juxtaposition whereby families are vital in supporting their children with behavioural feeding difficulties and clinicians may find families challenging to work with for a variety of reasons. Existing interventions for behavioural feeding difficulties have centred around the use of aversive procedures like extinction and punishment, and these are not likely to be appropriate for the UK context as there is some criticism of behaviour analysis in the UK (e.g., Milton & Moon, 2012; Milton, 2014; Milton, 2018). As such, a contextual and values-based intervention was implemented with two families, and it found that there was no change produced in the children's behavioural feeding difficulties related to increasing the number of bites taken and reducing the instances of food refusal. Despite this, parents reported the value of going through this intervention process and shifting their goals to creating a positive mealtime environment appeared to be significant for families. While the effectiveness of this intervention approach that was guided by an initial logic model has yet to be determined and requires further refinement and evaluation, this thesis has merged the perspectives of parents and clinicians and incorporated a literature review to come together to provide a research-informed initial model to guide the development of this intervention work going forwards.

A Note on Terminology

This PhD is concerned with exploring *behavioural feeding difficulties* amongst *children* with *intellectual and developmental disabilities*, the experiences, related support, and interventions for families.

Behavioural feeding difficulties

In this thesis, behavioural feeding difficulties have been conceptualised topographically as the presence of food refusal, selective eating, or challenging mealtime behaviours that are not solely medical or physiological in nature (i.e., dysphagia, allergies, malformations, etc.). An example of food refusal would be a child persistently turning their head away when presented with food or batting cutlery away. An example of selective eating would be a child only accepting/eating a small range of foods (based on colour, texture, brand, food group, etc.). An example of other challenging mealtime behaviour would be crying, screaming, hitting, pushing food to the ground, etc. during mealtimes, where the behaviour persistently affects the child's consumption of food. This list is not exhaustive.

Children

According to the Children's Act (2004), a child is anyone who has not yet reached their 18th birthday.

Intellectual and Developmental Disabilities

Throughout this thesis, the term intellectual and developmental disabilities is used broadly and includes autism, genetic syndromes where cognitive, intellectual or developmental delays are present, and general cognitive, intellectual or developmental delays. Children with developmental disabilities of a physical nature (i.e., cerebral palsy, cystic fibrosis, etc.) where no other intellectual or developmental disability was present (as previously defined) would not have been considered to have an intellectual or developmental disability.

Autism

In this thesis, where autistic children are specifically referred to, identity-first language will be used throughout in preference over person-first language (i.e., autistic child rather than child with autism), as it is typically considered that autistic people prefer identity-first language (Kenny et al., 2016).

Abbreviations

Summary list of abbreviations used throughout this thesis in alphabetical order.

Abbreviation	Term
ABA	Applied behaviour analysis
ABC	Antecedent behaviour consequence
ACT	Acceptance and commitment therapy
ARFID	Avoidant and restrictive food intake disorder
ASD	Autism Spectrum Disorder
ADHD	Attention Deficit/Hyperactivity Disorder
BCBA	Board Certified Behavior Analyst
BPFAS	Behavioural Paediatrics Feeding Assessment Scale
BST	Behavioural skills training
CAMHS	Children and adolescent mental health service
CBT	Cognitive behavioural therapy
DRA	Differential reinforcement of alternative behaviour
DSM-IV	Diagnostics and Statistics Manual, 4th edition
DSM-V	Diagnostics and Statistics Manual, 5th edition
EE	Escape extinction
FAI	Functional Assessment Interview
FD	Feeding difficulty
GERD	Gastroesophageal reflux disease
GP	General practitioner
ICD-11	International Classification of Diseases, 11th revision
IDD	Intellectual and developmental disabilities
IOA	Inter-observer agreement

Abbreviation	Term
IRAS	Integrated Research Application System
JBI	Joanna Briggs Institute
LD CAMHS	Learning disability – Children and adolescent mental health service
MBD	Multiple baseline design
NHS	National Health Service
OT	Occupational therapist
PBS	Positive behaviour support
PFD	Paediatric feeding disorder
SaLT	Speech and language therapist
SENCO	Special education needs coordinator
SOS	Sequential oral sensory
UK	United Kingdom
US	United States

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Chapter One Introduction to Behavioural Feeding Difficulties amongst Children with Intellectual and Developmental Disabilities

An Overview of Behavioural Feeding Difficulties

Feeding is highly important to development as it results in appropriate growth in various areas, including weight and height (Kerwin, 1999), yet some of the most common behavioural difficulties that children exhibit are feeding related (Berlin et al., 2009). Feeding is a highly integrated set of skills which requires the use of multiple systems (i.e., chewing, swallowing, interactions with family members, etc.), and difficulties may arise when one or more of the systems that contribute to feeding are dysfunctional (Rommel et al., 2003). The feeding process in typically developing individuals involves multiple successive steps: food being presented; food delivered to the mouth or brought to the lips through self-feeding or through being fed by others; food entering the mouth or acceptance of food into the mouth; if textured, the food is chewed; the tongue gathers the food, forming a bolus; finally, the food is propelled towards the back of the mouth, which results in the initiation of the involuntary swallowing reflex; and keeping the swallowed bolus or liquid down (Gulotta, Piazza, Patel, Layer, 2005; Kerwin, 1999; Milnes & Piazza, 2013). Difficulties with feeding can also occur during any of these stages, indicating how easy it can be for progress with feeding to go awry.

Most children develop feeding skills without the need for additional professional support, and while there is a developmental timeline or trajectory for the development of feeding skills, there are natural fluctuations which occur on an individual basis (Rappaport, 2015). In children there is also often a normal resistance to eating when new foods are introduced (i.e., food neophobia; Benjasuwantep et al., 2013). Food neophobia has been described as an avoidance of or unwillingness to try foods which are new or unfamiliar (Folta et al., 2020). This kind of ‘picky eating’ is a common developmental phenomenon (Williams et al., 2015). Usually, feeding difficulties exhibited by typically developing children do not need intervention or are easy to treat because they are often mild (Kerwin, 1999).

Diagnoses and Terminology

One of the long-standing, recognised difficulties in the field of feeding difficulties is that the classification of childhood feeding disorders is problematic (Burklow et al., 1998; Kedesdy & Budd, 1998; Williams, 2015). Currently, formal diagnostic terms for feeding difficulties are used, as well as topographical descriptions of these.

The previous Diagnostics and Statistics Manual 4th edition (DSM-IV; American Psychiatric Association, 2000) referred to the clinical diagnosis of feeding disorder of infancy and early childhood. Currently, the Diagnostics and Statistics Manual 5th edition (DSM-V; American Psychiatric Association, 2013) refers to the clinical diagnosis of avoidant and restrictive food intake disorder (ARFID). With the DSM-IV, the classification of feeding disorder of infancy and early childhood required children to be underweight to receive the diagnosis, which excluded many children with feeding difficulties if they were reliant on feeding tubes or supplements (Williams et al., 2015). The difficulty this posed was that children that exhibited feeding difficulties that were so limited they required feeding tubes or food supplements would not be underweight, due to these adaptations to support their eating, but they were unable to be diagnosed as they were missing a critical diagnostic component.

The introduction of ARFID as a new classification system was intended to capture individuals who do not consume appropriate varieties or quantities of food (Williams et al., 2015). As a result, receiving a diagnosis for ARFID requires individuals to meet one of the following: significant weight loss, failing to achieve expected weight gain, or faltering growth in children; significant deficits in nutrition; a dependence on oral nutritional supplements or enteral feeding; and significant interference with psychosocial functioning (Williams et al., 2015). The exclusionary criteria for ARFID are: the feeding issue is not explained better by cultural feeding practices or lack of food available to the individual; no evidence of bulimia or anorexia; and there is no concurrent medical issue that the feeding issue can be attributed to or mental disorder that better explains the feeding difficulty (Williams et al., 2015).

Some researchers have criticised these methods of diagnosing feeding difficulties by claiming that they do not consider the complexities involved with feeding difficulties, as they claim there are multiple mechanisms underlying feeding that need to be considered in a multidisciplinary context (Goday et al., 2019). Recently, this group of researchers proposed a consensus definition for paediatric feeding disorders (PFDs) using the World Health Organisation's International Classification of Functioning, Disability, and Health. They proposed the diagnostic term of PFD, defined as:

> "Impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction" (p. 124).

Another way to describe behavioural feeding difficulties is topographically, including topographies like food refusal, selective eating, disruptive behaviours at mealtimes which are incompatible with eating, rigid preferences of food, and failure to acquire self-feeding skills in accordance with developmental milestones (Davies et al., 2006; Lukens & Silverman, 2014). This is not a recognised diagnostic category, rather a topographical way of describing the behaviours a child with a feeding difficulty is exhibiting. This term (behavioural feeding difficulties) has been used previously in the literature (e.g., Goh & Jacob, 2012; Kerzner, 2009; Muldoon et al., 2021).

While this topographical approach has been used previously, these descriptions of topographies of behaviours can sometimes vary and overlap, and sometimes it is not clear what manifestations have been included in definitions. For example, food refusal has been described as batting the spoon away, crying, physically turning the head away, expelling food, gagging, throwing, screaming, vomiting, hitting, spitting out food, pushing away food, engaging in excessive talking, throwing tantrums, and negotiating (Kerwin, 1999; Patel, 2013; Piazza & Roane, 2009; Williams et al., 2010). Challenging mealtime behaviours are often described similarly to food refusal. These have been described as turning the head away from food or batting at the spoon (Sharp et al., 2010).

Similarly, food refusal has sometimes been described as including severe demonstrations of selective eating or refusing to eat particular food textures (Douglas, 2002), however selective eating and food refusal are two different forms of behavioural feeding difficulties. Selective eating involves accepting a limited number of specific foods, which can be related to texture, food preferences, brands, type of food, or specific food groups (Chung & Kahng, 2006; Field et al., 2003; Silbaugh & Swinnea, 2019). Selective eating can also include the refusal to eat developmentally appropriate food textures and is primarily differentiated from food refusal due to the consistent eating of a limited number or amount of food (Field et al., 2003).

One of the challenges with this topographical approach is that it can be difficult to compare studies since there are no clear definitions for specific feeding difficulties (Chatoor, 2009), as they include various topographies. Furthermore, certain feeding difficulties like selective eating have been defined inconsistently across countries and cultures (Lee et al., 2019), further compounding the difficulty with synthesising and interpreting findings. While this topographical approach to defining behavioural feeding difficulties poses some difficulties, in this thesis the terminology of behavioural feeding difficulties was used (defined previously in A Note on Terminology) to reflect a broad *topographical* conceptualisation which included food refusal, selective eating or challenging mealtime behaviours. It was considered that this was the most appropriate approach for this thesis as the diagnosis of PFD (e.g., Goday et al., 2019) was a very recent formal diagnosis at the start of this PhD. While the term PFD had been used previous to the official diagnosis of PFD, it was not considered to be appropriate to use this term after a diagnosis of PFD was formalised which had specific requirements that would likely be outside of the researcher’s abilities to assess (i.e., assessing issues with nutritional intake). It was also considered that this terminology would pose difficulties as the diagnosis was very new at the start of this thesis and it was unlikely that many people in the UK would be assigned this diagnosis as of yet, which would pose difficulties with recruitment. Additionally, the researcher was not able to use the term ARFID as this is a very new diagnosis in the UK, and it would have been extremely limiting to use this term to guide the inclusion of participants and the focus of the work. It was also not possible for the researcher to assess for ARFID as this was also outside of the researcher's abilities (i.e., the researcher was not a clinical psychologist). Finally, it was considered that there were likely to be many overlaps between PFD, ARFID and behavioural feeding difficulties, and that using a topographical approach to identifying these would be a pragmatic approach in an area of diagnoses that was rapidly evolving (i.e., ARFID, PFD).

Typically Developing Populations and Behavioural Feeding Difficulties

A detailed discussion about prevalence of behavioural feeding difficulties in intellectual and developmental disability (IDD) populations and typically developing populations will be explored later (Prevalence of Behavioural Feeding Difficulties in IDD section), however it is important to note that in the United States (US), concerns about the feeding of preschool aged children are one of the most common behavioural difficulties mentioned to primary health care professionals by parents (Davies et al., 2006).

Research on behavioural feeding difficulties amongst typically developing children has shown that these children can experience growth faltering affecting their natural growth trajectory and their selective eating could continue to be a persistent difficulty in childhood (Goh & Jacob, 2012; Lee et al., 2019). Additionally, family quality of life can be significantly impacted, the children may be fed less frequently, they may be less likely to be fed at the family table or at their own table, and mealtimes may last longer than 30 minutes (Benjasuwantep et al., 2013; Goh & Jacob, 2012). Parents of typically developing infants with feeding difficulties have reported feeling like their child's feeding situation occupied a great deal of their time, they experienced more negative feelings, felt more socially isolated, and felt more negative effects on their relationship with their spouses than parents of infants without feeding difficulties (Hagekull & Dahl, 1987). Additionally, in families with infants with feeding difficulties, the feeding difficulty appeared to influence the well-being of the primary caretaker, and mothers felt they had been impacted psychosomatically and emotionally

(Hagekull & Dahl, 1987). The control families in this study (parents of infants without feeding difficulties) allowed for a comparison, which illustrated that infant feeding difficulties had a clear relation to increased parent stress experiences.

Generally, behavioural feeding difficulties in typically developing toddlers and early pre-school children have been found to be most prevalent in a child's second year of life, and then gradually decrease during their third and fourth years (Benjasuwantep et al., 2013). Interestingly, Cano et al. (2015) examined typically developing children and the selective eating that they exhibited and found that only 4% showed persistent selective eating. Four percent of the children started exhibiting selective eating at or after six years old, and 32% showed a decreasing pattern of selective eating as they got older. Fifty-five percent of the typically developing children never exhibited selective eating patterns. Altogether, the literature shows that for typically developing children, behavioural feeding difficulties may be less likely to persist into older childhood and past this and may diminish as the children get older. Alongside this, typically developing children may require less support, as it appears that behavioural feeding difficulties may decrease in prevalence as they get older.

Individuals with Intellectual and Developmental Disabilities and Behavioural Feeding Difficulties

Intellectual and Developmental Disabilities

The term intellectual and developmental disabilities (IDD) is often used to describe autism, intellectual disability, and other developmental disabilities. Intellectual disability has been described in various ways. The DSM-V describes a diagnosis of intellectual disability as encompassing individuals who exhibit three criteria: deficits in intellectual functioning (e.g., solving problems, reasoning, planning, etc.), deficits in adaptive functioning (e.g., communication, etc.), and having had these difficulties since childhood (American Psychiatric Association, 2013).

In the United Kingdom (UK), intellectual disability is defined by the Department of Health as a:

> "Significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood" (pg. 14-15).

According to the DSM-V, autism is a pervasive developmental disorder (American Psychiatric Association, 2013). Autistic individuals often exhibit difficulties related to social imagination, social interaction, and social communication (Wing & Gould, 1978). While it is recognised that autism and intellectual disability are different, there are many areas where there are similarities in the difficulties exhibited by both (e.g., difficulties with social communication; Thurm et al., 2019). As mentioned previously (A Note on Terminology section), the terminology used in this thesis will be IDD and will encapsulate intellectual disability, autism, and other developmental disabilities. When research related to autism is described, participants will be described as autistic, as the use of identify first language has been described as being the preferred terminology by autistic individuals themselves (Kenny et al., 2016).

Children and young people with IDD often exhibit challenging behaviours or are at an increased risk of developing challenging behaviours (Hastings et al., 2013; Nicholls et al., 2020). Challenging behaviours are those which are culturally abnormal, and of an intensity, frequency, or duration that the physical safety of the individual or others is at risk, or which will limit the individual from accessing community facilities (Emerson et al., 2001). Emerson et al. (2001) carried out a total population study in two areas of England and concluded that 10-15% of people with an intellectual disability exhibited challenging behaviours. Challenging behaviour has also been associated with the presence of an autism diagnosis in children with intellectual disabilities in school settings (Nicholls et al., 2020). When people with IDD exhibit challenging behaviours, they can be at risk of experiencing social exclusion and at risk of not having opportunities to integrate with others and build relationships (Emerson et al., 2001).

A significant amount of people with IDD also experience communication difficulties (Wood & Standen, 2021). Communication difficulties can result in physical and mental health difficulties, increase the risk of social isolation, and have poor outcomes related to employment in this population (Emerson & Baines, 2011; Law et al., 2009; Smith et al., 2020). Bowring et al. (2017) highlight how communication difficulties have been linked to a higher risk of challenging behaviour in people with intellectual disabilities.

Having a child with an IDD also has implications for families. Families of children with IDD play an integral role in supporting their family members with IDD (Hewitt et al., 2013; Lee & Burke, 2020). Families of people with IDD are also known to be at a high risk of experiencing emotional difficulties and stress (Hastings, 2016).

Further to challenging behaviour and related needs, the presence of an IDD also brings a range of additional complexities that span health needs (physical and mental), school related needs, and increased vulnerability (Chambers et al., 2004; Collins & Staples, 2017; Einfeld et al., 2011; Fisher et al., 2012; Wei et al., 2015). Children with IDD are at an increased risk for obesity than their typically developing peers (Collins & Staples, 2017), and this may also extend to other health needs. Healthcare for people with IDD can be lacking in coordination and difficult to access (Ervin et al., 2014), and people with IDD tend to die younger and have a higher mortality rate than typically developing people (Lauer & McCallion, 2015). In terms of mental health, the prevalence of difficulties in this area in the IDD population is high, ranging from 30 to 62% (Dekker et al., 2002; Einfeld et al., 2011; Emerson, 2003). The presence of an IDD also increases the risk of having other psychopathologies by 2.8-4.5% (Einfeld et al., 2011). The higher levels of mental health difficulties in this population means that there is a need for more complex services for these (Lapshina & Stewart, 2019).

In school, children with IDD may also experience additional difficulties like struggling with academic skills (Wei et al., 2015), as they may have difficulties with executive functioning skills (e.g., organisation, planning, memory, etc.) and language which can impact their academic performance (Ozonoff & Schetter, 2007). Young adults with IDD may also experience more challenging transitions out of school than typically developing young adults (Bianco et al., 2009; Chambers et al., 2004). Importantly, people with IDD are also some of the most vulnerable to being excluded from society (e.g., experiencing poverty, health problems; Emerson, 2007). They are also more likely to experience social victimisation (e.g., theft, teasing abuse; Fisher et al., 2012). Clearly, individuals with IDD experience increased complexity in their lives, and this extends to feeding as well.

Behavioural Feeding Difficulties and IDD

Behavioural feeding difficulties in the IDD population have been the focus of much of the literature in this area. Behavioural feeding difficulties in this population have been described in different ways (as with the typically developing population; e.g., Ledford & Gast, 2006; Munk & Repp, 1994; Silbaugh & Swinnea, 2019; Sisson & Van Helt, 1989), however topographical definitions of behavioural feeding difficulties in the form of food refusal, selective eating, and challenging mealtime behaviours are also common (e.g., Bandini et al., 2019; Chen et al., 2022; Ulloa et al., 2020).

In applied behaviour analytic (ABA) research, operational definitions are used to describe the phenomena or behaviour which is being measured or observed. Often, behaviours which are measured or observed are used as outcome measures, or dependent variables, which illustrate the effectiveness or lack thereof of an implemented intervention (e.g., Alaimo et al., 2018; Haney et al., 2021; Rubio et al., 2015). In the existing intervention research surrounding behavioural feeding difficulties, the behaviours are measured and graphed, pre- and during intervention to illustrate whether a change in the dependent variable, behavioural feeding difficulty, has occurred as a result of the implemented intervention, or independent variable. Precise operational definitions are essential when researching interventions for behavioural feeding difficulties because they ensure all researchers or observers are looking at, measuring, and collecting data on the same behaviour or response class (Cooper et al., 2020). The use of varied definitions poses significant difficulties when drawing comparisons across studies and trying to establish prevalence of behavioural feeding difficulties in the IDD population.

Prevalence of Behavioural Feeding Difficulties in IDD

Prevalence statistics for behavioural feeding difficulties amongst children with IDD and typically developing children are vastly inconsistent. Behavioural feeding difficulties are very heterogenous, which contributes to the difficulty in estimating their prevalence (Piazza & Roane, 2009). Since feeding difficulties can present in a variety of ways or topographies across populations and individuals, this can present challenges when attempting to establish an accurate prevalence statistic. This is further compounded by the issue that exists in relation to different studies describing topographies of behavioural feeding difficulties differently or in an overlapping manner. In fact, the difficulties achieving prevalence statistics due to difficulties with diagnoses and definitions is a recognised challenge in the field (Benjasuwantep et al., 2013).

Table 1 shows a sample of studies aimed at establishing prevalence rates of behavioural feeding difficulties amongst children with IDD and typically developing children. This table illustrates how the prevalence rate can vary based on the type of IDD being explored (e.g., Field et al., 2003) and the type of behavioural feeding difficulty being assessed (e.g., Bandini et al., 2010; Ledford & Gast, 2006; Leiva-García et al., 2019). It is also clear that there are varying methodologies that are likely to influence the prevalence estimates yielded by studies (e.g., studies using parent report data, Bandini et al., 2010; Carruth et al., 2004; Reau et al., 1996; studies using direct observations, Esparo et al. 2004; Jacobi et al., 2003; Leiva-García et al., 2019; and record reviews, Field et al., 2003). For example, studies that establish and report prevalence based on parent reports or record reviews are likely to be reporting parent or clinician perceptions of a child's behavioural feeding difficulty, and could be considered more subjective, while studies that conduct direct observations are likely to be reporting prevalence rates that may be more objective. Many of these issues are also present in studies exploring and reporting prevalence amongst typically developing populations, excluding the variation in the type of IDD being explored. This leads to the conclusion that although estimates exist, the actual prevalence rates for behavioural feeding difficulties as a whole in individuals with IDD is presently unknown. Perhaps more significant is the lack of prevalence figures available for this population within the context of the UK.

Table 1

Sample Prevalence Data for Typically Developing and IDD Populations.

Study	**Sample size**	**Age**	**Definitions**	**IDD/No IDD**	**Methodology**	**Reported prevalence**
Ahearn et al. (2001)	*N* = 30	3.75 – 14.17 years	Food selectivity by type or texture, low to moderate food acceptance	IDD (ASD)	Direct observation	57% of children exhibited food selectivity by type or texture 87% of children exhibited low to moderate food acceptance
Bandini et al. (2010)	*N* = 53 (ASD) *N* = 58 (TD)	3 – 11 years	Food selectivity (FR, high-frequency single food intake, limited food repertoire)	Both (TD, ASD)	Parent report & food records	41.7% of autistic children exhibited FR, and 18.9% of TD children, indicating a statistically significant difference
Esparo et al. (2004)	*N* = 851	3 – 6 years	FR, extremely rigid eating habits	TD	Parent report	4.8%

Study	**Sample size**	**Age**	**Definitions**	**IDD/No IDD**	**Methodology**	**Reported prevalence**
Field et al. (2003)	*N* = 349	1 month – 12 years	Selectivity by type, selectivity by texture, FR	IDD (DD, CP, ASD, DS)	Record review	62% of autistic children showed selectivity by type 45% of children with DS showed selectivity by texture 30% of children with CP showed FR Total reported prevalence of 81.38% amongst the study sample
Hubbard et al. (2015)	*N* = 53 (ASD) *N* = 58 (TD)	3 – 11 years	FR based on texture/ consistency, taste/smell, mixtures, brand, shape, temperature, food touching other food, colour	Both (TD, ASD)	Parent report	FR texture/consistency – 77.4% ASD; 36.2% TD FR taste/smell – 49.1% ASD; 5.2% TD FR mixtures – 45.3% ASD; 25.9% TD FR brand – 15.1% ASD; 1.7% TD FR shape – 11.3% ASD; 1.7% TD Similar prevalence of FR temperature, foods touching other foods, or colour for both groups

Study	**Sample size**	**Age**	**Definitions**	**IDD/No IDD**	**Methodology**	**Reported prevalence**
Jacobi et al. (2003)	*N* = 135	3.5 – 5.5 years	Selective eating	TD	Direct observation and parent report	21%
Leford & Gast (2006)	*N* = 381	3 – 16 years	Food selectivity by type or texture, FR, low to moderate food acceptance	IDD (ASD)	Review of quantitative descriptive studies	46-89% (depending on definition of behavioural feeding difficulty)
Leiva-García et al. (2019)	*N* = 55 (ASD) *N* = 91 (TD)	10.7 (mean)	FR, selective eating, challenging mealtime behaviours, hyperselectivity	Both (TD, ASD)	Cross-sectional, case-control observational study	60.6% prevalence of hyperselectivity in the autistic group, and 37.9% in the TD group, indicating a statistically significant difference

Study	**Sample size**	**Age**	**Definitions**	**IDD/No IDD**	**Methodology**	**Reported prevalence**
Szdravou et al. (2021)	*N* = 742	2 – 7 years	Undesirable mealtime behaviours	TD	Parent report	8.2% of the sample had a high total frequency score 26.6% of the sample had a high total problem score

Note. FR = ASD = Autism spectrum disorder. Food refusal. IDD = Intellectual and developmental disabilities.

Risk Factors for Behavioural Feeding Difficulties in IDD

The existing literature reports some risk factors which can increase the likelihood that a child with IDD will develop or continue to exhibit a behavioural feeding difficulty. These risk factors pertain primarily to characteristics associated with IDD, social inequalities, and birth-related factors.

Characteristics Associated with IDD

Some risk factors that contribute to why feeding difficulties develop or continue to happen are related to characteristics associated with IDDs. These can include medical issues or illnesses, intellectual disability, developmental delays or disabilities, physical disabilities, anatomical abnormalities, neurological problems, cardiopulmonary problems, gastrointestinal problems, and renal disease (Field et al., 2003; Kerwin, 1999).

In their review, Sharp et al. (2010) found that 61.5% of children with severe feeding difficulties also had multiple medical concerns, indicating a high level of comorbidity between severe feeding difficulties and complex medical situations. The presence of complex medical concerns can in some cases be considered a risk factor for behavioural feeding difficulties and depending on the nature of the medical concern (i.e., need for supplementary tube feedings, etc.), these can directly contribute to the development of behavioural feeding difficulties.

Children who have physical disabilities, medical problems, chronic illnesses, intellectual disability, and developmental delays are also at risk for severe behavioural feeding difficulties (Kerwin, 1999). Field et al. (2003) reviewed records of child participants referred to an interdisciplinary feeding programme for the evaluation of a feeding difficulty and found that 64% of the children referred had developmental disabilities, demonstrating children from this population had an increased risk of developing a feeding difficulty. Of the five feeding difficulties they explored, three were of a behavioural nature (e.g., food refusal, selective eating by type, and selective eating by texture), and some feeding difficulties were more strongly associated with some developmental disabilities than others. Autistic children were most likely to exhibit selectivity by type, while children with Down Syndrome and children with cerebral palsy were most likely to exhibit oral-motor delays. These findings indicate that although children with developmental disabilities are at an increased risk to develop a feeding difficulty, whether that feeding difficulty is a of a behavioural nature may also be related to the specific developmental disability present. Rezaie et al. (2011) also found that the level of intellectual disability may influence the severity of behavioural feeding difficulties. They found that the severity of the presenting behavioural feeding difficulty was greater for the children that had severe intellectual disability, as compared to the children in their study that had mild and moderate levels of intellectual disability.

Gastroesophageal reflux disease (GERD) is a medical issue that commonly occurs in people with intellectual disability (Bohmer et al., 2001). Rommel et al. (2003) found that GERD was identified as the underlying medical condition of participants with feeding difficulties most frequently, which appears to be a logical connection as individuals with feeding difficulties often exhibit gastrointestinal tract disorders since this is the primary system involved in digestion. Gastroesophageal reflux can also exacerbate feeding difficulties and interfere with interventions targeting the reduction of feeding difficulties (Field et al., 2003). Thus, GERD may be a risk factor for the development of behavioural feeding difficulties.

Health and Social Inequalities

People with IDD experience health inequalities compared to typically developing people (e.g., higher rates of poor health) and this includes children with intellectual disabilities (Allerton et al., 2011; Iacono & Bigby, 2016). In the UK, high rates of health inequality have been found in relation to the provision of good quality care for co-morbid conditions related to IDD (Emerson et al., 2011). This has shown that people with IDD may receive lower quality healthcare, which can result in adverse health in this population. This can act as a risk factor for behavioural feeding difficulties as it is possible that children with IDD who experience difficulties with feeding (i.e., dysphagia, tongue-tie, GERD) may be less likely to receive good quality care. These conditions can make feeding uncomfortable, and children can learn to associate feeding with pain or discomfort and engage in behaviours to reduce how often or how much they have to eat (i.e., behavioural feeding difficulties), due to the pain or discomfort they experience while eating. Diagnostic overshadowing, or the failure to diagnose a psychosocial or health issue due to a pre-existing diagnosis of IDD (Fisher, 2004; Jones et al., 2008) is also a concern as it is a common problem in the field of IDD (Robinson et al., 2012). If a behavioural feeding difficulty is already present, children with IDD may experience diagnostic overshadowing, whereby the presenting feeding difficulty is not considered to be an issue, rather this is attributed to the child's IDD. This means that the child exhibiting an IDD would not receive support for their behavioural feeding difficulty and may be more likely to continue exhibiting this.

In addition to health inequalities, people with IDD may also be exposed to increased social inequalities than typically developing people as they are disproportionately represented amongst poorer groups and groups that are less healthy (Graham, 2005). For example, in 1999 estimates for Britain showed that 44% of children with intellectual disabilities between the ages of 5 and 15 were living in poverty, compared to 30% of other children (Emerson, 2003). Epidemiological studies have reported consistently that there appears to be a significant association between the prevalence of intellectual disability and poverty (Emerson, 2007). Social inequalities can act as risk factors, contributing to the presence or increased likelihood of behavioural feeding difficulties in children with IDD.

In the context of the UK, Emerson et al. (2009) found that children with IDD were likely to be exposed to socio-economic disadvantages on various different levels, including: parental health and social support; neighbourhood quality; hardships experienced at age three; family socio-economic hardships and material disadvantages; and household composition. These socio-economic disadvantages have the potential to impact a child's feeding process and act as risk factors for the development of behavioural feeding difficulties if one or multiple of these factors are present in a child's life.

Emerson et al. (2010) found that families with a child with intellectual disabilities were more likely to be poor or become poor, and less likely to overcome poverty. As families enter into or remain in poverty, this can result in decreased availability of food or varieties of food. This can place the children with IDD at a higher risk for developing behavioural feeding difficulties as they may come into contact with less variety of food, and some literature has illustrated a link between exposure to food and food acceptance (Kim et al., 2018). Thus, eating the same foods more consistently may put children at risk of not being able to try new foods when these are available to them. Clearly, health and social inequalities experienced by people with IDD can also act as a contextual influence on behavioural feeding difficulties, due to the additional challenges and complexities that come alongside these.

Birth Related Factors

Feeding difficulties also tend to be more common in children who were born premature (Volkert & Piazza, 2012), however prematurity is not the only risk factor related to gestational age. Rommel et al. (2003) found that amongst 700 participants in their study, behavioural feeding difficulties were significantly related to older gestational age and children with feeding difficulties had significantly lower birthweights for their respective gestational ages. These findings suggest that gestational age, birthweight, and premature birth could act as risk factors for the development of behavioural feeding difficulties. Interestingly, it is known that children that are born premature are also at an increased risk of intellectual disability than those that are carried to term (Huang et al., 2016). This could indicate a correlation between premature birth and increased risk of developing a feeding difficulty and having an intellectual disability. This could also indicate that children with intellectual disability may have been more likely to be born premature, and thus be more likely to develop behavioural feeding difficulties. The pathways of influence are unclear, however there appears to be a relationship between these three factors.

Lifetime Progression of Behavioural Feeding Difficulties in IDD

The presentation of behavioural feeding difficulties can fluctuate across development (Berlin et al., 2009). Feeding difficulties have been reported to emerge between 12-24 months of age, and are usually most common in early childhood, but these can also be present all the way through to mid-adolescence (Babbitt et al., 1994; De La Osa et al., 2015; Linscheid & Rasnake, 1985). Researchers have repeatedly reported that feeding difficulties of a severe nature usually persist or worsen over time, whereas mild feeding difficulties usually resolve themselves or can be addressed with low intensity interventions (Kerwin, 1999).

Some patterns surrounding the progression of behavioural feeding difficulties across the lifetime have been identified. As previously noted for typically developing children, these may diminish as children get older, however some researchers note that it may be more likely for autistic children to exhibit feeding difficulties that persist across time due to insistence on sameness and sensory sensitivities (Kuschner et al., 2015). Some cross-sectional studies exploring feeding difficulties in autistic children have found no relationship with age (e.g., Bandini et al., 2010; Williams et al., 2005), while others have identified that feeding difficulties exhibited by autistic children have decreased with age (Beighley et al., 2013). Some longitudinal studies exploring feeding difficulties in autistic children have also yielded similar discrepancies, either finding no changes in the level of selective eating (Suarez et al., 2014) or finding a significant reduction in food refusal and challenging mealtime behaviours, yet also finding that the children’s accepted foods remained mostly the same (Bandini et al., 2017). Interestingly, Peverill et al. (2019) found that in their sample of autistic children, most feeding difficulties reduced over time, however in a small subgroup, the behavioural feeding difficulties persisted into school age. Therefore, it appears there is a less clear pattern related to the trajectory of behavioural feeding difficulties in autistic children across the lifespan compared to typically developing children.

Recently, Ashley et al. (2020) examined the appearance and trajectory of feeding difficulties in young children that were later diagnosed autistic. They administered the Behavioural Paediatrics Feeding Assessment Scale (BPFAS) to parents of 93 toddlers at 15, 18, 24, and 36 months of age. They found that the frequency of feeding difficulties in children that were later diagnosed autistic increased significantly more rapidly between the ages of 15-36 months. By 36 months, the children that were later diagnosed autistic exhibited a higher total frequency score on the BPFAS than all other groups. Feeding difficulties exhibited by autistic children appeared to develop significantly more rapidly in the early toddler years.

While most of the research into progression of behavioural feeding difficulties across the lifespan has been quantitative, recently, Folta et al. (2020) interviewed 20 18 to 23-year-old autistic youth about their experienced impacts of selective eating on social domains. Importantly, participants in this study described outgrowing some of their food dislikes, that their food tastes had changed, that they became more open to trying new foods as they got older, and that they would push themselves to try new food and previously disliked foods as they got older, with some describing this in the context of their growing independence. The findings from this study were consistent with previous literature that has found that selective eating diminishes over time to some extent (e.g., Bandini et al., 2017; Beighley et al., 2013), and although selective eating clearly still persisted to some degree, most participants described an expansion in the range of food they consumed, and a diminished impact of their selective eating as a result. Although these findings show promising results for the progression of behavioural feeding difficulties in autistic individuals as they become young adults, an important limitation of the study is that the inclusion criteria specified the ability to participate verbally, to be able to respond to open-ended questions, and able to read and complete questionnaires independently. As a result, these findings may not reflect the experiences of autistic individuals who do not have these skills. This may be particularly relevant in light of previous links described in relation to severity of intellectual disability and behavioural feeding difficulties.

Impacts Arising from Behavioural Feeding Difficulties

The presence of behavioural feeding difficulties in children with IDD can have a large impact on the children themselves and their caregivers or family members.

Impact on Children Exhibiting Behavioural Feeding Difficulties

The literature around behavioural feeding difficulties has described how the presence of behavioural feeding difficulties amongst children with IDD can result in crisis feeding situations, long-term health risks, nutritional deficits, and social isolation. These will be explored in this section.

Feeding difficulties can sometimes result in physical health crises. This occurs when there are significant deficits in fluid, nutrient, or caloric intake (Milnes & Piazza, 2013). Feeding difficulties can result in acute dehydration, which usually require an emergency visit to the hospital for resolution (Milnes & Piazza, 2013). Feeding difficulties can also result in a highly limited diet, difficulties chewing or drinking, and feeding tube dependency (Seiverling et al., 2020). Additional to immediate risks are long-term risks. Children displaying selective eating may not experience immediate health risks as their weight gain or growth is not problematic in the short term, but in the long-term their restricted diets, particularly if solely inclusive of unhealthy foods, may result in long-term health risks like heart disease or diabetes (Patel, 2013). Failing to consume a well-balanced diet as a result of selective eating can also result in anaemia or vitamin deficiencies in children displaying selective eating behaviours (Patel, 2013).

In a study exploring dietary intake and behavioural feeding difficulties amongst autistic children, Cornish (1998) conducted a nutrient analysis of 17 autistic participants and compared the reference nutrient intake of a child matched according to age and gender using UK Department of Health data. The findings indicated that 53% of the child participants had diets which fell short of the reference nutrient intake in one or more nutrients. These results provide support for the concern related to selective eating in autistic children resulting in nutritional deficits (Ledford & Gast, 2006).

In a cross-sectional study in India, Yousafzai et al. (2003) investigated whether children with disabilities (*n* = 141) aged two to six years had a nutritional status that was worse than non-disabled sibling controls (*n* = 122) and neighbour controls (*n* = 162). Of the children with disabilities, 39 (27.7%) were identified as having a severe feeding difficulty. A relative risk analysis found that disabled children with feeding difficulties were more likely to be malnourished when compared to disabled children without feeding difficulties. Children with disabilities as whole were found to have a higher prevalence of moderate to severe levels of malnutrition when compared to the control group. Therefore, Yousafzai et al. (2003) concluded that feeding difficulties could result in inadequate nutrition amongst children with disabilities.

Feeding is a prominent feature in a child’s social development, with many social interactions during this developmental period centred around feeding, such as school lunchrooms, restaurants, and birthday parties (Ledford & Gast, 2006). When feeding is impacted, children exhibiting behavioural feeding difficulties may be prevented or limited from participating in these social activities. In a previously described study (Folta et al., 2020), participants reported that the impact of selective eating diminished as they grew older. Although participants described that their selective eating was generally accepted by their families and peers, when they were younger, they felt judged for this, mainly from peers but also from teachers and school cafeteria staff. In relation to the impact of their selective eating on social situations, participants described some concerns about whether there would be food available that they could eat, but that these concerns rarely concerned them sufficiently to keep them from attending. Participants also described having developed coping strategies to manage their selective eating in social situations. Altogether, it is clear that for children with IDD, having a behavioural feeding difficulty can result in an impact on them, and that this can evolve over time.

Impacts on Families and Caregivers

Additional to the impact that behavioural feeding difficulties can have on children with IDD who exhibit these, behavioural feeding difficulties can also impact their caregivers and family members. Family mealtimes are valuable times when families come together, communicate, and develop shared rituals and routines (Suarez et al., 2014), yet when children exhibit behavioural feeding difficulties, these valuable family times can become compromised. Qualitative research about the impact of behavioural feeding difficulties exhibited by children with IDD on families has described how parents of children with IDD and feeding difficulties characterise their child's feeding difficulty as a journey that evolved over time (Estrem et al., 2016). Parents have also described having to adapt their mealtime routines to manage their child's feeding, going to extraordinary efforts to manage their child's feeding and that their child's feeding was extremely time consuming (Estrem et al., 2018).

Parents of typically developing children and children with IDD exhibiting behavioural feeding difficulties also report higher stress levels and more caregiver related stress (Fishbein et al., 2014; Martin et al., 2013; Silverman et al., 2021). Parents have described other impacts, like being unable to travel due to the limited flexibility of their child's feeding difficulty (Estrem et al., 2018). Clearly, behavioural feeding difficulties result in a range of impacts for both the individual exhibiting these and their families and caregivers.

Behavioural Interventions for Behavioural Feeding Difficulties

In the literature there are many interventions for behavioural feeding difficulties, and the most common of these are behavioural interventions (e.g., Ahearn, 2003; Alaimo et al., 2018; Sira & Fryling, 2012). Recently, Gosa et al. (2017) carried out a systematic review exploring interventions for feeding difficulties and found that the behavioural interventions were the most effective interventions identified for the treatment of behavioural feeding difficulties. Behavioural interventions involve the use of consequence-based strategies like reinforcement (i.e., adding or removing a stimulus following a behaviour that increases the future frequency of that behaviour; Cooper et al., 2020), punishment (i.e., adding or removing a stimulus following a behaviour that decreases the future frequency of that behaviour; Cooper et al., 2020), and extinction (i.e., withholding reinforcement for a previously reinforced behaviour which results in the decreased future frequency of that behaviour; Cooper et al., 2020). Some behavioural interventions have also used antecedent-based strategies like modeling, shaping, fading, high-preference instructional sequence, simultaneous presentation, chaining, or visual supports (Tereshko et al., 2021). For example, Anderson and McMillan (2013) trained parents to implement an intervention for their child's behavioural feeding difficulty using reinforcement and extinction in the home setting. They found that parents were able to implement the intervention, and this resulted in the child increasing the bites that they accepted, and decreasing their behavioural feeding difficulty. In another example, Sira and Fryling (2012) explored the use of peer modelling and differential reinforcement in the treatment of selective eating exhibited by a nine-year-old autistic boy. They used a non-concurrent multiple-baseline design to assess the effects of the intervention across three pre-selected target foods. They found that the treatment package was effective in increasing the percentage of bites accepted by the participant, they maintained at the one-month follow-up, and the intervention package was able to be implemented by the child's parent in the parent implemented phase.

Predominantly, behavioural interventions for behavioural feeding difficulties have used single-case design methodology (e.g., Ahearn et al., 2001; Najdowski et al., 2012; Patel et al., 2002), a type of within-subjects design whereby an individual acts as their own control (Cooper et al., 2020). There have also been recent randomised controlled trials evaluating behavioural interventions for behavioural feeding difficulties. Sharp et al. (2016) carried out a between groups waitlist-control pilot study investigating the feasibility and efficacy of an intensive, manual-based behavioural feeding intervention for children with behavioural feeding difficulties. They found that there was a significantly greater increase in bites accepted & decrease in disruptions in intervention group compared to waitlist group. Recently, Peterson et al. (2019) used a crossover randomised controlled trial to evaluate the effects of a multicomponent behavioural intervention to increase food acceptance in children exhibiting behavioural feeding difficulties. They found that food acceptance and mouth clean increased for the behavioural intervention group but not waitlist-control until the behavioural intervention was implemented.

Functions of Behavioural Feeding Difficulties and Function-Based Interventions

The premise of behavioural interventions is to identify what the behavioural feeding difficulty is achieving and what is influencing it, and to tailor the intervention around this information, resulting in a function-based intervention. Function-based interventions are based around information obtained in a functional assessment or functional analysis. Function-based interventions have been used in the behavioural intervention literature (e.g., Piazza et al., 2003), and they centre primarily around breaking down the consequences following behavioural feeding difficulties which appear to influence why they continue to occur.

Functionally, behavioural feeding difficulties are often understood as occurring primarily due to an escape or attention function. Piazza et al. (2003) systematically tested the consequences that appeared to consistently follow occurrences of behavioural feeding difficulties (parental attention, giving the child a break from eating or avoiding eating, and giving the child a preferred toy). They found that using a functional analysis, it was possible to identify the maintaining contingencies that influenced why most of the children in the study were exhibiting a behavioural feeding difficulty, and that these were most likely maintained by negative and positive reinforcement contingencies. For example, in the case of negative reinforcement, the parent removes a spoonful of food after the child turns their head away, or in the case of positive reinforcement, the parent presents a preferred food after the child has refused a non-preferred food. Therefore, behavioural feeding difficulties are generally understood to be functionally maintained by these positive and negative reinforcement contingencies, and this information is used to develop function-based interventions. For example, Hodges et al. (2018) were able to identify the functions of behavioural feeding difficulties using a trial-based functional analysis with two children with developmental disabilities. They used these findings to implement a function-based intervention including reinforcement and shaping, which resulted in a decrease in the behavioural feeding difficulty and an increase in appropriate feeding behaviours for both participants.

Theories of Behavioural Feeding Difficulties

Many theories exist which attempt to conceptualise the development of behavioural feeding difficulties (see Table 2). Some consider the influence of single factors on the development of behavioural feeding difficulties, like developing associations or learning (i.e., learning theories), developmental approaches (Douglas, 2002), or biomedical approaches (Linscheid & Murphy, 1999). Few theories consider a range of factors that can influence the development and maintenance of behavioural feeding difficulties. Clearly, there are many risk factors for these (see Risk Factors section above), so arguably, any theory that attempts to understand behavioural feeding difficulties, why they emerge and continue to occur, also needs to consider this range of factors.

Table 2

Theories of the Development and Maintenance of Behavioural Feeding Difficulties.

List of Theories
Attachment theory (e.g., Benoit et al., 2001; Bowlby, 1982)
Biobehavioural model (e.g., Kedesdy & Budd, 1998)
Biomedical model (e.g., Linscheid & Murphy, 1999)
Biopsychosocial model (e.g., Berlin et al., 2009)
Developmental model (e.g., Douglas, 2002)
Oral-motor model (e.g., Sheppard, 2008)
Organic-nonorganic dichotomy (e.g., Burklow et al., 1997)
Parental psychopathological factors model (e.g., Karacetin et al., 2011; Petzoldt et al., 2016)
Parenting practices & the family system (e.g., Arvedson, 2008; Douglas, 2002; Davies et al., 2006)

List of Theories

Diagnosis-specific models (e.g., Keen, 2008; Twachtman-Reilly et al., 2008; Zhu & Dalby-Payne, 2019)

Ecological model (e.g., Black, 1999)

Feeding dynamics model (e.g., Satter, 1986; Satter, 1987)

Feeding tube dependency (e.g., Krom et al., 2017; Wilken et al., 2018)

Interpersonal model (e.g., Linscheid & Murphy, 1999)

Learning theory (e.g., Douglas, 2002; Silbaugh et al., 2016)

Psychoanalytic theory (e.g., Briggs, 2000; Freud, 1978; Winnicot, 1957)

Psychological model (e.g., Linscheid & Murphy, 1999)

Psychosocial model (e.g., Goday et al., 2019)

Sequential-oral-sensory approach (e.g., Benson et al., 2013; Toomey & Ross, 2011)

Transactional model (e.g., Davies et al., 2006)

One theory that is comprehensive and considers the range of factors that might influence the development of behavioural feeding difficulties is the biopsychosocial theory (Berlin et al., 2009; Engel, 1977). Throughout this thesis, the biopsychosocial theory will be used to describe the phenomenon of the development and continued occurrence of behavioural feeding difficulties (i.e., as a way of understanding how behavioural feeding difficulties emerge and persist). This application of a biopsychosocial theory has previously been used to conceptualise other areas of feeding (e.g., appetite regulation, Harrold et al., 2012; obesity, Liew et al., 2020).

The biopsychosocial theory ensures that the biological component influencing why a disease/disorder is occurring does not account for the entire occurrence, since full understanding of the condition requires additional information (Engel, 1977). For example, Engel (1977) argues that in order to understand a condition or disease, a medical approach needs to incorporate an account of the individual, their social context, and the wider societal context – in a biopsychosocial model. The biopsychosocial approach for understanding conditions or disorders is one that allows for the consideration of the range of relevant factors (Engel, 1977).

Berlin et al. (2009)'s biopsychosocial model acknowledges that the development of feeding requires incredibly complex interactions of a variety of factors, spanning behavioural, biological, and psychosocial domains. Other researchers have previously posited that even when biological difficulties are present, the development of behavioural feeding difficulties is often a result of a complex interplay between behavioural, social and biological factors (Crist & Napier-Phillips, 2001). There is a general agreement in the field that behavioural feeding difficulties are multidimensional and that the biopsychosocial model is well placed to describe the development of these (van Dijk, 2021).

The biopsychosocial model suggests that understanding behavioural feeding difficulties requires a wide-ranging theory that integrates known risk factors, relevant theories, and outcomes within a developmental framework. Berlin et al. (2009) discuss various existing theoretical models and their overlaps, concluding that many similarities across theoretical models can be subsumed into Ellyn Satter's Feeding Dynamics Model (Satter, 1986; Satter, 1987) and the biobehavioural model (Kedesdy & Budd, 1998) and that a biopsychosocial model should synthesise and integrate biobehavioural learning principles and the feeding dynamic model's emphasis on intake regulation.

The biopsychosocial model emphasises biomedical factors, caregiver variables, and socio-cultural contexts as influences on behavioural feeding difficulties. For example, they highlight the presence of physical disabilities, intellectual disability, prematurity, low birth weight, medical issues (e.g., cardiac problems, cystic fibrosis), GERD, gastrointestinal problems, cancer, swallowing difficulties, structural abnormalities, dysphagia as biological risk factors, or influences on the development of behavioural feeding difficulties. Other researchers have proposed that further biological contributors may include difficulties with absorption like cystic fibrosis, coeliac disease, lactose intolerance and sugar malabsorption and vomiting and diarrhoea from gastroenteritis (Sanders et al., 1993).

Berlin et al. (2009) also consider the proximal and distal caregiver variables, which they posit can impact whether a caregiver can provide the appropriate feeding structure. Proximal variables encompass caregiver characteristics such as, being too overactive, underactive, rigid or controlling, chaotic, or disorganised, whereas distal caregiver variables include parental mental health, their socioeconomic resources and their beliefs (Berlin et al., 2009). Proximal variables relate to the *bi-directional* nature of the feeding relationship, and acknowledge the role of the parent in the feeding relationship (Walton et al., 2017). The contribution of socio-cultural, socio-economic and family context are also considered in this model, which is key as the context of sociocultural factors in the overall feeding literature is not often considered (Berlin et al., 2009), but as discussed earlier, social inequalities can influence the development of behavioural feeding difficulties.

Additionally, Berlin et al. (2009) also consider children’s intake regulation and biobehavioural learning principles on the development of behavioural feeding difficulties. They propose that successful eating is enhanced by a child attending to their hunger and satiety cues, while also responding to the mealtime structure established by their caregiver, again incorporating the importance of the bi-directional feeding relationship (Walton et al., 2017). They propose that as children grow older, they shift their ability to regulate their intake from internal to external cues, but they may encounter difficulties with this if they encounter disruptions to regulating their intake, or if they have suboptimal or developmentally inappropriate mealtime structure. They also use biobehavioural learning principles to describe the processes by which behavioural feeding difficulties may develop or continue to occur (e.g., tube feedings lessening the discriminative stimulus functions of a child’s interoceptive cues indicating hunger which leads to mealtimes becoming paired with aversive stimuli).

The comprehensive nature of this approach proposes that the development of a presenting behavioural feeding difficulty is not attributed to a single factor, but rather to a multitude of factors and the ways in which these factors interact. Figure 1 illustrates the integration of risk factors, caregiver variables, contextual factors, and the processes of intake regulation and biobehavioural influences on the development of behavioural feeding difficulties. The benefits of using this model to understand the development and continued occurrence of behavioural feeding difficulties is that all the relevant factors which may influence why a behavioural feeding difficulty is occurring are considered, which leads to a contextual and holistic approach to understanding behavioural feeding difficulties. . Biopsychosocial approaches have also previously been used to describe the development and maintenance of challenging behaviour more broadly (e.g., Hastings et al., 2013). Given the ability of the biopsychosocial theory to capture the range of factors that influence why behavioural feeding difficulties emerge or continue to occur and consider these factors in the development of interventions for behavioural feeding difficulties, this is the theoretical approach that will be taken in this thesis to understanding behavioural feeding difficulties.

Figure 1

Biopsychosocial Model of Behavioural Feeding Difficulties (as seen in Berlin et al., 2009, p. 271).

[REDACTED]

Conclusion

This chapter aimed to provide an overview of the literature related to behavioural feeding difficulties, describe the difficulties presented by the current plethora of theories to understand why feeding difficulties occur and continue to happen in an individual’s life, and describe the biopsychosocial theory, which is considered to be the most comprehensive and contextual theory as it considers the range of different influences on behavioural feeding difficulties (see Risk Factors for Behavioural Feeding Difficulties in IDD). This is important when considering interventions, as it means that this range of influencing factors are all able to be considered with one single theory. There were also some difficulties highlighted with the prevalence of behavioural feeding difficulties in the typically developing and IDD populations, though it was clear that the estimates can be high for the IDD population. Finally, it is clear that behavioural feeding difficulties bring with them a range of impacts. As a result, this chapter has provided an overview of the current state of the literature on behavioural feeding difficulties and argued that any theory seeking to understand why behavioural feeding difficulties occur needs to consider the range of influencing factors and use this information to inform multicomponent interventions. Some next steps in research about behavioural feeding difficulties may involve ascertaining prevalence rates of behavioural feeding difficulties amongst children with IDD, with more robust or generalisable methodology; evaluating a biopsychosocial approach to interventions for behavioural feeding difficulties amongst children with IDD; and triangulating the stakeholder experience of behavioural feeding difficulties. This may be particularly important in the context of the UK, as it appears that a UK-centred exploration of parent experiences of behavioural feeding difficulties amongst children with IDD has not been carried out. Additionally, it may be helpful to learn about the experiences of other stakeholders, like clinicians, that deliver support or intervention for children with IDD exhibiting behavioural feeding difficulties. Finally, the experiences of stakeholders of support or intervention for behavioural feeding difficulties amongst children with IDD would be important to explore, in addition to understanding the utility of a biopsychosocial approach to understanding behavioural feeding difficulties.

There are some practical limitations to consider, such as time and resource constraints, which meant these areas could not all be explored in this thesis. Additionally, the perspectives of stakeholders and evaluation of a biopsychosocial approach to understanding behavioural feeding difficulties for intervention purposes were considered particularly important because behavioural feeding difficulties are clearly impactful, and it is not only important to explore the experiences of stakeholders, but also to translate this information into actions in a biopsychosocial approach to intervention that is informed by stakeholder perspectives. As such, the research questions guiding this thesis are as follows:

- What are stakeholders' experiences and understandings of behavioural feeding difficulties amongst children with IDD?
- What are stakeholders' experiences of support or intervention for behavioural feeding difficulties amongst children with IDD?
- How can a biopsychosocial approach to behavioural feeding difficulties be used to inform interventions for these amongst children with IDD?

Overview of Thesis

This thesis seeks to investigate parent and practitioners' experiences of behavioural feeding difficulties and related supports and explore interventions for behavioural feeding difficulties amongst children with IDD. The methodology used in this thesis is described in detail within each chapter. An overview of the thesis and the methodologies used will be described here.

It was considered important to first understand the lived experience of parents of children with IDD exhibiting behavioural feeding difficulties in England and related supports they have received for these, as there has not been much research exploring parent experiences in the context of the UK (e.g., Parr et al., 2021). As such, a qualitative project (Chapter Two) was undertaken to explore the experiences of parents in England and develop a grounded theory model of their lived experiences of their children's behavioural feeding difficulties and related supports. This study used qualitative methods in the form of semi-structured interviews and used grounded theory (Glaser & Strauss, 1967) to inform the procedures and the analysis process. Following this, it was considered important to acknowledge and synthesise broader qualitative research on parent experience without that was not UK-specific to identify shared experiences more broadly. As such, a systematic review and meta-synthesis of qualitative research (Chapter Three) exploring families' experiences of their child with an IDD's behavioural feeding difficulties was therefore carried out to further understand the lived experiences of families and to identify new patterns and themes in the literature. This systematic review and meta-analysis used meta-ethnography to inform the procedures and the analysis process (Noblit & Hare, 1988). It was considered that at this stage, parent and family perspectives were well understood and next, the lived experiences and perspectives of clinicians delivering support or intervention for behavioural feeding difficulties amongst children with IDD were sought in the form of a qualitative project (Chapter Four). This project used qualitative methods in the form of semi-structured interviews and grounded theory (Glaser & Strauss, 1967) to inform the procedures and the analysis process. This study presented a grounded theory model to understand how clinicians in the National Health Service (NHS) are able to provide support, what they consider to be the key aspects of support, and the challenges they face in delivering this support.

Finally, the findings in this thesis were used alongside the intervention literature for behavioural feeding difficulties and some key guiding principles to inform a logic model (Shakman & Rodriguez, 2015) for an intervention approach for behavioural feeding difficulties amongst children with IDD (Chapter Five). This logic model was then used to guide the development of an intervention approach for behavioural feeding difficulties that was tested using single-case design methodology in the form of a delayed multiple-baseline design (see Cooper et al., 2020) with families of children with IDD currently exhibiting behavioural feeding difficulties (Chapter Six). This study used a delayed multiple-baseline design to see whether the implementation of the intervention with families results in an observed change in the child's behavioural feeding difficulty. A rigorous functional assessment

(O’Neill et al., 2015) and formulation process (i.e., developing a hypothesis about the difficulties described and observed; Johnstone & Dallos, 2006) was carried out alongside families to identify why the child’s behavioural feeding difficulty was occurring and this served as the basis for shared intervention development with families. The interventions developed with families were individualised, and the introduction of these interventions were staggered (i.e., one family started the intervention phase, and after some days, the next family started the intervention phase) as is common in single-case design research where a multiple-baseline design is being used (Cooper et al., 2020). Pre- and post-intervention quantitative data was also collected to capture any changes in parents’ perceptions of their child’s behavioural feeding difficulties and their own behaviours during mealtimes. Qualitative data was also used after the intervention phase was over to obtain families’ perspectives of going through this intervention process and explore their perceptions of the social validity (Wolf, 1978) of the intervention process.

The final chapter in this thesis (Chapter Seven) presents a general discussion of the findings of the thesis and situates these findings within the larger body of literature related to behavioural feeding difficulties, interventions, working with families, etc. This chapter describes the contribution of this thesis to the evidence-base relating to the experiences and perspectives of stakeholders and those who deliver support for behavioural feeding difficulties, and the intervention process for behavioural feeding difficulties.

Chapter Two Parent Experiences of their Child's Behavioural Feeding Difficulties and Related Supports

Chapter Overview

In Chapter One, the current scope of the literature on behavioural feeding difficulties was presented and it was highlighted that there was a notable gap in relation to UK-centred explorations of parents' experiences of behavioural feeding difficulties amongst their children with intellectual and developmental disabilities (IDD). One of the research questions guiding this thesis is to explore stakeholders' experiences and understandings of behavioural feeding difficulties amongst children with IDD, and their experiences of related supports for these. As such, it was considered an important first step to gather the lived experiences of parents of children with IDDs exhibiting behavioural feeding difficulties in the UK, and their experiences of any related supports. The results of this analysis will contribute to understanding parents' experiences of behavioural feeding difficulties and related supports and the ways in which they understand why their children's behavioural feeding difficulties started and have continued to occur.

Introduction

Family mealtimes are valuable occasions when families come together, communicate, and develop shared rituals and routines (Suarez et al., 2014). The primary focus in the field of feeding difficulties has been on identifying aetiologies and testing interventions (Spalding & McKeever, 1998); families' experiences of their children's feeding difficulties has only recently been explored (e.g., Estrem et al., 2018; Curtiss & Ebata, 2021, etc.). Recent qualitative research has described the impact of feeding difficulties on families, parents, and children from parents' perspectives (e.g., Rogers et al., 2012; Suarez et al., 2014). Some of these impacts described by parents have been: significant family life difficulties, such as limited travel and planning their daily lives around mealtimes (Estrem et al., 2018); worry and guilt in mothers of autistic children exhibiting selective eating (Suarez et al., 2014); and descriptions of their children having significant nutritional issues and facing hospitalisation due to their feeding difficulties (Rogers et al., 2012).

Recent qualitative research in this area has also yielded rich descriptions of the ways that parents understand their child's feeding difficulties. Estrem et al. (2016) found that parents characterised their child's feeding difficulty as a journey that evolved over time; the authors described this as a unique perspective that provides a viewpoint healthcare professionals lack. Some examples of the journeys described by parents include Adams et al. (2020) who interviewed seven mothers of autistic children exhibiting feeding difficulties in South Africa and found they all struggled with understanding what was wrong with their child's feeding. Suarez et al. (2014) interviewed four mothers of autistic children exhibiting food selectivity and found that mothers described searching for answers, attempting to understand, and trying many strategies to achieve an acceptable mealtime experience. Contrastingly, some research has suggested that parents might have their own understandings (i.e., implicit theories) about the causes of their child's feeding difficulty. Estrem et al. (2018) interviewed 12 parents of nine families of children who were receiving outpatient intervention for their feeding difficulties. They found that parents of eight of the children viewed their child's feeding difficulty as a functional manifestation of a concurrent condition (e.g., partial paralysis due to brain damage, etc.), indicating an implicit understanding of why their child's feeding difficulty was occurring. This discrepancy in descriptions of families' experiences shows that what families understand about why their child's feeding difficulty is occurring has not been fully explored and understood.

Notably, there is not much research related to parent experiences of behavioural feeding difficulties that has been carried out in the context of the United Kingdom (UK). Recently, Parr et al. (2021) found that parents in the UK described the stresses experienced during mealtimes and the importance of understanding children's feeding and swallowing difficulties. Parents discussed that this understanding was important for them to be able to implement changes during mealtimes. This showed that families described understanding why their child's feeding difficulty was occurring as being important to them and described that this understanding supported them in making changes during mealtimes. Of importance is that this appears to be the only UK-focused study to date.

However, the rich lived experiences of parents of children with feeding difficulties receiving support for their children's feeding difficulties in the UK has not been explored in detail.

Currently, there are gaps in the qualitative literature about feeding difficulties in children with IDD. First, as noted previously, research in this area in the UK context is lacking. The UK has a health-care system that is different to the United States, where most of the qualitative research about feeding difficulties and families appears to have been carried out (e.g., Estrem et al., 2016; Estrem et al., 2018; Suarez et al., 2014). It is therefore important to explore the experiences of feeding difficulties of families of children with IDD within the UK context, as these may be different to the experiences of feeding difficulties of families in other parts of the world with different health-care systems. Second, most of the existing qualitative literature about feeding difficulties in children with IDD has focused on autistic children that exhibit feeding difficulties; experiences of families of children with intellectual disability that are not autistic exhibiting feeding difficulties have not been explored in depth.

Finally, while there has been some work developing an explanation or theory about the processes that influence mealtimes in families that have autistic children (e.g., a dialectic of control and acceptance; Curtiss & Ebata, 2021), it is not currently understood what role parents' implicit theories about their children's feeding difficulties play in their overall experiences of their children's feeding difficulties. Some research suggests that this may influence the changes that families make during mealtimes (Parr et al., 2021), however, the mechanisms through which this occurs are not well explored and the development of a grounded theory to explain the role of understanding on the overall experience of feeding difficulties has not been carried out to date.

The aim of this study was to understand the experiences of parents of children with an IDD in England in relation to their child's behavioural feeding difficulties. The aim was also to use grounded theory methodology and analysis to allow for an understanding of parents' implicit theories of their child's feeding difficulties and the role of these in the experiences of behavioural feeding difficulties of parents of children with IDD. The objective was to understand parents' implicit theories about the development and continued occurrence of behavioural feeding difficulties amongst their children with IDD, the supports which they may have received for these, and their ideal supports. The research questions guiding this research were as follows:

- What are parents' descriptions of their child's behavioural feeding difficulty?
- What supports have parents in England received to date for their child's behavioural feeding difficulty?
- What are parents' ideal supports for their children's feeding difficulties and themselves managing these feeding difficulties?
- What implicit theories do parents of children with an IDD have about their child's behavioural feeding difficulty and what are their perceptions of what influences this feeding difficulty?

Methodology

Research Design

A qualitative approach was selected for this study as the intention was to carry out exploratory research of parents' experiences of their children's behavioural feeding difficulties and related supports. Qualitative methods can capture intricacies related to feelings, emotions, thoughts, and processes that are difficult to learn about in the same way through other research methods (Strauss & Corbin, 1998). It was deemed that qualitative methods would yield rich data that would allow for a deeper exploration of parent experiences and would therefore be the most appropriate methodology to address the research questions.

Interviews

Semi-structured interviews were selected as these allow for the gathering of information from stakeholders who have personal experience, perceptions, and beliefs about a topic of interest

(DeJonckheere & Vaughn, 2019). The flexibility of the semi-structured approach was also appropriate given that the topic was of a sensitive nature and semi-structured interviews allow for the deep exploration of a sensitive issue (DeJonckheere & Vaughn, 2019), while still ensuring that information related to the research questions was being asked. Through this approach, participants' leads could be followed and probed further, while still obtaining data related to the research questions. The use of semi-structured interviews allowed for richer data to be obtained as participants were able to provide elaborate responses. A final reason why semi-structured interviews were selected was to help to establish rapport with participants. Interviews were selected over surveys as it was expected that interviews would yield richer data as parents would be able to elaborate.

Interview Schedule

An interview schedule (Appendix A) was developed along with probes. Interview schedule question areas corresponded closely to the research questions for this study. The questions on the interview schedule were developed as a guide to obtain specific information related to the research questions, and probes were available to follow up on topics or areas which participants might talk about. These questions were developed along with supervisors. The questions on the interview schedule were broadly about the focal child and their feeding difficulty, supports that they had received for their child's feeding difficulty, things families had tried to improve children's eating, their thoughts about what would be an ideal support for their child's feeding difficulty, and parents' thoughts about why their child's feeding difficulty may have started or continued to occur. These areas were all included as they related directly to the research questions.

Participants

Twenty interviews were carried out. In the case of two interviews, two parents contributed to the interview. Participants were 22 parents of children with IDD who were currently exhibiting a behavioural feeding difficulty. Participants met the inclusion criteria if they were parents of children between the ages of 1.5-18 years (exclusive) with an IDD who were currently exhibiting a behavioural feeding difficulty. This age range was selected based on the World Health Organisation guidelines for starting babies on solid foods around 6-months of age and the consideration that refining the new skill of feeding can take between 6-12 months (Rappaport, 2015). The upper age range was selected as according to the Children's Act (2004) a child is anyone who has not yet reached their 18th birthday.

Demographic information for the participants and their children can be seen below on Tables 3 and 4.

Table 3

Parent Study Participant Demographic Information.

Characteristic	**Category**	**Number of participants (%) (*n* = 22)**
Gender	Female	20 (91%)
	Male	2 (9%)
Race/ethnicity	White British	16 (73%)
	Asian	5 (22%)
	Mixed	1 (5%)
Age (in years)	30-39	4 (18%)
	40-49	10 (45%)
	50-59	7 (32%)
	60-69	1 (5%)
Number of children in household	1	1 (5%)
	2	13 (65%)
	3	4 (20%)

Characteristic	**Category**	**Number of participants (%)** (***n*** **= 22)**
	4	2 (10%)

Table 4

Parent Study Child Demographic Information.

Characteristic	Category	Number of participants (%) (*n* = 20)
Gender	Female	3 (15%)
	Male	17 (85%)
Age (in years)	1.5-9	7 (35%)
	10-17	13 (65%)
Diagnoses [a]	Autism	19 (95%)
	Global developmental delay	5 (25%)
	Sensory processing disorder	2 (10%)
	Moderate intellectual disability	2 (10%)
	Severe intellectual disability	4 (20%)
	Learning difficulties	4 (20%)
	Genetic syndrome	4 (20%)
	Attention deficit hyperactivity disorder	1 (5%)

Note. [a] Participants could identify their children as having multiple diagnoses; therefore, the totals do not equal 100%.

Ethical Considerations

There were a variety of ethical issues that were considered in the development of this study. No payment was offered for participation, as participation was entirely voluntary. As PhD research, this project was not funded, so participants could not be paid, however it was not anticipated that lack of payment would impact participation as it was believed that parents would be motivated to take part in the study given the demonstrated impact of feeding difficulties on families.

Furthermore, there was a concern that paying participants could establish a power differential where participants might not feel confident in requesting to withdraw from the research.

It was considered that as this was a sensitive topic, parents may have become distressed during the interview. To minimise this, it was decided that if this occurred, the interview would be stopped, and participants would be asked if they would like to withdraw or continue the interview at a later date, and their choice would be respected. Only one participant experienced distress during the interview (i.e., crying and becoming visibly upset). As planned, the interview was stopped, and the participant was given a break where she went to make a cup of tea. When the participant returned, she was asked if she would like to withdraw or continue to interview at a later date. The participant chose to continue the interview and the interview was continued after first reassuring the participant that it could be terminated at any point if she changed her mind.

For all participants, at the end of the interview, some resources for accessing emotional support were discussed (see Appendix B). One of these resources was specifically for families with children with feeding difficulties, and the other was family support services information for a national charity in England. Parents were also sent this information immediately after the interview, and they were told at the time the information was discussed that they would receive this as soon as the interview ends. Due to the individualised nature of the development and maintenance of behavioural feeding difficulties, it was not considered possible to provide participants with advice about feeding difficulties without first carrying out a comprehensive assessment, which was beyond the scope of the current study. It was considered that providing non-individualised advice could result in causing more harm since it is likely that the advice might not help families, which could further increase their stress levels and lead families to feeling helpless about their child’s feeding situation. It was also not possible to provide families with written advice in the form of leaflets or links to websites because the quality of much of the information available online in relation to feeding difficulties if of questionable utility to families because it is very generic and could result in similar ethical issues as previously stated.

Given that this study was carried out during COVID-19, it was considered that participating could pose an additional burden on parents. This was minimised by being flexible when scheduling interviews, including mornings, evenings, and weekends. It was considered likely that there would be some power imbalance due to the researcher/participant nature of the exchange. This was addressed by ensuring it was clear to participants that they could withdraw without giving a reason, that their participation was not assumed because they had been in contact requesting information about the study (i.e., consent was not assumed), and their decision to participate was completely up to them.

It was expected that parents might be culturally and ethnically diverse. Parents were asked about their ethnic background in the demographic information sheet to understand the cultural and ethnic context of the family's feeding or mealtime practices. There were some ethical considerations related to the impact of this research on the researcher. It was considered that it would be possible for the interviews to cause the researcher distress as it was clear that these would be emotional for parents. This was mitigated through reflexivity and discussions with supervisors. All these issues were considered on the ethics application.

Procedure

This study was granted ethical approval by Tizard Centre Ethics Committee on October 21st, 2020.

Recruitment

Research information was disseminated through social media and email lists starting in October 2020 and concluding in January 2021 (see research poster in Appendix C). Purposive sampling was used as participants needed to be grouped and recruited according to pre-determined criteria (i.e., parents of children with IDD and behavioural feeding difficulties).

Upon receiving inquiries about participation from potential participants, a preliminary conversation through email or telephone occurred to confirm inclusion requirements and answer any questions. Once inclusion requirements were confirmed, parents were sent a Participant Information Sheet (PIS; Appendix D). A total of 41 parents expressed an interest in participating, and a total of 20 interviews were carried out, with 22 participants (in two interviews, a mother and father contributed to the interview). Not all parents who came forward for participation met the inclusion criteria, and some did not respond to emails seeking to confirm that they met the inclusion criteria, and thus were excluded from participation.

Consent and Demographic Information

Informed consent and demographic information (Appendices E and F) were obtained from participants either through the completion of a form prior to the interview or recorded verbally at the start of the interview. An interview schedule was used in all interviews.

Pilot Interviews

The interview was piloted with fellow PhD students, with PhD supervisors and with one parent who provided consent. The pilots were meaningful to this research as they enabled a variety of situations to be considered and feedback from various sources to be obtained and applied to the subsequent research interviews. This allowed the researcher to be prepared for multiple possible scenarios and to practice handling sensitive topics prior to undertaking interviews with research participants.

Research Interviews

Interviews were anticipated to last between 1-1.5 hours, however where families had received multiple supports for their child’s behavioural feeding difficulty, these interviews lasted significantly longer, and as a result, interviews lasted between 1-2.5 hours. A short demographic questionnaire was also used to capture some additional contextual information about participants and factors related to feeding (i.e., ethnicity for cultural considerations and number of children in the household).

Interviews were conducted online, and video and audio recorded via MS Teams primarily; on one instance Zoom was used as there were connection difficulties using MS Teams at the time the interview was scheduled. All recorded interviews were stored on Stream.

All interviews were transcribed verbatim and anonymised. All names and identifiable information (including names of cities, counties, services, professionals) mentioned were redacted from the transcription. Participants were assigned names different to their own to ensure that participants' real names or identities are kept confidential. Pseudonyms are used throughout this report. Data collection ceased when the maximal number of interviews was reached, and this also coincided with reaching theoretical saturation.

Following the conclusion of each interview, all participants were sent a follow-up email with the support resources and a comments form (Appendix G) if they wished to provide any feedback to the researcher. Only one participant provided feedback following the interview, and this was provided via email (Appendix G).

Data Analysis

Grounded theory was used to analyse the data.

Grounded Theory Selection

Data analysis used a grounded theory approach. Grounded theory was selected as the most appropriate data analysis method as data from this study will contribute to the generation of a new theory of family experiences of behavioural feeding difficulties, which will emerge from the data gathered and analysed (Howard-Payne, 2016). The type of grounded theory used was Straussian grounded theory, as Strauss' approach is applied within a contextualistic epistemological positioning that acknowledges the inter-subjective interpretation and understanding of the topic (Howard-

Payne, 2016). A Straussian grounded theory approach was also considered to be the most appropriate approach to grounded theory given the research aims and questions. A Straussian grounded theory task analysis (Appendix H) was developed to ensure rigour in the data analysis process, and to ensure that the complexities of Straussian grounded theory were all accounted for in the analysis process.

Concurrent Data Collection and Analysis

The interviews were scheduled and carried out between November 2020 and January 2021, meaning that the co-occurrence of data collection and data analysis, a hallmark of Straussian grounded theory, was modified to accommodate the rapid influx of data. All interviews were carried out by the PhD researcher, as well as transcribed and reviewed, as the data was being collected. As this went on, ideas about the recurring themes that were coming up in the first interviews were formed. The interviews were carried out in three sets. Set One was in November, Set Two was in December and Set Three was in January. There were six interviews in Set One and seven interviews in Sets Two and Three. The interviews, transcriptions, and reviews of transcriptions from Set One collectively produced ideas to explore further in the next set of interviews. As such, the interviews from Set Two were more targeted. The interviews from Set Three further refined the ideas and themes that came from earlier interviews.

Member Checking

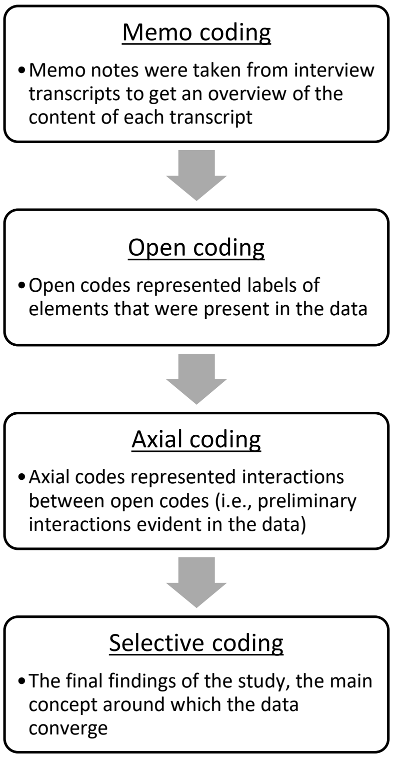
For the final interview set an element of member checking was able to be incorporated, whereby participants were presented with prominent preliminary themes and asked how those interpretations sounded to them, and whether there was anything they would add to the presented interpretation. This resulted in participants checking and confirming the preliminary results to a degree (Birt et al., 2016). This process allowed for theoretical sampling by enabling the focus of the interviews to be guided by the data collected, as it was being collected, in the form of the interview questions asked and the widened scope of the existing interview questions (Ligita et al., 2019).

Memo Coding and Open Coding

An overview of the stages involved in analysis and how the analysis process changes across these is evident in Figure 2. After all data were collected, interviews and researcher notes were coded into memos. Memos were reviewed and grouped, outlining a preliminary set of 28 open codes (as seen in Appendix I). This preliminary set of open codes were sent to a supervisor (NG), who provided feedback, which was subsequently applied. This resulted in seven main open codes, each with subcategories of specific elements which were present in the data. The final open coding framework (Appendix J) was input to NVivo. Interviews were coded into the open coding framework in NVivo. At this stage, a portion of the interviews coded into each code were sent to a supervisor (CP) for feedback and to ensure the content of each code reflected what that code meant to capture.

Figure 2

Overview of the Stages Involved in Straussian Grounded Theory Analysis.



Axial Coding

After coding the raw data into the open coding framework, the researcher hypothesised about some potential interactions that might be present in the data. At this stage, relationships between codes were not looked at on an individual code level (i.e., judgement, mothering, willingness to starve), rather categories of codes (i.e., the overarching category, as an example: food as a battle vs survival). This approach was deemed most appropriate to identify dynamic interactions between the open codes and ensure the data is relating back to itself and maintaining a Straussian grounded theory approach to analysis at each step.

The hypothesised relationships between codes are outlined in Appendix K. Matrix queries were run in NVivo to explore the hypothesised relationships and confirm their presence or identify their absence. The results of the matrix query indicated that meaningful interactions between the data existed in only 50% of the hypothesised relations.

As a result of this, a more systematic approach to explore the relationships between the codes was undertaken. Matrix queries were run in NVivo comparing all code categories to each other, resulting in a 6x6 grid (Appendix L). This allowed for an overview of the relationships between all the code categories. This also ensured that the data were being related back to itself in an objective way, in keeping with a Straussian grounded theory approach. The results that indicated many interactions or powerful interactions suggested relationships between code categories that were selected for further exploration (Appendix I).

There were two criteria which were used to determine if a relationship between code categories should be explored further:

1. There were many interactions between the categories, as it was presumed that this would be a strong demonstration of the data relating back to itself.
2. The interactions between the code categories represented powerful lived experiences.

After running matrix queries, eight relationships between code categories were identified for further exploration, as seen in Appendix I These relationships were explored further to identify the nature of the interaction in the data. In most cases, there were multiple facets in each identified relationship that warranted further exploration. As a result, the matrix query results for the identified relationships were reviewed, synthesised and analysed to identify the relationships between code categories in detail. The most prominent or rich facets of the relationships were selected for further exploration as axial codes.

This resulted in 13 axial codes illustrating dynamic interactions between code categories. Appendix M illustrates the resulting axial coding framework. This process was reviewed and checked with a supervisor (NG) to increase confidence in the validity of the process, and it was determined that the process demonstrated high integrity.

Selective Coding

Following the development of the axial coding framework, the raw transcripts were coded into this framework. At this stage, if further relationships between code categories were identified that were not otherwise captured after following the process above, these would have been added into the axial coding framework and raw transcripts rechecked to ensure all representations of the identified axial codes in the raw transcripts were captured. However, this was not used as no further axial codes were identified while coding the data. After coding the data into the axial coding framework, the researcher hypothesised about how the axial codes would interact. Predictions and the outcome of the matrix query can be seen in Appendix N.

These hypothesised interactions were derived from being immersed in the data. There were five main interactions, and all of these were verified by repeating the same systematic matrix query process described above. This means that the relationships between all the axial codes were checked and displayed as a 13x13 grid in Appendix O. This systematic process provided an overview of the interaction between axial codes and a mixture of this systematic process and researcher interpretations were used to select the final selective codes and findings of the study. This was possible as the researcher was the only person immersed in the data throughout the entire project and allowed for rich interpretations that might have been missed in a matrix coding query. The criteria for deciding if an interaction between axial codes exists was as follows:

- The interactions between the axial codes represent an important contribution to the research questions.
- The interactions between the axial codes capture a rich and powerful lived experience.
- There are many interactions between the axial codes.

At this stage, the analysis process was reviewed with a supervisor (NG). Appendices M and N were reviewed together, and conclusions made about the final findings of the study.

Results

This study sought to understand parents' implicit theories of their child's feeding difficulties and their experiences of their child's feeding difficulty and related supports. From this study, it was evident that families are significantly impacted by feeding difficulties, families understand feeding difficulties in a variety of ways, and that understanding their child's feeding difficulties changed the impact of the feeding difficulty for families. Table 5 illustrates the themes and subthemes which will be explored further in this section.

Table 5

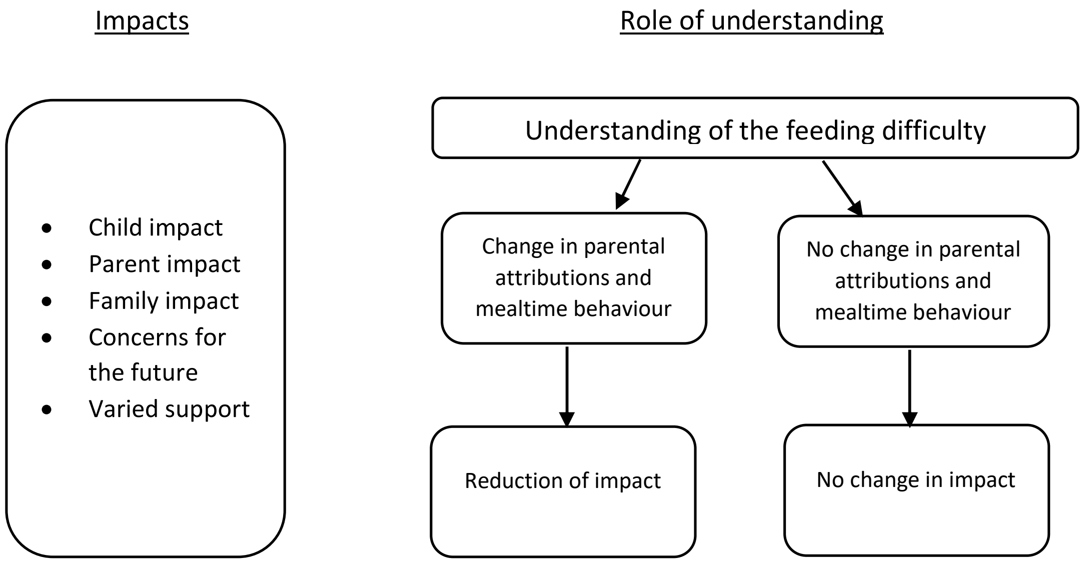
Parent Study Themes Identified along with Subthemes.

Themes	**Subthemes**
Impacts of the feeding difficulty	Child impact
	Parent impact
	Family impact
	Concerns for the future
	Support is varied
Parents' understanding of the feeding difficulty	Stable factors
	Factors that change over time
Understanding changing the impact	Changing attributions
	Changing parental behaviour during mealtimes

The main themes identified in this study work together to explain the role of parents' understanding of their child's feeding difficulty on the impact they experienced and the ways in which families support their children with their behavioural feeding difficulties (Figure 3). This interaction will be detailed first, followed by an in-depth exploration of each of the individual themes.

Figure 3

Grounded Theory Model of How Understanding Feeding Difficulties Mitigates the Impact of These on Families of Children with IDD



Grounded Theory of the Impact of Feeding Difficulties on Families and the Role of Understanding

There were a variety of impacts described by parents. These are outlined in depth below (Theme 1: Impacts of the feeding difficulty) and an overview of the contents of this theme can be seen on Table 4. From this research, it was evident that various aspects of families' lives were impacted.

> "It's still very traumatic for him every meal… He still vomits…on a daily basis, he has since more or less three months old…. he can vomit up 20 times in in the morning. And that is

> sometimes involuntary, sometimes he'll gag and retch himself and bring it up as well.” (Interview 11)

> “A few years ago, I used to run marathons…and I swear it is easier to run a marathon than it is to feed kids like Noah.” (Interview 6, Dad)

> “I don't know when it will be family time sitting round a table together. I just can't see that happening anytime soon.” (Interview 17)

> “I just think the sense of guilt because when you’re a parent…you’re meant to be the person that helps your child to thrive…sometimes professionals would write on his file…failure to thrive … I know that that has implications for social services as though you're negligent.” (Interview 21)

Families spoke about various understandings they had about their why their child’s feeding difficulty might have started or why it has continued to occur. These are outlined in depth below (Theme 2: Parents’ understanding of the feeding difficulty) and an overview of the contents of this theme can be seen on Table 4. It was clear that each family had a unique understanding of their child’s feeding difficulty.

> “I personally think that is 100% correlated with the sensory processing.” (Interview 2)

> “That rigidity, not wanting to try something and just wanting to stay with what he knows is safe for him is.” (Interview 10)

> “I just think it's part of his condition…I don't think there's a magic wand to it at all. It's the way his brain’s wired, it's the way he connects with food. As it’s not a necessity to him, it is just something that he has to do.” (Interview 16)

The understandings parents had about their child’s feeding difficulty sometimes changed the ways they experienced the impact of the feeding difficulty. While all parents had some implicit theories about why their child’s difficulty might have started or continued to occur, not all experienced a change in the impact of the feeding difficulty because of this understanding. When parents' understanding had an effect (i.e., changed their attributions or their mealtime behaviours), they described experiencing a change in the impact of their child's feeding difficulties. It was essential for their understanding to change something, as it appeared that having a reason for their child's feeding difficulty alone was not described as producing a change in impact for parents.

> "We took him to one of these big Japanese, eat all you can…and we all got a massive plate of food, so he didn't feel embarrassed if he didn't want to eat all of it…I know that he's not doing this to be difficult… I totally understand that you know his tolerance levels for certain tastes and flavours mean that it's just not palatable to him." (Interview 7)

> "He could not have been any other way, he was always gonna have that issue, now we didn't know that until his diagnosis happened, so before that you're going 'hang on, what's going on? I don't understand it. Why is it happening?' So diagnoses do help in terms of saying 'well we know every child with this syndrome has feeding problems'…but I think that the cause was not…one single incident… so I don't think it was the tube…or the reflux entirely or the lack of oral skills, or this sensory processing, all that. I think it's multifactorial but, in the main, I think his syndrome…if he didn't have the syndrome, I don't think he'd have the feeding problems." (Interview 11)

Theme One: Impacts of the Feeding Difficulty – "It's Just Too Much"

All families described significant impacts due to their child's feeding difficulty, but not all families were impacted in the same way. The various ways in which parents described the impact experienced by their child's feeding difficulty will be explored in detail in this section.

> "Mealtimes…they're not relaxing unless we're making something that he really loves. The problem is that we can't give him something he loves every night because it would be really bad for his health…he's getting tummy aches….It's probably his diet, he's not eating enough

> of the good foods and eating too many of the bad foods…I'm with them all day and I've got to finally do that last leg of the journey and it's just too much." (Interview 6, Mum)

Child Impact

Parents described their children's feeding difficulties as having a direct impact on the child themselves due to missing out on social mealtime experiences, increased anxiety during mealtimes, and medical or physical health impacts on the children. Parents also expressed concern about their child's nutrition and health. Parents felt like their children were being held back from social mealtime experiences. One parent described how her son "can't have the same sort of social life as other people because he can't join in meals or parties or celebrations in the way that everybody else does" (Interview 18).

There was a general understanding that food is often a key part of the social environment for children, however, the pressures of food not only held their children back from engaging in social mealtime experiences, but also caused them anxiety. One parent described how her son would ask to get picked up from friends' houses because he did not want to eat the food that would be served:

> "The other parents will get terribly offended and he would never get invited again because he hadn't eaten the foods, the lovely food, which I'm sure these super mums and dads had prepared for him. But it was the anxiety. He just didn't want to eat it." (Interview 7)

The parent of one child described that trying new foods was akin to torture for her son:

> "For him, trying a different food is torture. The anxiety is, do I have to try anything different?" (Interview 5)

Parents also discussed concrete medical or physical health impacts experienced by their children. One parent described how when her daughter was assessed, the doctors concluded that she was malnourished due to her feeding difficulties:

> “At the end of it they said…one of the most horrible things to me as a parent, was that she was borderline malnourished. Now how cruel is that? She’d got to almost six, seven and she was borderline malnourished.” (Interview 13)

Other parents described how their child’s height was impacted and how their children experienced bouts of constipation:

> “He would refuse to eat for long periods of time…his kind of height potential was impacted, so he's not as tall as he should have been from his birth predictions.” (Interview 20)

> “We had an awful lot of exploratory stuff about trying to get his bowel moving. He was on Lactulose and Movicol at some points.” (Interview 7)

Parents also expressed concerns for their children’s nutrition and health. These centred around their child’s development and the foods consumed by their children. Parents had to balance and manage their child’s food intake, and reassurance that their children were healthy was important for parents. Concerns were expressed about their child’s ability to develop properly without adequate amount and variety of food intake:

> “The amount he was eating like when he was like for example eight years or 10 years old, he’s still eating the same amount, but because he is growing, he needs to eat more but he's not eating more.” (Interview 15)

A major concern for parents was the content of the food their children consumed, primarily related to foods that are unhealthy for them: “That for me is a problem – not having a balanced diet, you know, really not having that and just eating so much sugar” (Interview 19).

Further to the concern for the quality of the food that their children were consuming, was the sense of guilt that they were feeding their children food that was unhealthy for them:

> “I read about the damage these foods do, cancer, diabetes, heart disease. And I thought…what if I'm actually, you know, killing him slowly? You know, the guilt.” (Interview 6, Mum)

Parents also had to work within the limits of what their children consumed, often having to increase the quality of food on their own, in efforts to improve the quality of what they were eating: “So you end up finding recipes with about five eggs in so that they're eating a load of rubbish, but there's five eggs as well” (Interview 19). “I sneak [supplements] in his drink and he has probiotic powders in his drink because his guts not that great” (Interview 16).

A prominent experience for parents was that of having to manage their child’s food intake to ensure they were consuming enough food and the right foods. In some cases, there was a delicate balance between giving their children food that was acknowledged to not be the best for them, with an awareness that their children simply needed to get calories in them to survive.

> “He has crisps and buttons for breakfast, because if he didn't have crisps and chocolate buttons for breakfast, he wouldn't eat anything all day. And I get the calories in.” (Interview 20)

Another parent expressed frustration upon encountering professionals that patronised her food choices for her daughter while she was doing her best to balance her daughter’s limitations in this way:

> “It’s really patronising, I remember the doctor said, ‘oh juice is bad’, and I said ‘well of course I know juices are bad for her… but I've also got to counter it with getting, you know, sort of like, you know, calories into her’.” (Interview 13)

Throughout these concerns, some parents found relief by having regular blood tests or thought that having had blood test would have provided reassurance or abated their fears of their children being unhealthy:

> "He'd get regular blood tests done as well…He's not deficient in anything, so then I would relax. It's me, I need to change and, you know, learn how to, you know accept this." (Interview 9)

Parent Impact

Parents described impacts to their emotional and mental health, feelings of isolation, and feeling responsible for their child's survival amongst their struggle. Further to this, most participants in this study were mothers; mothers described a unique impact of feeding difficulties related to feelings of judgement, guilt, blame, and mothering. One parent described intense worry around their child's feeding difficulty, ruminating on ways to improve her child's eating situation:

> "Food is such a basic thing that if your child has a feeding difficulty, you're worried about it all the time…I didn't sleep at night for the first few years of his life… I was literally just you know constantly worrying about what we were going to do next." (Interview 21)

Other parents described the emotional impact of a loss of what could have been in relation to family mealtimes. One parent described how both of her children had specific eating preferences, which left her on her own during mealtimes:

> "We don't really have that family sitting around the table… we don't have those cosy family dinners around the table…it used to quite upset me really. (Interview 10)

One parent whose child's feeding difficulties were significant and present from birth reflected on the pervasive emotional and psychological impact on her daily life and career, and the feeling of loneliness that exacerbated the situation for her:

> "It's the worst, worst time of my life basically, absolute worst time. I've never been through anything quite as bad. I hit depths that I never knew possible…The psychological impact it had – I was literally crying all day, every day. I didn't leave the house. I had to give up my career. And I felt there was no support. That's from family as well, because family just didn't

> get it. I would get constant advice, try him with this food, try him with that food. Try this. Try that. But like he doesn't want to eat. He won't put anything near his mouth, if he does, he just gags and vomits it up. Try this. Try this. Try that. Nobody understood. Nobody got it. It was just such a lonely place to feel - and there was no, no one to reach out to you."
> (Interview 11)

The feeling of isolation, stemming from a sense that no one else could understand what they were experiencing related to feeding was shared amongst other parents:

> "It can be more isolating when you realize that you're special within a group of special, you're like OK, I'm even more special… I haven't found that, kind of that cohort, the super special ones." (Interview 14)

Changes to parental mental health were also described, including feelings of depression and anxiety:

> "Sometimes I feel depressed…in my life…everything totally focused, you know with him… if he does not eat then I get more, you know, distressed and frustrated." (Interview 15)

> "I actually had anxiety and depression and I would link it to [how he ate when he was little] because from when he was weaning, he would only eat if you sung, and he used to rock so hard the whole chair would move." (Interview 21)

Importantly, parents described a balance between the personal impact they experienced and the responsibility that they felt to ensure their children's survival. There was a stark awareness that the children were on the brink of death at times, and parents' sole focus was to keep their children alive.

> "It was really traumatic because to me, it was a life and death situation, because he's not getting any nutrition, he's not gaining weight, which means he's gonna die basically, so every

> day my job was to get enough into him to survive basically, but no one really took that very seriously." (Interview 11)

This was also reflected in descriptions which depicted the desperation that parents felt for their children to consume food:

> "When suddenly he will refuse to have something that has been previously been safe…that was deeply stressful. Whenever you only have such a very small cohort of food, when you drop one, that's like, you know, an eighth of what you'll eat…that was very difficult, I was trying to be very cool about that, trying not to let him know that I'm desperate for him to eat this." (Interview 14)

Most participants in this study were mothers; there was a unique impact of feeding difficulties in relation to their roles as mothers. This was characterised by feelings of judgement, guilt, and blame, and mothers often described emotionally and passionately the unique impact they experienced in their mothering role. Mothers described the instinctual role of mothers in feeding their children, and the stark obstruction to that role posed by feeding difficulties:

> "There's this instinctual drive to nurture and feed your child.... And it creates a huge sense of anxiety when your child doesn't eat because I think it's almost that innate primeval, you know, reaction as a parent was, I must feed my child. It's like the mother bird feeding the baby birds, you know, you've gotta get in there." (Interview 7)

> "I had to go on antidepressants. I was suicidal, to be honest, 'cause I just didn't understand what was going on and I think the main thing is…as a mother your first instinct is to feed your child, and if you can't do that, nothing's right." (Interview 11)

Other mothers described how the weight of the mothering role in feeding their children meant that when things went wrong with their child's feeding, they felt like bad mothers, and like they were failing:

> “Being a mummy it’s part of your intrinsic thing to feed your child, isn't it? We all…want to feed them the best things so that they grow properly, and you sort of feel that you’re failing really, a lot of the time.” (Interview 10)

There was also significant blame and judgement passed on mothers, and feelings of guilt for mothers. The blame mothers felt came from multiple sources: themselves, their spouses, their families, and professionals. Mothers also discussed different experiences with the blame they felt. This varied from making peace with the efforts put into supporting their children, marital conflict, and experiencing feelings of anger and frustration at feeling misunderstood by others.

> “You blame yourself…did I miss something when he was a baby? Did I not try hard enough with food for him? So it's a difficult situation in all sorts of ways, but I think I've done as much as I can do for him, really.” (Interview 18)

> “My husband's mother blamed me…so I got blamed for every - all his feeding problems and then I was getting all this advice which wasn't obviously going to work and didn't work, and then I got very angry.” (Interview 11)

> “[My husband] was absolutely adamant that our son should be made to eat food, that somehow it was probably me not being a very good mother…it was very difficult, so I think a lot of criticism comes on the wife.” (Interview 7)

> “It almost feels like you're not being heard because they don't properly understand what you're saying…I remember the first time that we went to one of the dentists and the dentist was talking about what he eats, and you know going on about well, ‘why don't you switch him to water? And why isn’t he eating?’ It's like, you're not hearing what I'm saying…If I could switch him to water, he would have been switched to water a long time ago. So I think there is a lot of judgment without understanding and a lot of, this is what the textbooks say, so it should work for you because it's worked for other parents, so you feel like it's your fault

> to an extent. Even though you've got other children who can eat perfectly well, but you do, you are made to feel like it's something that you're doing wrong." (Interview 20)

Most families described encountering situations where they felt judged by others or felt guilty about their child's feeding situation due to others' reactions. There was a general concern about the way their child's eating habits reflected on them, as parents:

> "I'm surprised that he can eat these chewy bars now, and like cereal bars…they reflect on me as a parent, I'm not giving him too much rubbish." (Interview 9)

One parent spoke about reframing constructions of food as healthy or unhealthy, which were not helpful:

> "Most things are fatty and bad for you and people really look at you like you're mad, don't they? When you're feeding your child a load of rubbish, but really, it's just food." (Interview 19)

Another parent described working within her child's limits as a survival strategy, but encountering judgement for doing so:

> "In general people thinking, oh why your child has a bag full of not healthy snacks, well, because it's my survival strategy for that day." (Interview 2)

One mother described how she had been blamed constantly, and when there was a genetic cause for her son's feeding difficulty was identified, she felt relief that her son's feeding difficulty was something that would be recognised professionally. This was significant for her, as it gave her validation that she had not been the cause of her son's feeding difficulty, as had been perpetuated to her by others:

> "Within that group of children is feeding disorders, so – which was sort of a bit of a personal acknowledgement for me because…I was always made to feel like perhaps I was a mother that was over anxious or that I myself had mental health difficulties… and to see it written

> down was actually a moment for me to feel OK, I can…feel at ease now that it wasn't me. It was something else." (Interview 21)

Family Impact

Parents also described significant impact caused to their families more broadly, such as problems within family relationships and controlling families' lives. One mother spoke about how her son's feeding difficulty was "causing…problems within the family dynamics" (Interview 12). Another parent discussed the breakdown of family relationships:

> "Even grandparents didn't want to feed Theo 'cause they were too scared…it broke down intergenerational relationships and… I can talk about it without crying, but if you interviewed me when he was ten, I don't think I could have got through this interview." (Interview 21)

A major point for families was feeling their family lives controlled by their child's feeding difficulties: "Our whole life revolves around him… Everything we do revolves around him and his feeding" (Interview 11). The implications of this were that families were not able to experience and enjoy normal family bonding activities, like going out for dinner, celebrations, or going on holiday. Some also experienced social exclusion.

> "Everything social is related to food…and we can't be anywhere near food with him, and because he so averse to it all, really. So yeah, so the impact was catastrophic." (Interview 11)

> "In the past we couldn't go into a cafe or a restaurant or go out for lunch as a family because Oliver would not eat out of the house at all. So we could only do short outings because we had to get home and feed him…so it made life extremely difficult for quite a long time for us." (Interview 18)

> "Mealtimes were always… totally dedicated to him. So there's no such thing as a kind of family meal… we didn't go abroad I think for 10 years because we just didn't know we could

> get food that he would eat…so massive impact in terms of family, friends, travel and I think it, it has resulted in us being excluded a lot. People stopped inviting us places 'cause they found that it was too difficult, too stressful for them. And so quite a lonely, I'd say quite a lonely space." (Interview 21)

Interestingly, there was a sense from families that although some of their lives felt controlled and they experienced a significant impact, they adapted to their child's feeding needs, and these became their new normal:

> "Whenever we going out I have to make sure that we have the right snacks and that wherever place we're going to the food that he is agreeing with is available… but it's kind of becoming a second nature…you just do this automatically." (Interview 2)

Concerns for the Future

The concerns of parents for the future of their children centred primarily around the independence of their children in adulthood and, for the parents of children with more complex needs, concerns about adult care. Parents expressed concern about how their children would be able to live independent lives as adults:

> "Being able to feed yourself is a basic human need for survival, he's so dependent on me unfortunately that I worry about how he will manage as a grown up…is he ever going to be able to live independently?" (Interview 18)

Although parents found ways to manage their child's feeding difficulties at home, there was a sense of frustration that previous services had not anticipated, prioritised, or planned for their children's future feeding needs appropriately.

> "No one's ever taken any appropriate action…No one said, well, actually, in order to for her to function independent of her parents…she at least needs to actually learn that you eat

> when you're out or you eat you know at set times to not graze all through the day." (Interview 13)

> "I think that's the big worry, you know you can sustain this as a parent at home when they're little, but if they're transitioned into either supported living or residential care, who is going to maintain that calorific intake? Who is going to make sure they don't revert to just eating a packet of crisps in the corner? … If your child has got very restricted feeding…they're going to go into more restrictive settings as they're older… so it does have big lifelong cost implications as well." (Interview 21)

The parents of children with more complex needs also spoke of the concern they felt about how their children would cope in adult care as adults with restricted diets in an environment where they were not likely to be appropriately supported:

> "In a few years' time he'll be legally an adult. At this point, feeding will be a real issue...We're not there yet in that journey, but if we don't deal with some of these food issues now, we could end up with an adult with extremely limited food patterns and diets. And again, you know you've got a carer who, with the best will in the world, if they're on zero contract… tick the boxes, some fish fingers. They won't be there to make sure he actually eats the fish fingers… the horror stories that…we special needs parents hear all the time about caring issues." (Interview 12)

A father of a child with a severely restricted diet echoed this concern and expressed frustration that although there were many professionals involved in his son's care, no one was planning for a transition to adult care. His primary concern for his son's future was that in adult care a feeding tube would be put into his son, which was something that neither himself nor his son's mother wanted:

> “He’s got to have some way of surviving. And then there needs to be someone actually transitioning him into adult care…and say, well, this isn't going to work in adult care…And their answer is, oh we’ll just stick a stent in him…someone needs to say well look we need to transition him into bit more independence in care.” (Interview 3)

Support is Varied

Families experienced a paradox between having no support or having support that was significantly limited and often left parents in a similar situation. The primary issue was that families experienced significant difficulties in having professionals recognise that feeding was an issue that the children and parents needed support on.

Parents often described feeling let down with the services they encountered, describing feelings of desperation and frustration upon recognising that professionals were not providing support for their children in a way that resulted in meaningful change for them:

> “Unbelievably frustrating…if I take my child to the doctors and he's malnourished, surely they’re going to look at repairing him…I just felt like I was banging my head against a brick wall.” (Interview 5)

> “It was really upsetting, devastating, shocking as well because there's a presumption when you have a problem that you can find somebody to answer your questions, to give you support…it was shocking, really, the lack of knowledge, the lack of acceptance. And worse still to be told you're crazy as well. Or that you're exaggerating…the situation.” (Interview 11)

When parents were able to access support for their children, this often did not address the core issue, as parents regarded it. One parent described their experience with a dietician, where she felt like the support was not addressing her son’s needs, and like nobody cared to offer further support:

> “All [the dietitian] did was weigh him and do his height. And well, she didn't really offer that he wasn't getting any iron… It's almost like they didn't want to know…nobody wanted to know and there isn't really a person that you feel like you can go to.” (Interview 19)

Another parent discussed how they received nutritional support from a professional, which they found helpful, but the support did not target the core issue of supporting her son to consume more food:

> “Going to these [nutritionist] sessions were really helpful for me to discuss what I was doing in terms of food…but at the end of the day…the discussions I had with the nutritionist were more about the nutritional components within the food. Nobody has helped us with actually getting the food into him.” (Interview 12)

Occasionally, families described receiving advice from professionals that was not suitable for their child’s needs. One parent described receiving advice that resulted in exacerbating her son’s feeding difficulty:

> “We are in touch with a dietitian who initially started saying to us like when he were having the chicken nuggets, try like breaded fish for example, or try to change what was in it, and it made him worse, he literally completely stopped eating that food group.” (Interview 8)

Significantly, one father described how there were many professionals involved in his son’s care, and he had the sense that the feeding issue went back and forth between them, without being resolved and importantly, feeling that the professionals involved had given up on addressing his son’s feeding challenges.

> “They just come back to this old messy play. If he could put his fingers in the food… or if he could just taste things…I just think it's missing it every time… they always go around the same regime, and then they finally realize it's hopeless, as we have, and they give up…so you

> might get a physio…occupational therapists…and dietitian, and they will bounce it between them…none of them solve it completely. (Interview 3)

One parent whose child had a severely restricted diet expressed dissatisfaction with their experience of receiving support in the National Health Service (NHS). She described their experience of having to look for support elsewhere, at their own expense. This family fought two tribunals to get funding for a private company and working with this company resulted in the family receiving the support they needed and seeing significant improvements with the child's feeding difficulty.

> "The NHS do not understand whatsoever… And like I said, intervention really only comes into play when your child is near death. So we enlisted an independent company…quite costly." (Interview 11)

The major issue noted by families was the lack of recognition of feeding difficulties as a genuine issue of concern by the very professionals that parents expected would be supporting them. Families felt like it was a fight to get services to acknowledge that the feeding issue was an important one that needed addressing: "I'm the one raising this. Nobody else is. I'm flagging up that this is a problem" (Interview 12). There was a sense that the feeding issues were not being taken seriously because the children were not drastically underweight and they were consuming food, though limited and restricted. This approach lacked the understanding of the impact that their child's feeding difficulty had on parents.

> "It's been more just keep an eye on it and see how we go. I think because he's eating…because he was putting weight on and he wasn't underweight, [the dietitian] wasn't concerned." (Interview 8)

> "I think the main point is that no one sees that his feeding is one of the top priorities…The top priorities are his cognitive abilities, his speech and language development…and getting

> him ready for school. No one gives a rat's ass whether he eats or not, cause he is eating, he's eating something." (Interview 6, Dad)

Theme Two: Parents' Understanding of the Feeding Difficulty – "I Think It Would Have Always Been There"

In the same way that all families experienced significant impacts from their child's feeding difficulty, all families also had an interpretation or understanding of why their child's feeding difficulty was occurring. Importantly, parents' understanding, or interpretation of their child's feeding difficulties varied across families, but all families understood that multiple things may have contributed to why their child's feeding difficulty started or had continued happening. There were two main ways in which parents described the factors that they believed influenced their child's feeding difficulty: fixed or changing over time. Fixed factors involved descriptions about their children that were unlikely to change, while factors that changed over time involved descriptions about factors described as having changed over time. It is important to note that while these factors have been discriminated in this way, families clearly described how multiple, not single factors contributed to their child's feeding difficulty. This meant that families could identify both fixed factors and factors that could change over time as influencing their child's feeding difficulty.

> "The autism around the age of three… and that was the kind of point in time when it coincided with the breaking of the leg, the reduction in being able to feed her food, so she never learned the skills." (Interview 13)

Stable factors

There were many descriptions provided by parents about things that contributed to their children's feeding difficulty that were described as stable, or that would likely have been present from early on for their children and which may be more difficult to change. These related to: physiological deficiencies, genetic syndromes, difficulties with interoception, children's diagnoses, associated conditions to children's diagnoses, children's personalities, and anxiety or fear felt by the children.

The father of a child with very complex needs and a severely restricted diet discussed how his belief was that his son's feeding difficulty was related to an existing issue with his son's ability to swallow:

> "It's based in his inability to swallow properly…there was a therapist way back about 10 years ago who said, you know the reflex for sucking on a teat is different from swallowing food and that suddenly clicked in my brain and I thought, yeah that would explain it." (Interview 3)

Two mothers of children with rare genetic syndromes understood that their child's feeding difficulties were present due to the biological predisposition of these genetic syndromes:

> "I mean his [genetic condition] actually means he's got muscle tone weaknesses, and so I think from birth he'd have just found it difficult to, to swallow and to feed. So I think it probably was linked to his chromosomal condition." (Interview 21)

> "I think it would have always been there, as in his syndrome…would have always, always caused an issue with the skills to eat and the hypersensitivity around food." (Interview 11)

Interestingly, at various points both these parents discussed how having that genetic diagnosis was validating for them, as it meant that they understood why the feeding difficulty was occurring and they could approach professionals with more confidence that they would be listened to in relation to the feeding issues.

Two other parents discussed how they believed their children lacked a biological instinct or ability to eat. For one parent, the interpretation that their child could not recognize that they were hungry was presented by a professional:

> “Her instinct to feed herself didn't even kick in… [Professional A] …he said that he didn't think that Kimmy felt hunger …which is why also, when she walks around the house aimlessly looking for food that she doesn't want, it's just a behaviour rather than her, than an instinct to a certain extent.” (Interview 13)

Another parent described how the ability to eat was not instinctual for their child:

> “I just think it was not having, just not having the ability to know how to do it. It’s not as natural as you think. Everything has to be explicitly taught.” (Interview 19)

Interestingly, this parent described that her child not having the ability to eat as a stable factor, but that this was something she believed could be changed through teaching.

Parents often understood that their children’s diagnoses (autism, intellectual disabilities, ADHD, etc.) could have contributed to the development of their child’s feeding difficulty or the reasons why it continued to happen after it emerged:

> “Well I think it's, it's part of these other things. The ASD, ADHD things really.” (Interview 12)

One parent considered that it was possible that her son was continuing to exhibit his feeding difficulties due to having acquired a routine that he was sticking closely to, due to being autistic:

> “This might be also a part of his habit now as well… autistic children are very habitual, habits and routines they are very clinging to it, so this is another aspect of it.” (Interview 2)

Another parent also discussed the rigidity of thought associated with autism, and how she considered that this rigidity of thought continued to influence why her son, aged 12, had continued to be inflexible about trying new foods, and in fact had regressed further with his eating:

> “The rigidity of thought, because autistic people have that rigidity of thought…they’re very often completely inflexible. I think for him, in his head, it's like this is what I eat.” (Interview 18)

Another parent discussed how autism could influence feeding difficulties due to the nature of repetitive behaviours and difficulties with change that are often associated with autism.

> “I think with autism you will get that repetitive behaviour that lack of wanting to change, and change is always difficult.” (Interview 7)

There was also an understanding that some conditions like communication difficulties and differences in sensory processing, that often co-occur with ID or autism, could also have contributed to why their child’s feeding difficulty emerged or continued to occur. Some parents of children that did not communicate verbally expressed frustration at not being able to understand what their children were trying to communicate to them, and how this made it more difficult for them to understand what their children would or would not accept:

> “She can't communicate what she doesn’t like or what she does like so if she's got something in her mouth, she doesn't like then she just spits it out… She is communicating to me nonverbally by her actions and I don’t always pick up on them.” (Interview 4)

> “He can't speak, so if he would speak then he could, he could have tell me, Mommy, I, today, I don't want this, today I want this, so he can’t tell me and I don't know. So this is the problem.” (Interview 15)

One parent explained how her son clearly had an idea about the criteria that food needed to meet before he would consume it, but that he had no way of communicating this to her, so she was constantly guessing, which made it difficult for them to work within her son’s limits, as they did not know what these were:

> “The refuse always is based on his criteria…which he can't explain to me, for what is acceptable and what isn't. And they, they can and do change…I think that's why it's difficult to actually get a handle on it because is he rejecting this because of the shape of it, or the temperature, or the texture, or just because he doesn't want it, or it smells bad or, you

> know, you’re like, I just don't know 'cause he can't tell me, he's giving me no indication other than that he's thrown it.” (Interview 14)

Parents were also acutely aware that their children experienced difficulties with sensory processing and that these influenced their child’s feeding difficulties:

> “All I can think of is sensory issues. I have no other answers other than that, just sensory issues…But, no, apart from that, I haven't a clue…” (Interview 8)

They were able to describe the parameters of food that their child’s sensory preferences allowed them to accept:

> “It's based on texture, sight, temperature, the look and feel of it. So he's very, very specific about what food looks like and feels like, so he can reject things based purely on that, even if it's a previously accepted food, if it's in a different format, then it's a no.” (Interview 14)

They also considered the ways in which sensory processing difficulties influenced the development and continual occurrence of their child’s feeding difficulties:

> “He's always had really complex sensory issues, and he's got particular oral sensitivities, so I think all of that had an impact on him being able to kind of cope with lumps and then moving onto solids.” (Interview 20)

> “I just think it's a sensory autism processing thing…he still can't tolerate certain textures …but he just doesn't like it and I think it's also recognizing that sometimes there's just things we don't like. But trying to find food that you know is, is it in a form that he enjoys eating and you know, maybe sometimes it's rethinking what we eat.” (Interview 7)

Some parents also considered that the children themselves perpetuated the feeding difficulty in ways related to their personality or the food choices that they made for themselves. The parent of one child considered that her son’s feeding difficulty continued to occur due to: “pathological demand avoidance. He knows we want him to eat food. But he's hard wired to enjoy…foods that are just really bad for him" (Interview 6, Mum). Likewise, other parents considered that their children were stubborn, and provided that understanding of why the feeding difficulty had continued:

> "I feel like I'm just fighting a losing battle… she's so stubborn." (Interview 4)

> "Some of it is just downright stubbornness, and like I want what I want when I want, you know?" (Interview 13)

Other parents considered that their children may have been making active choices about what foods they did or did not want to eat:

> "I'd probably given her too much choice so she can kind of pick and choose what she eats." (Interview 4)

One parent discussed how she interpreted her autistic son's feeding difficulty as him making the choice to stick to certain foods, which she attributed to her son's need to control his environment and stick to the things that he knew:

> "He's old enough now to make that choice. That decision is decided, he doesn't want any of that…and a lot of people with autism, they do want to control their environment, don't they, because everything else is quite scary." (Interview 10)

Other parents discussed the need for control more broadly as influences on their children's feeding difficulties:

> "He will just refuse to eat. If he's ill, he'll refuse to eat. If he vomits, he's probably unlikely to eat anything for about two weeks afterwards. So it is, it's all, there's a lot of it tied around anxiety for him and it's, I can control what I eat, so if I can't control anything else." (Interview 20)

One parent considered the autonomy of her child in his food decisions, since he had very little choice in his life:

> “I suppose it's part of the control he has in a life that's very much, you know, led for him, so it's his control to say whether or not he likes a particular food and whether he's going to eat it.” (Interview 12)

Clearly, parents also considered that their child’s feeding difficulties were influenced by factors like anxiety or fear and spoke of the feeding difficulties making the children feel safe within their comfort zones and providing predictability for them. As above, other parents also discussed the role of anxiety:

> “From my perspective, he must have an anxiety about it because it's the first thing on his mind and he needs to know what's happening.” (Interview 5)

> “I think that he's probably never had the big opportunities to change his perspective on food. I think…food to him is always associated with anxiety so he's never seen food in a positive light.” (Interview 21)

The parent of a young girl expressed that she believed her daughter was frightened of trying new foods, which kept her from continuing to try something even after she had already tasted it:

> “I can only say that she's frightened…because it's not that she doesn't like the taste because she can taste something and really like it and she'll come forward to eat it again, but then she’s scared. So it's the texture that puts her off rather than the taste, and I can see that she really – there’s certain foods where she really wants to eat it, but something is holding her back, so it's getting her over that fear.” (Interview 17)

Parents also spoke of their children perceiving their selected foods as ‘safe’ for them. They spoke of their children exhibiting difficulties expanding their food repertoires because of staying in their comfort zones with their designated ‘safe’ foods and being unwilling to expand beyond them:

> “I think for him, in his head, it's like this is what I eat. This keeps me safe. I don't need to eat anything else. I suspect he's afraid of eating other things.” (Interview 18)

> “It’s become engrained to the point where she just feels comfortable eating what she is because it's safe, isn't it? ... They're perfectly safe.” (Interview 13)

> “Well, I think because it's safe. You know, that's his safe food…I think it’s that he feels safe, I suppose, but he doesn't tell me that. But that's what I feel.” (Interview 10)

One parent expanded beyond this that sticking to the foods that her son consumed also helped ensure that he was able to predict what was coming, which likely helped him feel safe related to food:

> “I think it is just a safety thing, he knows what to expect and I think it does seem to be better when he's got a routine, like if he knows what's coming next, again because of the communication issues that we've got, so, I think it's just predictability as well…he knows what's coming.” (Interview 8)

Factors that change over time

There were many descriptions provided by parents about things that contributed to their children’s feeding difficulty that were described as resulting in a change in the feeding difficulty over time. These related to: weaning transition, triggering events, missing developmental milestones, being stuck in a developmental stage, or as a result of learned behaviour.

Some parents described noticing that their children started having difficulties during the weaning transition:

> “I think it was the change in texture, so from, going from the weaning stage… I presume it was the change in the format that then became difficult for him. It was as early on as that I think.” (Interview 9)

> “I think it started over time…just a change from his weaning to starting to get more sensory lead.” (Interview 12)

> “It started as I was started moving from the baby food to main adult food, it started from then.” (Interview 15)

Various triggering events were described as having contributed to the development of their child’s feeding difficulties.

> “Ever since that really bad tonsillitis where he couldn't really eat anything for three weeks, his eating habits just totally changed…it kind of never went back to normal.” (Interview 5)

> “He caught hand, foot, and mouth when he was about three…suddenly, having anything in his mouth was very, very painful…So I think that perhaps also exacerbated the food intolerance from the sensory intolerance because he’d had this very sore throat.” (Interview 7)

Parents also described their interpretations of their child’s feeding difficulties as having occurred due to their child missing a developmental milestone related to feeding or becoming stuck in a developmental stage and having difficulties moving forward in their feeding development:

> “I think it's a development that he's missed, and it's sadly been overlooked” (Interview 9).

> “He hasn't gone through the development steps…if a child doesn't go through this natural development steps that they get stuck in whatever steps that they're stuck in and he was stuck in that puree stage for years and years.” (Interview 21)

One parent discussed how he believed that his son had missed the critical period for eating instinctually, though he strongly believed that his son could learn to eat:

> “There are plastic phases where you develop certain things and then the brain stops, and that's fixed…I think if you don't develop…the right mechanisms for eating and liking food by

> a certain age you never will. And you have to acquire it through learning, rather than it being instinctive…my amateurish understanding of psychology is that…it's gone through the plastic phase and now it's too late so he will never, instinctively want to eat, it will never come…I think he's lost it. There's a piece of development that's not going to happen now, and so it has to be a learned behaviour." (Interview 3)

While this father had an understanding that his son could learn to eat, some parents interpreted their child's feeding difficulties as a learned behaviour that continued to occur across their development. One parent discussed how she understood that her son engaged in challenging mealtime behaviours as a way of getting attention during mealtimes. She explained how her son exhibited more feeding difficulty behaviours with her husband than with herself, and that her husband often reacted strongly to her son's challenging mealtime behaviours. She explained how she did not give a reaction when her son engaged in challenging mealtime behaviours, and he engaged in these less frequently with her.

> "I think as he started to see food as a way of control as well and a way of gaining attention." (Interview 12)

Another parent spoke about her son learning to refuse to eat foods presented to him, as in the past when he refused, he had the opportunity to eat preferred foods later. She believed that he had learned these patterns and was continuing to respond in this way:

> "He knows that oh well, if I don't eat, later, I will eat what I like, things like that maybe so, pretty easy in his brain, isn't it? He is getting a little bit clever so he is, every day he's getting clever and in this way is doing some more fussy things." (Interview 15)

It is important to reiterate that parents in this study reported multiple things as influencing their child's feeding difficulties, and while they often had a good understanding of many factors that influenced their individual child’s feeding difficulties, it was not common for parents to understand all the factors that were likely influencing their child’s eating.

Theme Three: Understanding Changing the Impact – “He’s Not Trying to Hurt Me, There’s Always A Reason for Why He’s Doing It”

A prominent theme in the data for this study was that for some families, understanding their child’s feeding difficulty changed the impact of the feeding difficulty for them. This occurred when parents’ understanding facilitated a change in their attributions, often resulting in them shedding blame and gaining acceptance of the situation, and when the understanding resulted in them changing their own mealtime behaviours in ways that helped them better support their children.

Having a meaningful explanation for why their child’s feeding difficulty was occurring mattered greatly to parents. One parent described how she wished that she had been supported in understanding why her child’s feeding difficulty was occurring sooner. Having this explanation and understanding took the blame off her:

> “I would have liked somebody to have said to me this isn't your fault. I would have liked somebody to have explained what was going on. So to have explained it a bit like [the feeding service] did for me, to say look this is neurological and there's not a magic wand, you know, I kept saying somebody needs to sort this problem out for me, so I needed explanation.” (Interview 11)

This parent had the unique experience of having been supported in her understanding by a private feeding service, and this resulted in her changing the way she saw her child’s feeding difficulty, and importantly changing the way she and her family managed her son’s feeding difficulty.

Other parents described receiving psychoeducation and information about feeding difficulties from professionals that supported them in their understanding. One parent had a serendipitous experience of having met feeding professionals while on a postgraduate course that provided her and her classmates with psychoeducation about Avoidant/Restrictive Food Intake Disorder (ARFID). This helped this parent understand why her child was engaging in a feeding difficulty, took the blame off her as a parent, and provided useful information on how to support her son more appropriately:

> “Everything she said…just fit Joseph completely, so that made a lot of sense to me, so that changed how we do things and I think got rid of a lot of the guilt for me as a parent…I think hearing that lecture really made a massive difference to me and got rid of a lot of guilt for us. But also gave me some really good tips as to how to manage it as well.” (Interview 20)

For some families, just learning to understand their child’s limits was enough for them to understand their child’s current feeding situation. One mother described how learning the limits of her child’s feeding difficulties helped her understand that her son’s challenging mealtime behaviours were not targeted at her, rather a manifestation of his strict limits around the food he would accept:

> “He's not doing it to make you upset, he is doing it for his reasons… I always try and remind myself in the bad times that it's not, he's not trying to hurt me or upset me, there's always a reason, and especially because of the autism it is usually a fairly logical reason that, in his criteria of, why he's doing it.” (Interview 14)

> “To be his mum and love him, I have to love all bits of him…So I have to embrace those feeding issues, as it's part of him, he can't help it. He's not doing it to annoy me or to be difficult…so it's just another facet of Craig…it's one of those things you've got to, if, if you fight it, it hurts you, 'cause he's not doing it deliberately. If you keep fighting it and then you'll make him miserable and then you'll make you miserable. And so you have to kind of work with what you're given and try and move forward.” (Interview 14)

One parent discussed the importance of putting herself in her child’s shoes to understand why he wasn’t eating something. Her attributions of her son’s feeding difficulty changed, and she was able to understand why her son struggled with certain foods.

> “So if someone tried to make me eat some haggis or something, then what would it be like? And then you kind of get the idea…the task is so monumental…You’ve got to put yourself in their shoes.” (Interview 19)

This shift in attribution was powerful for participants and was described by other parents as well. One parent discussed how learning to work within her son’s eating limits and accepting a new normal for her family meant that she no longer felt controlled by her son’s feeding difficulty. The feeding difficulty was still difficult to accommodate, but the attribution shift reduced the weight of the impact on her:

> “I have in the past felt quite controlled by it, but I've had to change my relationship with that and decide…I'm not going to see it as being controlled by…this is just the way our family is. You know if we can get that right for him, he's happy.” (Interview 7)

Parents not only described experiencing an attribution shift, but some also described changing the ways they approached supporting their children with their mealtime challenges. One parent discussed changing her behaviours during mealtimes so that she could reduce the anxiety and fear that her child felt during mealtimes:

> “So, it's still been a continuous problem…but there's more understanding from him now, and there's more understanding from me because, while I was quite new to it, now, I kind of get him and I get what he kind of can't do so I put in place [things] so mealtimes aren’t as scary for him.” (Interview 5)

One parent discussed how after learning from a feeding service about ARFID, she and her family changed their behaviours during mealtimes, reducing the pressure on them to prepare multiple foods, and the pressure for her son during mealtimes, so he could eat what he felt comfortable with:

> "I think just knowing that…if he wanted to have chicken nuggets and chips every night then that was OK. Was he eating? Was he growing? Yes. So, it took a lot of stress out of mealtimes…there wasn't that panic about, you know, what will he eat? Will he eat tonight?... Prior to that it wouldn't be unusual for me to cook two or three things in the hope that we could get him to eat something new and then eventually we always ended up cooking the thing that he would eat. So after doing their sessions it was like well actually it's absolutely fine for him to just have the things that he'll eat and we'd obviously try to introduce new foods every so often. We still try to introduce new foods, but there's no pressure on that." (Interview 20)

The same parent discussed how this reframing of the situation and understanding her son's limits meant that they changed their behaviours in the way that they supported their son to try new foods. This was all facilitated by the shift in their understanding by the feeding service.

> "Rather than trying to get him to eat beef or pork or anything, we just worked on getting him to eat different types of breaded chicken, and then different types of breaded fish because he would eat fish fingers." (Interview 20)

Another parent discussed how her understanding of her son's feeding difficulty meant that she stopped pushing him outside of his comfort zone with food and respecting his limits, and as a result the child did not engage in challenging mealtime behaviours.

> "You…don't push the bait out very much at mealtimes so that you don't get all the weird behaviours and then you can praise the sitting, and the looking and joining in. But if he doesn't want a drink, he won't have it." (Interview 19)

Significantly, data in this study showed that meaningful change in children’s behaviours could be facilitated by parents changing the way that they understood and approached their child’s feeding situation:

> “I hate having the TV on when he's eating, but that is the only thing that's actually worked. So we have to just carry on with that, 'cause he's eating something, you have to let go of a lot of what things you anticipated or wanted… oh, let's have a dinner around the table kind of thing that you're hoping for. It's all gone out the window and he's sitting in front of C. Beebies, but he's actually eating something.” (Interview 14)

Some parents, however, described having implicit theories that did not result in a change in attribution or parent behaviour, and they did not experience this change in the impact of their child’s feeding difficulty.

Discussion

This study explored parent’s experiences of behavioural feeding difficulties amongst their children with IDD and related supports received in England. This study showed that families in England experience a variety of significant impacts related to their children’s feeding difficulties. Parents also have varied understandings of implicit theories about why their child’s feeding difficulty has developed or continued to occur throughout their life. Many parents understood that a range of areas contributed to their children’s feeding difficulties, usually more than one, but they were not usually able to identify all the factors that may be influencing their children’s feeding difficulties, unless they had been professionally supported to arrive at this understanding. For some parents, understanding their children’s feeding difficulties appeared to change the impact of the feeding difficulty for them, through the changes in attributions and mealtime behaviours that this understanding facilitated.

An important finding of this study was the variety of impacts experienced by families of children with feeding difficulties. Previous literature has shown that caregivers experience significant mealtime challenges when feeding autistic children. The current literature shows that feeding difficulties in children can pose different daily challenges to mothers than would be faced by mothers of children without feeding difficulties (Winston et al., 2010). The qualitative literature in this area has outlined the many ways that caregivers have experienced the impact of their children's feeding difficulties. Studies have outlined how caregivers have experienced financial difficulties, unsupportive networks, letting go of the idea of eating together as a family, concerns with the nutritional intake of their children, experiencing psychological impacts related to their child's feeding difficulty, and experiencing significantly disrupted family lives (Adams et al., 2020; Adams et al., 2021; Ausderau & Juarez, 2013; Burkett et al., 2022; Estrem et al., 2016). The current study provided support for previous findings in all these areas except financial difficulties. Interestingly, the studies that have indicated financial difficulties related to feeding difficulties as a finding have both been carried out in South Africa (i.e., Adams et al., 2020; Adams et al., 2021). All the participants in the current study lived in England, and while demographic information related to socio-economic status was not collected, it is possible that the participants in Adams et al. (2020) and Adams et al. (2021) were of a lower socio-economic status than participants in the current study, thus explaining why financial difficulties were not commonly discussed in the current study.

Importantly, while the impacts experienced by families of children with IDD have been discussed previously, in the context of this study it was an important finding as exploring these was not part of the research aims, but it was discussed in detail and emotively by parents in every interview. A strength of this research was the inductive grounded theory approach taken which allowed this theme to be explored in depth throughout data collection, and in the analysis process, and resulted in the development of a participant- and data-driven grounded theory.

A previous grounded theory study in this area has described a dialectic of control and acceptance as being central to the mealtime experiences of parents of autistic children (Curtiss & Ebata, 2021). Curtiss and Ebata (2021) sought to understand the processes that facilitate family meals and explain the challenges that families of autistic children face during mealtimes. They were also interested in exploring how families overcome the mealtime challenges they faced to maintain family wellbeing and functioning. They found that families manage a dialectic of expressing love through control and acceptance, using mealtimes to set expectations for their autistic children and provide them with support. Curtiss and Ebata (2021) proposed the first grounded theory exploration of family mealtimes with autistic children and the processes which families experience during mealtimes. While this information is valuable to understanding the mechanisms that may drive families' actions during mealtimes (i.e., control, acceptance), it does not provide a comprehensive understanding of how the impact of feeding difficulties can be mitigated for families. The current study resulted in a grounded theory that the understanding that parents have of their children's' feeding difficulties may change the impact of the feeding difficulty experienced by families, if this understanding results in attribution shifts or changes in parents' mealtime behaviours. A significant difference between these studies is that Curtiss and Ebata (2021) focused on families with autistic children, while the current study included parents of autistic children and children with intellectual disabilities.

As explored in Chapter One, there exist a wide range of theories in the literature to explain why feeding difficulties may start and continue to occur. The existing qualitative research in the area of feeding difficulties has contributed depth to the understanding of families, experiences of feeding difficulties, and how families view the ways these develop and continue to occur. As described earlier, qualitative research in the area of feeding difficulties has described how parents characterise their child's feeding difficulty as a journey that evolved over time (Estrem et al., 2016). Parents have also described looking for explanations for their child's feeding difficulty, struggling to understand what was wrong with their child's feeding and trying to find ways to support their children with their feeding difficulties (Adams et al., 2020; Stoner et al., 2006; Suarez et al., 2014). Previous research has also indicated parents have their own beliefs about the causes of their child's difficulties (Estrem et al., 2018; Ismail et al., 2020; Rogers et al., 2012). It is evident from the current literature that parents look for explanations for their child's feeding difficulties and actively engage in strategies to try to improve their families' mealtime situations. The current study reiterated the importance of the unique parent perspective about the implicit theories of their children's feeding difficulties. Parents in this study presented a wide range of interpretations or understandings of why their child's feeding difficulties may have emerged or continued to happen. It is significant to note that parents were aware that more than one factor contributes to their children's feeding difficulties, but they were not usually able to identify all the factors that may influence their child's feedings. Only one parent was able to do this, and they had been extensively supported through this process by a clinical psychologist in a private feeding service to understand all the factors that influenced their child's feeding. Importantly, this study demonstrated that the understandings parents had of their child's feeding difficulties did not appear to be enough to mitigate the impact of the feeding difficulty on them (i.e., it was not enough to have an implicit theory). The key factors were that the understandings parents had of their child's feeding difficulties appeared to need to result in an attribution shift or a change in parental behaviour at mealtime, for the reduction on the impact of the feeding difficulty to be felt.

This finding provides some implications for clinical practice. It may be helpful for clinicians to be aware that it is important to acknowledge that parents have their own interpretations of why their child's feeding difficulty might have started or has continued to occur. Clinicians may also find it helpful to be aware that these implicit theories are likely to need to result in attribution shifts or changes in parental mealtime behaviour for these interpretations to reduce the impact of the feeding difficulty on families. This means that it may be beneficial for clinicians to explore families' understandings of why their child's feeding difficulty is occurring, and work with families to develop a shared understanding of their child's feeding difficulty, where necessary, to enable an attribution shift and changes in parental mealtime behaviours. Interventions for behavioural feeding difficulties may also benefit from considering this in the support that is provided.

Previous research has indicated that parents of children with feeding difficulties may feel as though health care professionals do not believe their feeding struggles (Tan et al., 2021). The parents in this study noted how there was a lack of recognition by health care professionals of feeding difficulties as an issue that was genuinely important to families. There was a sense amongst parents that the feeding issues were not paid sufficient attention by health care professionals because the children were in fact consuming food, though limited and restricted, and they were not drastically underweight. This is an important finding for clinicians to consider when working with families of children who exhibit feeding difficulties. Families clearly need support, and it is important to them that their concerns about their child’s feeding difficulty are validated and treated with concern by health care professionals.

Strengths

The largest strength of this research is the inductive, data-driven approach which was taken throughout data collection and analysis. The inductive approach to data collection meant that the topics that were discussed by participants could be explored further and that the interactions in the data that were identified could be explored further as they were identified, rather than checking them against and mapping onto an existing theory (e.g., as would be done in a deductive approach). This inductive approach, along with a rigorous grounded theory data analysis process means that there is confidence that the findings represent the true nature of the grounded theory identified in this study.

Another strength of the current study is the number of parents that participated in the interviews. There were 22 parents that participated across 20 interviews; in the context of grounded theory research, this is a very large number of participants. Given that so many participants were interviewed, and that by the end there were no new ideas or codes that emerged, there is confidence that theoretical saturation was reached. This means that there is confidence that the presented grounded theory is representative of the role of attribution shift and change in parental mealtime behaviour on the impact experienced as a result of their child's feeding difficulty.

Finally, as evident above, the findings from this study mapped on well to the existing qualitative literature on parents' experiences of their child's feeding difficulties. This indicates that the experience in the UK may be similar to the experiences of parents reported in other parts of the world, despite differences in health care systems and ways of accessing support, meaning that there appears to be a wider issue around recognition of feeding difficulties. As well as extending the current findings, this study has taken the understanding of family experiences of feeding difficulties further, by presenting a new grounded theory that has implications for clinical practice for those providing support or intervention for families of children with IDD that exhibit feeding difficulties (as outlined under Discussion).

Limitations

There are some limitations to this study that are important to highlight. As described in the methods section, there was an element of a post-hoc analysis to the interview data collected, which is in contrast to the simultaneous approach to data collection and analysis that is usually used in research that uses grounded theory methodology and analysis. In grounded theory, it would usually be expected that coding and data collection occur simultaneously, however this was difficult in practice due to the rapid influx of data. Although a limitation, it was not believed that this impacted the grounded theory nature of this study as the PhD researcher, carried out all of the work completely independently. This meant that she was immersed in the data entirely and able to carry out constant-comparison of the data, member checking, and theoretical sampling as the interviews were occurring.

Unfortunately, like much existing research, this study did not recruit a very diverse sample. While not many factors related to cultural diversity of families emerged from the data, the cultural context of food was mentioned by most families that were ethnically or racially diverse (highlighted briefly in Family impact section under Theme 1). Future research should seek to explore the meaning and cultural context of food when an ethnically or racially diverse family has a child with a feeding difficulty, as there are likely to be unique impacts related to cultures where food is central to the cultural practices, or where foods are unique to certain cultures, but children are unable to consume them. Additionally, nearly all the participants in the current study were mothers. While this is not a limitation that is unique to this study, it does present a limitation in that paternal perspectives were not able to be explored in depth in the same way as maternal perspectives were.

Another limitation that relates to demographics is that, as mentioned previously, most of the existing qualitative literature about feeding difficulties in children with IDD has focused on autistic children that exhibit feeding difficulties and the experiences of families of children with intellectual disability exhibiting feeding difficulties have not been explored in similar depth. This study used a broad definition of IDD and sought to include parents of autistic children and children with intellectual disability. Most of the children discussed were autistic or were dually diagnosed autistic and with intellectual disabilities, meaning that although there were attempts to ensure there would be more representation of children with intellectual disabilities, this was not achieved. This was representative of the parents that came forward for participation, however it is still a limitation of this study. Additionally, most of the children that participants discussed were older than ten years old. The age range accepted for inclusion in this study was broad (up to 18, exclusive), and this posed a limitation in that the families of these children could have experienced their children’s behavioural feeding difficulties differently to families of children who had recently started exhibiting a behavioural feeding difficulty, or who had a shorter history of this.

Finally, the interviews from this study produced an extremely large data set, which was difficult to manage given selected Straussian grounded theory analysis methodology. Once it was evident that the data set would be very large, a very rigorous and methodical analysis process was developed (i.e., the Straussian grounded theory task analysis) to ensure that the data was managed and considered appropriately in the subsequent analysis. There was also a balancing needed to ensure that the most salient pieces in the data would be focused on, as there was a large amount of data. The data that was focused on was influenced by the overall goal of this PhD thesis, which is to lead to the development of an intervention approach for feeding difficulties, that is informed by parent and health care professional perspectives. The results that have been focused on and which were explored further were therefore influenced by this goal and the researcher's positionality as a clinician and a researcher in applied psychology, where the focus is to solve practical problems that people encounter.

Conclusion

In conclusion, the findings from this study show that clinicians and the relevant health care professionals need to acknowledge feeding difficulties as important issues that families need support for and validate families when they describe their child's feeding difficulties. Parents expressed feeling a weight off their shoulders when their child's feeding difficulties were acknowledged, and clinicians and relevant health care professionals should be aware of this when they encounter families that mention issues with feeding. Families clearly have their own interpretations or understandings of why their child's feeding difficulty may be occurring, but these may not represent the full picture of the factors at play and clinicians need to support families through understanding all the factors that influence their child's feeding. It may also help for clinicians to be aware that having an understanding about why the feeding difficulty might be occurring may not be enough to produce a change in the impact experienced by families of children with feeding difficulties. These understandings may reduce the impact felt by families if the understanding results in an attribution shift or change in parental mealtime behaviours. This means clinicians may need to work with families on developing a shared understanding about their child's feeding difficulty that is different to families' original interpretations. This needs to be done sensitively, as families have expressed frustration when their opinions or understandings of their child’s feeding difficulties are not acknowledged by the relevant clinicians or health care professionals. Finally, it may be important to incorporate meaning-making when supporting families of children with feeding difficulties. Supporting families with meaning-making may allow families to understand their child’s feeding difficulty in a way that can support attribution shifts and changes in parental mealtime behaviours, potentially resulting in reduced impact of the feeding difficulty on parents. Clearly parent perspectives and experiences of feeding difficulties and related supports offer valuable contributions, particularly as these experiences and perspectives have been lacking in the context of the UK. However, drawing on broader qualitative literature from outside the UK could be helpful in furthering understanding of stakeholder experiences because it will provide further context for stakeholder experiences and understandings of behavioural feeding difficulties and related supports. Therefore, there is a need to acknowledge and synthesise existing qualitative literature on this topic to explore shared experiences more broadly (i.e., outside the context of the UK). The next chapter will explore and synthesise what the current qualitative literature on this topic states, to provide more context for understanding stakeholder experiences and understandings of behavioural feeding difficulties, and their experiences of supports or interventions they may have received for these.

Chapter Three Meta-Synthesis of Qualitative Research on Family Experiences of Behavioural Feeding Difficulties Amongst Children with Intellectual and Developmental Disabilities

Chapter Overview

In Chapter Two, the lived experience of parents of children with intellectual and developmental disabilities (IDD) in the UK was explored in depth and the breadth of impacts that families experienced when their child with an IDD exhibited behavioural feeding difficulties was presented. From this study, it appeared that having a reason for why their child's behavioural feeding difficulty was occurring could play a role in mitigating these impacts for families (i.e., taking away guilt, blame, etc.) when this understanding resulted in a change in attribution or parent mealtime behaviours. In order to situate Chapter Two's findings, a systematic review and meta-synthesis of the current qualitative literature about families' experiences of their child with an IDD's behavioural feeding difficulties will be explored. While Chapter Two focused on the UK context, the current chapter will acknowledge the broader qualitative context and the contributions of shared parent experiences more broadly (i.e., without being UK-specific). Meta-ethnography (Noblit & Hare, 1988) will be used to identify consistencies and inconsistencies in this body of literature. This will ensure that family experiences are comprehensively understood. One of the research questions guiding this thesis is to explore stakeholders' experiences and understandings of behavioural feeding difficulties amongst children with IDD, and their experiences of related supports for these. Following on from Chapter Two, which was UK-specific, a broader exploration of the available qualitative literature on family experience that was not UK-specific was considered the next step to gather the lived experiences of parents of children with IDDs exhibiting behavioural feeding difficulties, and their experiences of any related supports. The results of this analysis will contribute to synthesising the current literature of parents' experiences of behavioural feeding difficulties, their understanding of their children's behavioural feeding difficulties, and their experiences of supports received for these.

Introduction

Families of children with feeding difficulties experience a multitude of impacts. Some of these impacts are related to increased parental stress, family anxiety and difficulties receiving support (Jackson et al., 2022a; Jackson et al., 2022b; Luscombe et al., 2021; Miles et al., 2021). In Chapter Two, the rich lived experience of parents in the UK was explored and many impacts to the child, parent, family system, parental concerns for their child’s future, and difficulties with receiving support were identified. This study showed that while all parents described experiencing significant impacts, there was an important role of understanding why their child’s feeding difficulty was occurring, that appeared to mitigate the impacts of feeding difficulties when this resulted in changes to parents’ attributions and behaviours at mealtimes. Clearly, parents and family members have perspectives of their experiences of caring for these children and receiving support for feeding difficulties that can contribute valuable information about ways to support families of children with intellectual and developmental disabilities (IDDs) exhibiting behavioural feeding difficulties.

Previous research has used meta-ethnographic methods to synthesise qualitative literature and derive conclusions about patterns in the available qualitative literature on a specific topic (e.g., Griffith et al., 2013; Griffith & Hastings, 2014; Wolstenholme et al., 2020). Meta-ethnography is described by Noblit and Hare (1988) as a synthesis of research that is interpretivist in nature. The goal in a meta-ethnography is to synthesise qualitative research using an interpretivist perspective, by going beyond what single studies report to create or describe analogies between accounts reported across studies (Noblit & Hare, 1988). Thus, meta-ethnography attempts to arrive at a synthesis of knowledge following an inductive and interpretivist process by translating studies into one another (Noblit & Hare, 1988). This is a higher order analysis that aims to go beyond the content in the original included studies by identifying master themes that encompass all identified themes in the included studies and which has explanatory power (Griffith & Hastings, 2014).

Meta-ethnography has previously been used in the field of IDD. Griffith and Hastings (2014) used meta-ethnography to carry out a meta-synthesis of qualitative research about the experiences of caregivers of individuals with intellectual disabilities and behaviours that challenge in relation to their experiences of support services. They identified five themes: love, altered identity, crisis management, support is not just ‘challenging behaviour’ services, and the future (low expectations, high hopes). They found that carers described loving their family members deeply and experiencing extreme demands due to their caregiving roles, which could be exacerbated by support services, rather than these alleviating their caring demands. They conclude that the synthesis of existing qualitative research in the field of intellectual disability can be valuable and can contribute to other areas of research on intellectual disability.

Meta-ethnography has also been used in relation to family experiences of behavioural feeding difficulties in a typically developing population. Recently, Wolstenholme et al. (2020) conducted a meta-synthesis of the qualitative literature from 2008 to 2018 that examined family experiences, perceptions, and practices when their typically developing children had non-clinical behavioural feeding difficulties. Their objective was to explore the relationships between perceptions and experiences of selective eating, and practices related to selective eating that have been described in qualitative studies using a meta-ethnographic approach (Noblit & Hare, 1988). Ten studies were included in their synthesis and findings resulted in a proposed conceptual model of the experience of families when children exhibited selective eating. Ultimately, this synthesis described an association between self-efficacy, attributions of selective eating, and hunger regulation as influencing the different feeding practices that parents used. They describe how these three factors influence parents’ feeding practices (e.g., modifying foods so the sensory properties of food are disguised; repeated exposure of non-preferred foods if parents understand their child’s selective eating to be influenced by an environmental variable). This study shows that parents of children with selective eating have an understanding of why their child’s feeding difficulty may be occurring, and this can influence the way they feed their child. Their child’s selective eating can also have an impact on the parents themselves, for example experiencing low self-efficacy related to their ability to feed their child properly. This meta-synthesis yielded a comprehensive understanding of the conceptual model that relates parenting perceptions, experiences, and their practices, however the focus of the meta-synthesis was not specific to children with IDD that exhibit feeding difficulties. As mentioned, children with IDD may have an increased risk of exhibiting behavioural feeding difficulties due to increased risk factors. Thus, it is important to explore family experiences of behavioural feeding difficulties that are specific to children with IDD, to further our understanding of how to support families in these complex situations.

Given the importance of exploring family perspectives of behavioural feeding difficulties that are specific to children with IDD, this meta-ethnographic approach may be particularly well-suited to provide a synthesis of existing qualitative research on this topic. Further, qualitative research is particularly well-placed for exploring families' experiences of feeding difficulties exhibited by children with IDD, and while research has explored families' experiences of feeding difficulties, to date no synthesis has been carried out of the existing qualitative literature with this population.

The aim of the present review was to synthesise and examine the qualitative research exploring families' views and experiences of behavioural feeding difficulties exhibited by children with IDD. The objective was to explore family experiences more broadly and identify similarities and differences in these experiences. The research questions guiding this research were:

- What does the literature report about family views and experiences of behavioural feeding difficulties exhibited by children with IDD?
- What does the literature report about families' descriptions of the supports they have received for their child's behavioural feeding difficulty?
- What does the literature report about families' understandings of why behavioural feeding difficulties occur?

Methodology

A systematic review was carried out to explore the existing literature about families' views and experiences of behavioural feeding difficulties exhibited by their children with IDD.

Article Identification

Potential articles for inclusion were identified in Web of Science, SCOPUS, and PubMed with no restrictions on publication year. Search terms were divided into 4 categories: (1) family; (2) behavioural feeding difficulty; (3) child; and (4) IDD. All the search strings were run using an 'ALL' or 'full-text' option across all databases. The Boolean operator "AND" was used to unite all search strings. Final searches of the literature were conducted on July 26th, 2021. The search strings can be found on Table 6.

Table 6

Search Strings Used in Article Identification Process.

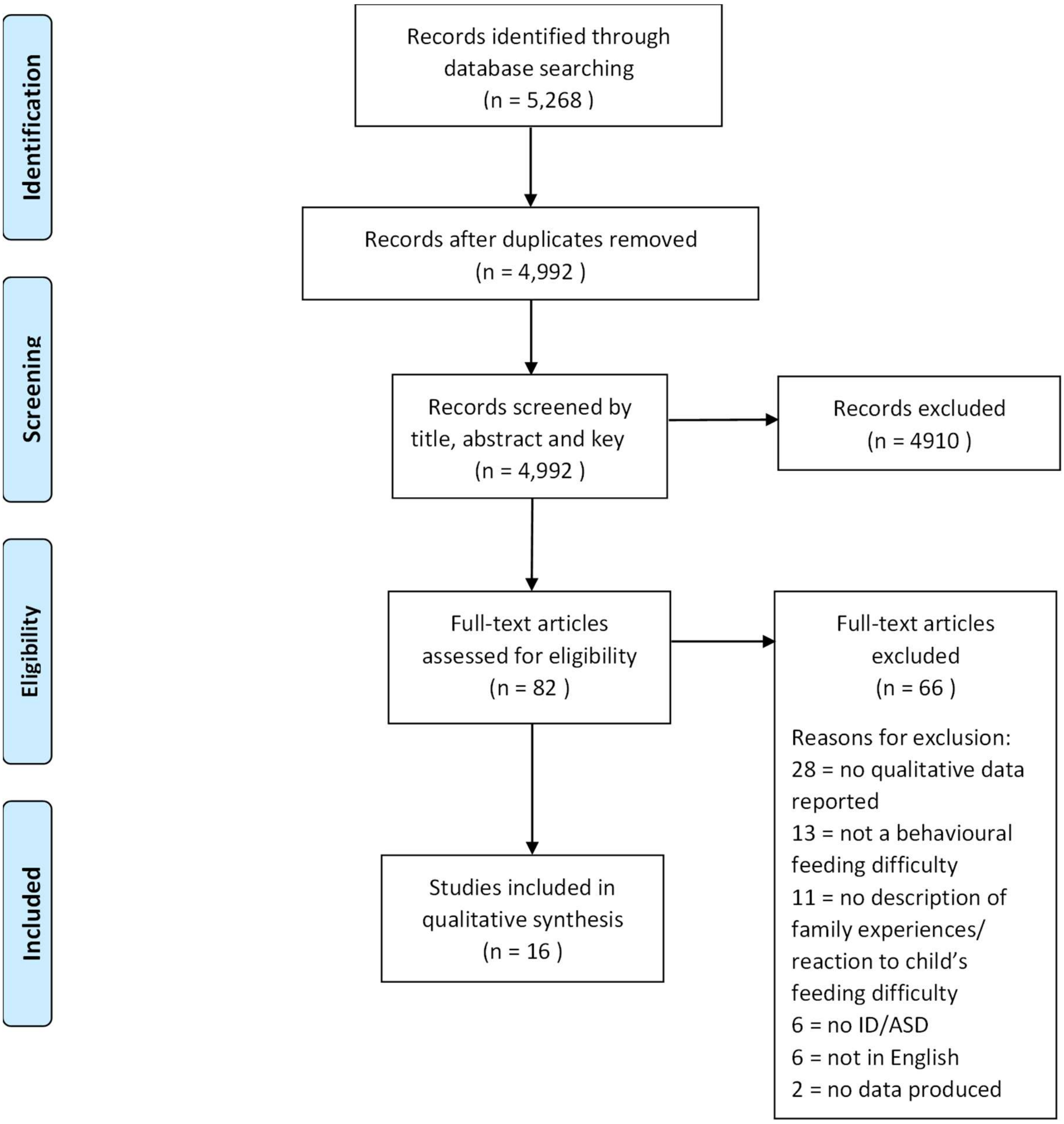
Search string	Family	Feeding difficulty	Child	IDD
	(parent* OR famil* OR care* OR mother* OR father*)	("feeding difficult*" OR "feeding problem*" OR "behavioural feeding problem*" OR "behavioral feeding problem*" OR "behavioral feeding difficult*" OR "behavioural feeding difficult*" OR "food refusal" OR "selective eat*" OR "food selectiv*" OR "food avoid*" OR "challenging mealtime behaviour*" OR "challenging mealtime behavior*" OR "inappropriate mealtime behaviour*" OR "inappropriate mealtime behavior*" OR "feeding disorder*" OR "feeding issue*")	(child* OR infant* OR toddler OR adolescent* OR "young person" OR "young people" OR "young adult")	("intellectual disab*" OR "learning disab*" OR "developmental disab*" OR "neurodevelopmental disab*" OR autis*)

Article Screening

The PRISMA checklist (Moher et al., 2009) was used as a guide for conducting the review. All articles retrieved from the initial search were combined to determine the total number of identified articles. Duplicates across all databases were subsequently removed. All articles were then screened by title and abstract. Following this, all articles identified as being relevant in the title and abstract screening were screened by full text. A total of 16 articles were included in this synthesis. A PRISMA flowchart of the various stages of the systematic review, article selection process and reasons for exclusion can be found in Figure 4.

Figure 4

PRISMA Flowchart of Database Searches with Reasons for Exclusion.



Inclusion Criteria

For inclusion in the systematic review, articles needed to meet predetermined criteria. They needed to provide descriptions of family experiences or reactions to feeding difficulties. The focus of the study needed to be on a behavioural feeding difficulty and the child exhibiting a behavioural feeding difficulty needed to have an IDD. Studies were included if they had at least one family member discussing a child with an IDD. Mixed samples of participants (i.e., IDD and no IDD) were included as it was assumed the descriptions provided by families would still be relevant for both populations. Where studies with mixed samples were included, great care was taken to ensure that only data related to the child with an IDD was extracted.

For inclusion, the child with the behavioural feeding difficulty being discussed had to be under 18 years old (exclusive). This age range was selected as according to the Children's Act (2004) a child is anyone who has not yet reached their 18th birthday. Where there were studies with children 18 years old or older, great care was taken to ensure that the data extracted was only for the child participants that met the inclusion criteria (i.e., they were 17 years old or under). Studies also needed to be published in a peer-reviewed journal. Although including solely published studies could result in a publication bias, it was deemed appropriate to exclude any grey literature due to the likelihood of not demonstrating high quality methodology. Studies were only included if they were studies that produced and reported qualitative data, as review or commentary articles are common in the behavioural feeding literature, and these were not the focus of this review. There were no restrictions placed on publication year. In the case of one study (Parr et al., 2021), it was a part of a larger health report that included multiple studies, as such only the chapter including the relevant study that met the inclusion criteria was included.

Exclusion Criteria

There were also criteria by which studies were excluded. Studies were excluded if they were grey literature. They were also excluded if they were not published or available in English, as there was no funding to translate articles. Studies were also excluded if the focus of the study was on feeding difficulties that were solely medical or physiological as the focus of the research was on behavioural feeding difficulties.

Data Extraction

All articles identified for inclusion were reviewed and data was extracted from the final selection of texts. The data that was extracted can be seen on Table 7.

Table 7

Data Extracted from Included Studies.

Data extracted	Additional information
Participant characteristics (family member and child)	Number of participants
	Age
	Gender
	Race/ethnicity
	Diagnosis (child only)
Study aims/objectives	
Country	Geographical location
Stated method	Qualitative research methods reported (i.e., semi-structured interviews, focus groups, etc.)
Topical focus	
Theoretical approach to analysis	
Main themes or summary of main findings	
Detailed synthesis of each theme or summary of main findings	Themes were broken down into the components within each theme for a comprehensive and contextualized analysis

Quality Appraisal

All included studies were assessed for quality using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research (2017). This tool assesses the quality of studies on a variety of different features (see Appendix Q). The JBI provides a detailed description of each of the quality indicators, which was used to guide the quality appraisals in this study. Each of these indicators is assessed based on whether they are present, not present, unclear, or not applicable. For this study, quality was appraised, but studies were not excluded on this basis as the sample of studies was fairly small.

Data Analysis

As has been used in previous research to synthesise qualitative literature (e.g., Griffith et al., 2013; Griffith & Hastings, 2014; Wolstenholme et al., 2020), Noblit and Hare's (1988) meta-ethnography was used to guide the data analysis to arrive at a synthesis of the literature. This meta-ethnographic approach was selected as it provided a comprehensive way to integrate the existing literature on families' experiences of their child with an IDD's behavioural feeding difficulties. This approach has also been used previously to explore the experiences of caregivers of individuals with intellectual disabilities and challenging behaviours (e.g., Griffith et al., 2013; Griffith & Hastings, 2014) and the experiences of parents of typically developing children that exhibit behavioural feeding difficulties (e.g., Wolstenholme et al., 2020).

After becoming familiar with the included studies, the results from these were analysed to determine how to integrate these, followed by translating them into one another and synthesising those translations into a higher order analysis. This involved reviewing the main themes or summaries of findings of each study thoroughly. The main points within each article were coded into NVivo following an inductive process, and the codes were organised and grouped into four main master themes. This reflected the process of determining how to put the studies together. Within each theme, the findings from the literature were reviewed to identify whether these were reciprocal or refutational (i.e., translating studies into each other). These were identified for studies that roughly described similar things or competing explanations, respectively. Finally, a lines-of-argument synthesis was carried out by holistically interpreting studies, and the ways that they relate (reciprocal and refutational) and their contexts. To do this, the data was constantly compared between studies, allowing their similarities and differences to be identified and putting these together into a new interpretation of existing qualitative research. This process resulted in a higher-order analysis that allowed for the identification of master themes that brought together all identified themes in the included studies, and which has explanatory power (Griffith & Hastings, 2014).

Results

After completing a systematic review of the literature, 16 studies published between 2012 to 2021 were identified for inclusion. Four main master themes were identified (see Table 8). Data were extracted (as described earlier) and can be found in Appendix P.

Table 8

Master Themes and Corresponding Inductive Codes.

Master themes	**Codes**
Impacts to the family system	• Family system • Judgement and blame from others • Unique experience of mothers • Constructions of mealtimes & letting go of these
How families cope	• Managing the feeding difficulty • Adaptations at first, then routine

Master themes	Codes
	• Capitulating to get food 'in'
	• Extreme measures
(Non) support	• Lack of support & impact
	• Systemic issues
	• Interventions
	• Things that (might) help
Understanding & acceptance	• Looking for explanation
	• Varied understanding
	• Understanding helped with support
	• Acceptance

Study Characteristics

Study Aims

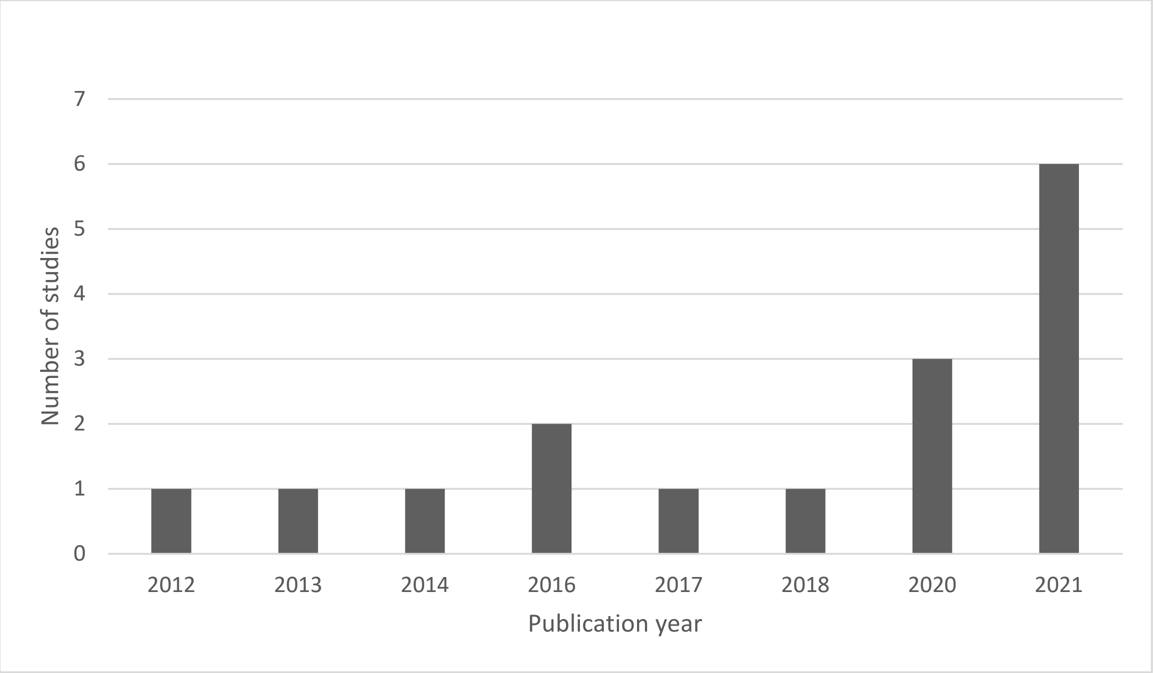
The aims of the included studies varied, however the aim of most studies (*n* = 11; 68.6%) was broadly about exploring what mealtimes are like (Adams et al., 2020; Adams et al., 2021; Ausderau & Juarez, 2013; Burkett et al., 2022; Curtiss & Ebata, 2021; Estrem et al., 2016; Estrem et al., 2018; Glasson et al., 2021; Lazaro et al., 2016; Rogers et al., 2012; Suarez et al., 2014). Many studies (*n* = 5; 31.3%) were broadly about identifying what caregivers do when the child they cared for exhibited a feeding difficulty (Adams et al., 2020; Curtiss & Ebata, 2021; Estrem et al., 2018; Lazaro et al., 2016; Rogers et al., 2012). Two studies (12.5%) aimed to describe feeding difficulties (Adams et al., 2020; Estrem et al., 2016). Finally, there were single studies (*n* = 1; 6.3%) that aimed to: explore the cultural context of feeding difficulties (Adams et al., 2021); inform interventions (Adams et al., 2021); use a specific research method to reflect on diet and food choices (Floríndez et al., 2021); explore grandparents' experiences of autism (Hillman et al., 2017); explore nutritional knowledge and how it affects food provision (Ismail et al., 2020); explore the direction of future feeding research (Parr et al., 2021); and identify what is supportive and where support is sought (Tan et al., 2021). These were not discrete categories; where studies reported multiple aims, all aims were considered.

Publication Year

Most of the literature in this area has been published between 2020-2021 (*n* = 9; 56.3%). The earliest identified study from this synthesis was in 2012. There has recently been an increase in the number of qualitative research articles in this area (see Figure 5).

Figure 5

Number of Studies Identified in this Synthesis Published Each Year.



Geographical Location

Half of the research (*n* = 8; 50%) identified was carried out in the United States (Ausderau & Juarez, 2013; Burkett et al., 2022; Curtiss et al., 2021; Estrem et al., 2016; Estrem et al., 2018; Floríndez et al., 2021; Hillman et al., 2017; Suarez et al., 2014). This was followed by two studies (12.5%) carried out in South Africa (Adams et al., 2020; Adams et al., 2021), and two (12.5%) studies carried out in Australia (Glasson et al., 2020; Tan et al., 2021). One study (6.3%) was carried out in Brazil (Lazaro & Ponde, 2016), Canada (6.3%; Rogers et al., 2012), Malaysia (6.3%; Ismail et al., 2020), and the UK (6.3%; Parr et al., 2021) each.

Qualitative Methods

Most of the studies (*n* = 9; 56.3%) reported using semi-structured interviews as the method of data collection. This was followed by focus groups (*n* = 3; 18.8%), a questionnaire (*n* = 1; 6.3%), secondary analysis of semi-structured interview data (*n* = 1; 6.3%), a survey with open ended questions (*n* = 1; 6.3%), and interviews, with the specific method of interviewing (i.e., semi-structured, unstructured, structured) not reported further (*n* = 1; 6.3%). One study also reported using mealtime observations as part of their research, alongside interviews (Curtiss & Ebata, 2021). One of the studies that reported using semi-structured interviews used photo elicitation to facilitate the interviews (Floríndez et al., 2021).

Qualitative Data Analysis

Thematic analysis was the most reported approach to data analysis (*n* = 6; 37.5%), followed by grounded theory (*n* = 3; 18.5%). Two studies provided detailed descriptions of their approach to data analysis but did not identify it as any particular analytic approach (*n* = 2; 12.5%; Estrem et al., 2018; Lazaro & Ponde, 2016). One study (6.3%) reported using concept analysis framework alongside qualitative content analysis (Estrem et al., 2016). One study (6.3%) reported using directed content analysis (Glasson et al., 2020), another (6.3%) phenomenological analysis (Suarez et al., 2014), one (6.3%) used a theory-specific approach to analysis (Burkett et al., 2022), and one study (6.3%) did not report their approach to data analysis (Parr et al., 2021).

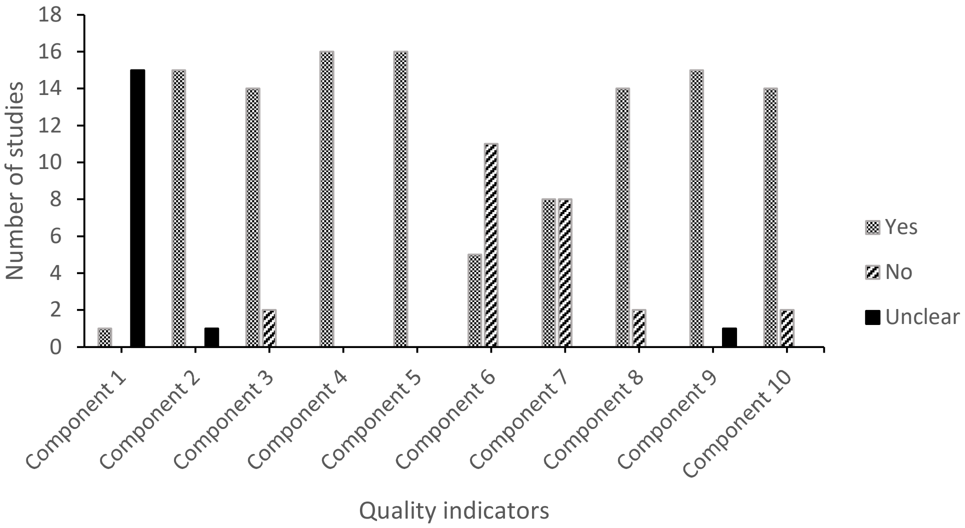
Quality Appraisals

Quality appraisals were carried out using the JBI Critical Appraisal Checklist for Qualitative Research. The quality appraisals found that most of the studies in this review (*n* = 9; 56.3%) addressed 80% or more of the quality indicators (Adams et al., 2020; Adams et al., 2021; Ausderau & Juarez, 2013; Burkett et al., 2021; Curtiss & Ebata, 2021; Estrem et al., 2018; Floríndez et al., 2021; Glasson et al., 2020; Tan et al., 2021). Some studies (*n* = 5; 31.3%) addressed 60-70% of the quality indicators (Estrem et al., 2016; Ismail et al., 2020; Parr et al., 2021; Rogers et al., 2012; Suarez et al., 2014), with fewer studies (*n* = 2; 12.5%) addressing 50% of the quality indicators (Hillman et al., 2017; Lazaro & Ponde, 2017). Notably, almost all the studies did not clearly report their philosophical perspective (*n* = 15; 93.8%), making it unclear whether there was congruity between the stated philosophical perspective and the research methodology; only Floríndez et al. (2021)

clearly stated this. For a study to meet this indicator, they must clearly state the philosophical or theoretical premises on which the study is based. In the case of most studies, the philosophical or theoretical premises were not clearly stated, resulting in ratings of 'unclear'. Another common missing piece of information was a statement locating the researcher culturally or theoretically, with 11 studies (68.8%) not addressing this information (Adams et al., 2020; Adams et al., 2021; Ausderau & Juarez, 2013; Floríndez et al., 2021; Glasson et al., 2020; Hillman et al., 2017; Ismail et al., 2020; Lazaro & Ponde, 2017; Parr et al., 2021; Rogers et al., 2012; Suarez et al., 2014). The influence of the researcher on the research and vice-versa was not addressed in 8 studies (50%; Estrem et al., 2016; Estrem et al., 2018; Hillman et al., 2017; Ismail et al., 2020; Lazaro & Ponde, 2017; Parr et al., 2021; Rogers et al., 2012; Suarez et al., 2014). Figure 6 provides an overview of all the components that were present, absent, or unclear.

Figure 6

Cumulative Illustration of JBI Quality Indicators for Included Studies.



Demographic Characteristics

Demographic characteristics of participants were extracted individually for family members and children; these will be explored separately. One article (Hillman et al., 2017) was an outlier as this article had 1870 family participants speaking about 2053 autistic children. Therefore, the results will be presented both with and without this article, to account for the outlier and the influence this may have on the results.

Family Members

A total of 2087 family members participated in the studies. Without the outlier, 217 family members participated in the studies. Excluding Hillman et al. (2017), the range of the number of family members participating per study was 4-40; this represents a range of number of participants that is more common in qualitative research. Of these 2087 participants, 1704 (81.6%) were female, 350 (16.8%) were male, and 33 (1.6%) were unspecified or unreported. Without the outlier, 171 participants (78.8%) were female, 13 (6%) were male, and 33 (15.2%) were unspecified or unreported. Of the total family members, 1870 (89.6%) of these were grandparents and 217 (10.4%) were parents. Excluding the outlier (Hillman et al., 2017), all (100%) of the family members were parents.

Ages of family members were reported in different ways (i.e., ranges, means) by the studies. Nine of the 16 included studies (56.3%) did not report ages of the family members. These 9 studies represented 111 family members (5.3%, with the outlier or 51.5%, without the outlier) included in this synthesis . For the studies that did report age, 66 participants were reported to fall between or average at between 28-53 years (3.2%, with the outlier, or 30.4%, without the outlier). One study (Adams et al., 2020) reported a large age range of 18-65 for 40 participants (1.9%, with the outlier, 18.4%, without the outlier). Another study (Hillman et al., 2017) reported participants as falling either under 65 (1047; 50.2%) or over 65 (823; 39.4%).

Similarly, 10 studies (62.5%) did not report participants' race or ethnicity. Most participants were White (1813; 86.9%). There were some Latinx (*n* = 87; 4.2%) and Black (*n* = 44; 2.1%) participants, with smaller numbers reported as Asian (*n* = 1; 0.05%) or American Indian or Native Alaskan (*n* = 1; 0.05%). Excluding the outlier, race or ethnicity data was reported for only 38 (17.5%) family members. Of these, most participants were White (*n* = 18, 47.4%), followed by Latinx (*n* = 12, 31.6%), Black (*n* = 7, 18.4%), and Asian (*n* = 1, 2.6%).

Children

Three studies (18.8%) did not report the number of children with feeding difficulties that were discussed by their family members (Lazaro & Ponde, 2016; Ismail et al., 2020; Parr et al., 2021). From 13 articles, 2215 children with feeding difficulties were discussed by their family members or 162 without the outlier. Most of the children were male (*n* = 1647; 74.4%). There were 337 (15.2%) female children discussed, and 231 (10.4%) children whose gender was not reported. When this was adjusted for the outlier, there were 89 (54.9%) male children, 25 (15.4%) female children, and 48 (29.6%) children whose gender was not reported. One study said all the children were male but did not provide a number of children (Lazaro & Ponde, 2016). Two (12.5%) studies included in this review did not provide any gender information about the children discussed and it was not possible to quantify how many children this pertained to, as these studies did not report the number of children for context (Ismail et al., 2020; Parr et al., 2021).

The ages of some of the children with feeding difficulties discussed ranged from 1.17-14 years old (*n* = 141; 6.4%). Two studies reported 2,074 (93.6%) children between the ages of 1-18 years old but did not provide further breakdown of age groups (Glasson et al., 2020; Hillman et al., 2017). When this was adjusted for the outlier, most of the children discussed in the studies were between 1.17-14 years old (*n* = 141; 87%). Glasson et al. (2020) reported 21 (13%) children between the ages of 2-18 but did not provide a further breakdown of age groups. One study reported age ranges of 4-7 years old (Ismail et al., 2020), and one study reported an age range of 5-28 years old

(Lazaro & Ponde, 2016), however neither of these studies provided a number of children discussed so it was not possible to quantify these. For Lazaro and Ponde (2016), great care was taken when extracting data to ensure that only data related to the included age ranges (as specified in the inclusion criteria) were extracted. One study did not report age ranges of the children or the number of children that were discussed (Parr et al., 2021).

Eleven studies (68.8%) did not report race or ethnicity of the children discussed. This equated to the race or ethnicity of 2160 or 107 children (97.5% or 66%, with and without the outlier, respectively) not being reported. Three studies (18.8%) did not report race or ethnicity of the children, but they also did not report how many children were discussed so it was not possible to quantify this (Ismail et al., 2020; Lazaro & Ponde, 2016; Parr et al., 2021). Of the children whose race or ethnicity was reported, most were White (*n* = 29; 1.3% with the outlier, 17.9% without), followed by Latinx and Mixed/multi-ethnic (*n* = 11; 0.5% with the outlier, 6.8% without) each; and finally, Black, or Asian (*n* = 2; 0.09% with the outlier, 1.2% without) each.

Most of the children discussed were autistic (*n* = 2167; 97.8%). Adjusted for the outlier, this resulted in 114 (70.4%) autistic children discussed. Some children had identified developmental delays (*n* = 16; 0.7% with the outlier, 9.9% without), cerebral palsy (*n* = 11; 0.5% with the outlier, 6.8% without), a genetic syndrome/diagnosis (*n* = 9; 0.4% with the outlier, 5.6% without), an intellectual disability (*n* = 4; 0.2% with the outlier, 2.5% without), sensory processing disorder (*n* = 3; 0.1% with the outlier, 1.9% without), and failure to thrive (*n* = 2; 0.1% with the outlier, 1.2% without). One study listed diagnoses for nine children but did not provide the number of children with each diagnosis (Estrem et al., 2018). Two studies reported that all the children were autistic but did not provide a number of children (Ismail et al., 2020; Lazaro & Ponde, 2016). One study discussed the children as having neurodisability but did not report the diagnosis of the children, or the number of children discussed (Parr et al., 2021). Some of the children had multiple identified diagnoses, meaning that these were not always reported as discrete categories in the studies, this also meant that children were double counted if they had more than one diagnosis.

Meta-Synthesis Findings

The 16 included studies varied in their topical focus. Broadly most studies focused on exploring what mealtimes are like and what caregivers do during mealtimes when their child has a feeding difficulty, while others focused on specific aims like grandparent experiences of autism, cultural context of feeding difficulties, etc. All studies provided information about families' experiences of feeding difficulties exhibited by their children with IDD. A detailed synthesis of the themes or summary of main findings for each study was also extracted from the included studies (see Appendix R).

From the meta-synthesis, four 'master' themes (Griffith & Hastings, 2014) were identified, and each had its own subthemes (see Table 9). This table also shows the translations of each theme and subtheme as reciprocal or refutational. Appendix S provides examples of quotes for each subtheme.

Table 9

Master Themes and Corresponding Subthemes along with Translations.

Master theme	Subthemes	Translation
Impacts	Daily life difficulties	Reciprocal
	Caregiver impact	Reciprocal
	Constructions of mealtimes & letting these go	Reciprocal
How families cope	Capitulating to get food 'in'	Reciprocal
	A new normal	Reciprocal
(Non) support	Lack of support – families	Reciprocal
	Lack of support – healthcare professionals	Refutational
	Interventions	Reciprocal
	Systemic issues	Reciprocal
	Things that (might) help	Reciprocal
Understanding & acceptance		Reciprocal

The 'master' themes and subthemes will be explored in depth in this section, however what was salient in the existing literature of families' experiences of feeding difficulties was that feeding difficulties bring with them a whole new journey for families. Having a child with a feeding difficulty is immensely challenging; their care needs are often not met, and parents are often left to figure it out on their own, leaving a heavy footprint on the lives of the families affected by feeding difficulties. Behind the struggle and impact of feeding difficulties, were family members desperate to understand what was going on and how they could help and trying to support their children with their feeding difficulties, often on their own.

Theme One: Impacts to the Family System

There were many impacts salient across studies. These mainly related to the family system, and there were specific impacts on the daily lives of families, caregivers, and the constructions of mealtimes that will be explored in depth as these contribute specific conceptualisations of the impact of feeding difficulties on families and they are important to unpack.

Daily Life Difficulties.

One of the ways that families experienced daily difficulties was financially. Families noted that their child's food preferences were expensive for them (Adams et al., 2020; Adams et al., 2021). Interestingly, this financial struggle was highlighted prominently as a finding in both studies carried out in South Africa.

> "It is difficult because of money…It is so much money." (Adams et al., 2020; p. 5).
>
> "It do affect us a lot because it costs money…I am a single parent and I am not working." (Adams et al., 2021; p. 169).

Other daily life struggles described related to the need to purchase and prepare more food, often providing multiple meals which took extra planning and time (Adams et al., 2020; Ausderau & Juarez, 2013; Suarez et al., 2014). Families also noted that it was difficult to plan and prepare foods when the foods that children accepted changed weekly (Burkett et al., 2022).

> "I have to cook, like, at least two different dinners. So that is another hardship" (Suarez et al., 2014; p. 105).
>
> "It's very frustrating…because I have to try different menus sometimes…the stress at the table, sometimes, it's difficult to manage…I'm always looking at her plate like "she's not eating, she's not eating"…it affected me, because we eat different foods. There were at least two menus. I knew that I had to change the…food for her…because she has to eat!" (Ausderau & Juarez, 2013; p. 319-320).

Other daily life struggles were descriptions of family lives revolving around feeding their child, experiencing limits to what they could do as a family, and increased family tension and breakdown. This meant that families changed the way they lived their daily lives (Estrem et al., 2018).

> “Our family life is pretty much dictated by her feeding times… So, our schedules are largely based around eating” (Estrem et al., 2016; p. 5).
>
> “So basically, our lives have changed to revolve around him…We haven’t been to a restaurant with him in maybe three years.” (Adams et al., 2021; p. 170).

Families also faced limits related to going on holidays, travelling, and unplanned outings (Estrem et al., 2016; Estrem et al., 2018). Additionally, Parr et al. (2021) discussed how the high levels of stress caused to parents by having a child with a feeding difficulty could affect their relationship with their child. This increased tension was also noted in Tan et al. (2021), with the family difficulty ultimately resulting in family breakdown for the family of one participant:

> “All our family arguments are about food” (Tan et al., 2021; p. 5).
>
> “He was down to five foods; it ended my husband and my relationship” (Tan et al., 2021; p. 5).

Caregiver Impact.

The impact on caregivers was prominent. Families described feeling guilt, psychological distress, having feeding commitments that went above and beyond normal parenting duties, and they described experiences of food as a fight. One parent described intense feelings of guilt when providing her son with his preferred, unhealthy, food:

> "He wants the dollar pack of hotdogs…I feel like I’m killing my child because I’m giving him crap. But I don’t know what else to do" (Burkett et al., 2022; p. 2592).

Families were also described as experiencing psychological distress related to their child's feeding difficulty. In Burkett et al. (2022), mothers described feeling anxiety when their children refused to eat food. This was echoed by a parent in an earlier study: "I am just SO weighed down with the anxiety…I feel kind of defeated" (Estrem et al., 2018, p. 10).

Parents in Burkett et al. (2022) described frustration when their children cycled between accepting a new food and then refusing to accept or even touch that same food later. One parent described this by referring to their son as: "He is so rollercoaster" (Estrem et al., 2018; p. 6).

Caregivers described commitments above and beyond normal parenting duties related to their child's feeding difficulty, such as putting in an extraordinary amount of time and effort into managing their child's feeding difficulty (Estrem et al., 2018). These parents described being tied to their children, finding themselves personally limited in what they could do, as they had to feed their children:

> "We are still tethered to our child four times a day" (Estrem et al., 2018; p. 9).

Finally, caregivers described experiencing food as a fight:

> "Just sit down and eat it because those are two things that you like… that's where the stressful part comes in because I'm thinking to myself please don't let things blow up or escalate to the point of people being irritated with each other" (Curtiss & Ebata, 2021; p. 7).

> "And [feeding solids] just always seemed to be like a struggle…if it wasn't milk, it was fight" (Estrem et al., 2016; p. 4).

Constructions of Mealtimes and Letting Go of These.

Families reported having their own meanings of mealtimes and what these should look like, often centring around "the whole family sitting together at the table and eating" (Adams et al., 2021; p. 170). Adams et al. (2020) related how "caregivers reported that to them a successful mealtime was when all family members sat at a table, ate together and shared their stories" (p. 5).

Families found that achieving these mealtime ideals were difficult, as the feeding difficulties "prevented family participation in the majority of mealtimes" (Ausderau & Juarez, 2013; p. 318). This meant that families were not able to experience what they envisioned as 'mealtimes', and share in a family moment together:

> "That's the one special time of the day where a whole family can get together and connect. And instead, the entire mealtime is spent trying to get Sam to sit in a chair or chasing him around trying to get him to eat food. It, it just isn't relaxing" (Suarez et al., 2014; p. 104).

Families described feeling deeply dissatisfied with their mealtimes, like they were unable to experience typical mealtimes or like they were missing out on normal family activities (Adams et al., 2021; Ausderau & Juarez, 2013; Suarez et al., 2014). Families had to adapt to make mealtimes less chaotic, even if this meant letting go of their constructions of mealtimes (Suarez et al., 2014). While a significant loss for families, Ausderau and Juarez (2013) reported that these families showed resilience to the feeding challenges they encountered by creating more supportive feeding environments for their children.

> "So, now, as of this point, we have given up, and we as a family do not sit down and have a meal together at the table." (Suarez et al., 2014; p. 105).

In the face of not being able to experience important family bonding during mealtimes, families experienced loss, and resorted to feeding their children in ways that did not fall into their ideas of what mealtimes should look like. In doing so they demonstrated resilience to the unexpected challenge their child's feeding difficulties brought.

Theme Two: How Families Cope

There were many descriptions amongst the studies about how families coped with the impact of the feeding difficulty that they experienced. Families went to great lengths to support their children in consuming food, and this was detailed extensively across the studies. Some participants in the studies described capitulating to their child’s restrictive preferences to ensure that they ate something. In the cases of many families, the strategies they put in place became their new normal.

Capitulating to Get Food ‘In’.

Interestingly, as part of their ways of coping with their child’s feeding difficulties, some families described capitulating to their child’s restrictive preferences or food rules to ensure that they ate something and to avoid challenging mealtime behaviours. Some families described needing to do “whatever it takes to get something in [the children’s] mouth” (Burkett et al., 2022; p. 2592); however this was difficult for some families as it meant that they needed to give in to the child’s unhealthy food preferences for the sake of ensuring they ate something:

> “I have guilt feeding him what I feed him because it’s awful food, but that’s all he’s going to eat… it’s all he’s going to eat and you can’t let him starve” (Burkett et al., 2022; p. 2593).

Other families described capitulating to avoid challenging mealtime behaviours and the stress and frustration that comes alongside ‘challenging’ their children’s feeding difficulties:

> “If you ever saw those meltdowns you wouldn’t want to offer [non-preferred] food either” (Rogers et al., 2012; p. 24).

> “Having a huge battle with dinner time being miserable every night, or just living and eating whatever [the child wants]. There is really no grey area. It’s just one or the other. It’s awful” (Burkett et al., 2022; p. 2592).

Regarding capitulating, some families expressed being aware that this was not ideal but feeling like they had no other option because that was truly all their children would accept.

> “‘Oh my god, I can’t believe I let him have that.’ He’s such a picky eater…That made me think like ‘okay what should I change? Should I not give in to him when he wants to eat all these

> things?' Especially these things that are just not even remotely good for him" (Floríndez et al., 2021; p. 7).

> "I know those snacks are not good. However, that is what he always wants to eat" (Ismail et al., 2020; p. 9).

A New Normal.

There were a variety of strategies and approaches described as having been adopted by families in response to their child's feeding difficulty and the impact of this. Participants spoke of using a gradual approach when implementing strategies with their children and following their child's food rules and their lead (Ausderau & Juarez, 2013; Rogers et al., 2012). They described implementing techniques aimed at increasing eating and participating in mealtimes, staying at the table, and alleviating caregiver's stress (Adams et al., 2020; Ausderau & Juarez, 2013).

Caregivers reported attempting changes in the mealtime environment during mealtimes. These were often distractions added to the mealtime environment:

> "We always start him at the table…sometimes I'll take his food and put them on the stool or in front of the TV, because he'll zone and he'll wind up eating everything and not realize it" (Ausderau & Juarez, 2013; p. 319).

Other participants described completely changing the mealtime environment to accommodate their child's eating needs (Adams et al., 2021). In Lazaro et al. (2016) some families described feeding their child separate to other family members or taking their children outdoors for mealtimes to completely change the environment in which they ate.

Families also had to find ways of being innovative to support their children in their eating (Burkett et al., 2022). Some families tried to take the pressure off mealtimes by making food fun for their children:

> "I put on mushroom ears, and we did olive eyes, and a tomato nose, and the pepperoni was the smile, and broccoli hair so…He only ate the pepperoni, but it was fun" (Ausderau & Juarez, 2013; p. 319).

Other families tried putting in specific strategies that were aimed at increasing their child's food consumption or staying at a table (i.e., they were attempts at positive reinforcement):

> "We would have a little explosion where he was eating some new things all because of this sticker book…We went through three books like that and then he just couldn't care less" (Burkett et al., 2022; p. 2592).

> "He knows the rules are if I want the reward, I have to sit at the table…you do this for me and this is the end result-you get to play the game" (Curtiss & Ebata, 2021; p. 5).

Some participants also described being innovative by trying to sneak other foods in with the foods that their children already consumed:

> "Roll [the vegetables] up in bread, into a ball. So, then he'd see a ball of bread and he'd eat it. He got smart onto that and he started checking and when he saw vegetables, he wouldn't eat it" (Burkett et al., 2022; p. 2593).

> "I put a whole bunch of stuff in his waffles" (Rogers et al., 2012; p. 28).

Despite having to make changes, these adaptations became part of families' mealtime routines and were viewed as a normal part of their children's daily lives by parents (Ausderau & Juarez, 2013; Estrem et al., 2018).

The importance of routine in supporting children with their feeding difficulties was evident. Curtiss and Ebata (2021) described parents needing to manage mealtimes through some level of control that was born out of love as a means to an end, specifically, for a mealtime routine to be achieved and preparing their children for the future. Other participants also described how they needed a mealtime routine to successfully feed their children, and sticking to the routines that they knew worked for their children:

> “We are more centered around that structured routine to another degree than you would be normally … you need the quiet environment, I mean to the point where if we have guests over, they go to another room or they go outside while we feed” (Estrem et al., 2016; p. 5).
>
> “I feel like maybe other moms will go out for longer periods of time, you know with their kids? But because of the way Ava eats, I really try to be home, whenever we’re feeding…. In order to get the best results with her eating, she needs to be in her home environment” (Estrem et al., 2018; p. 9).

Estrem et al. (2018) also described how parents felt less able to manage if mealtime routines were not established or these were disrupted, further highlighting the importance of establishing mealtime routines to manage children’s feeding difficulties, and these becoming a new normal for families.

Theme Three: (Non) Support

From this review it was evident that despite the significant impact described by families, there was a general lack of support available to support their children’s feeding difficulties. Support was described as varied, and there were some issues highlighted with some of the interventions suggested to them by healthcare professionals, as well as some systemic issues that made it more difficult for families to access support. Finally, there were ideas or suggestions expressed by families about what might help or had helped them support their child better.

Lack of Support.

Families reported experiencing a lack of support from family members and healthcare professionals. In terms of family members, this included partners, parents, children’s grandparents, wider family members and friends (Adams et al., 2020; Ausderau & Juarez, 2013; Burkett et al., 2022; Estrem et al., 2016; Tan et al., 2021).

In relation to her partner, one mother related the following:

> "It's bad…He has no idea. He doesn't even know what to feed Justin…so it's me 24 hours a day and…He knows I struggle with feeding Justin and that's all he knows. He doesn't know the strategies and things I do every day" (Ausderau & Juarez, 2013; p. 320).

One mother described feeling dismissed by her own mother:

> "She just doesn't always understand, and she's just big on 'well if he doesn't eat that, you don't give him anything else'…They just don't get it" (Burkett et al., 2022; p. 2593).

Participants also outlined several ways in which support coming from healthcare professionals had been lacking. Often, the descriptions from parents were that their healthcare practitioners "did not take [their] perspective into consideration" and this resulted in "feeling like [they were] not being heard" (Burkett et al., 2022; p. 2593). The feeling of not being heard was echoed by participants across studies:

> "I've definitely lost count of the amount of times that I've approached a professional about issues around eating and then they've said to me 'well its OK, because he's tracking his height and weight chart' and I'm saying but it's not OK. This eating environment for all of us and for him is not OK and its reassuring that he's still growing. It would feel much better if I was able to get him to enjoy food and be wanting to eat and be involved" (Parr et al., 2021; p. 84).

Interestingly, there was one report in Rogers et al. (2012) of a family where their healthcare professional did listen to their concerns and action them, however this was a singled-out instance in the wider body of included studies:

> "[The doctor] put him on Pediasure. They said, 'You have two weeks. Be back here in two weeks. If he has not gained weight, we will admit him. They will put a tube in,' and they were really worried …. They classified him as 'failure to thrive.'… It was very scary" (p. 27).

Parents also reported frustrations at healthcare professionals that might have missed things related to their child's feeding difficulty:

> "Why we didn't get to [feeding team] until she was almost three? We feel like we wasted…years for her, where she could have felt better. And made progress. [Tearful] Instead of learned pain and learned bad habits" (Estrem et al., 2016; p. 4).

> "Finally I really put my foot down and told the doctor 'Don't look at his autism; look at him as not autistic and then look at the problem, it is a throat problem', and they gave him a scope and then they found the reflux, it burned him really bad. It took three years to be diagnosed" (Rogers et al., 2012; p. 26).

Parents that did receive some support described experiencing difficulties with this. Suarez et al. (2014) noted how for some families there had been some support from professionals received, however this was not ongoing and the strategies that were suggested to them did not result in meaningful change for the families. Some examples of these were provided in Tan et al. (2021):

> "They were getting us to force feed her but as soon as she was able to fight us off, she wouldn't let us feed her that way" (p. 7).

Tan et al. (2021) also related mothers' concerns related to support they received from specific healthcare professionals (e.g., speech pathologists, general practitioners, and nurses):

> "They were just very uneducated. She had no idea what we were dealing with" (p. 7).

Ultimately, this fight with services itself was reported to result stress for families (Parr et al., 2021).

> “I’m sick of going into battle. Just to fight for something that’s a basic human right” (Tan et al., 2021; p. 6).

Interventions.

There was a sense that some of the interventions families had received did not meet their needs and sometimes required a lot from them. Burkett et al. (2022) describes how mothers had to decide between implementing strategies that were recommended to them and having difficult mealtimes, or having easy mealtimes and accepting what the child would eat:

> “It’s a lot of stress on the family… So that’s when we say ‘okay we are going to do this so we can have a peaceful nice dinner every night. Chicken fries- that’s fine” (Burkett et al., 2022; p. 2592).

Other families described how they received recommendations that were not financially sensitive to their situations and required too much of a financial commitment from them:

> “At the beginning we used to try gluten-free food. They are so expensive. We couldn’t afford all those things” (Adams et al., 2021; p. 169).

A family in Estrem et al. (2018) also described how the intervention suggestions they received required a lot of effort from parents and they found that it was difficult to consistently implement them:

> “I guess that it is still hard to make yourself do the hard things. It’s great that we know how to put the food in her mouth, but working on the lateral placement, trying to make her eat crumbs three times a day…it is stressful because it’s new and, that’s the hard part…is us finding the discipline to do the hard stuff, not just stay with the easy reliable stuff” (p. 7).

Another family emphasised the pressure they felt at implementing professionals’ suggestions, particularly when the parents did not agree, or they were unclear about how long the timeline for the implementations would be:

> "There's pressure – it's really, really tough . . . thinking about meeting what some professional wants you to do, against what you think is right, or even knowing what timescale they're talking about, that can be quite unclear" (Parr et al., 2021; p. 80).

Systemic Issues.

There were some systemic difficulties with accessing support that families faced. In Estrem et al. (2018), one family discussed how it was challenging taking on the role of care coordinators and synthesising information across all the professionals involved in their child's care:

> "The hard part, frankly, was that we were the coordinators…. We were the synthesizers of the information…You have to understand what the specialists do, and how they overlap, or how they don't…and then fill in the blanks" (p .8).

Issues with referrals were also identified by families. Parr et al. (2021) discussed how in the UK, some services only provide assessments and advice, and discharge families after this, relying on local teams to review the children again after this. This posed a systemic difficulty for families as there were often issues with waiting for a re-referral to a service, such as long waiting lists. These issues were also highlighted in Tan et al. (2021):

> "I didn't get seen by the feeding team until XX was 12 months, so she sat on a wait list for four months" (p. 8).

> "I think the referral is 18 months old and I've heard nothing" (p. 8).

Importantly, one family described how it was difficult to access support when it was not clear who they needed to see for help with feeding:

> "There's no obvious, 'Does your child not eat properly? Come and see us. Does your child not hear, well that's obvious: go to an audiologist. But with meals it's like, where do I even start? Where do I even say to someone, 'My child won't eat?' …You just needed to know the door to knock on" (Tan et al., 2021; p. 5).

Things that (Might) Help.

There were some things that participants highlighted had helped them with regards to the support they had received or that they thought would help. One of these was contact with people that understood the struggle of having a child with a feeding difficulty and which made them feel heard:

> "It's great to talk to the other people. Sometimes even more so than talking to the doctors themselves because they don't experience it every day" (Burkett et al., 2022, p. 2593).
>
> "When you feel like you're alone in this struggle, it's always refreshing to be around other people who get it" (Burkett et al., 2022; p. 2593).

In Burkett et al. (2022) it was highlighted that parents valued being able to learn from others that also encountered these difficulties at home:

> "I am always learning new things from people who have been there or have done that…They all teach you a lot of things of what not to do right now. It will prevent big mistakes for the future" (p. 2594).

Other helpful practices related to providing support for parents themselves, taking the time to explain things to parents, providing information, facilitating contact with other parents, and having a well-rounded approach.

> "It would be quite good for the parents to get some support because it can be very frustrating and an anxious time when you're trying to feed a child which is just going to choke and vomit the whole time" (Parr et al., 2021; p. 85).
>
> "She was the best she just took time to explain things to me" (Tan et al., 2021; p. 5).
>
> "I'm still trying to get information for myself…It'd be wonderful to have someone who said, I know all about this I can help you" (Tan et al., 2021; p. 5).

> "I think in reality you'd use a number of strategies in conjunction wouldn't you, to try and improve your child's eating…you'd use a combination to reduce stress and anxiety and optimise their feeding" (Parr et al., 2021; p. 79).

> "Need holistic approach, nobody joining the dots" (Tan et al., 2021; p. 7).

Theme Four: Understanding and Acceptance

Parents in the included studies reported looking for explanations about why their child was exhibiting a behavioural feeding difficulty and struggling to understand what was wrong with their child's feeding (Adams et al., 2021; Rogers et al., 2012).

> "You try to think about everything it could be. Could it be the flavor, could it be the color, could it be the sensory aspect…could it be constipation? It's overanalyzing things…to the point of exhaustion…" (Burkett et al., 2022; p. 2592).

> "We are doing everything that we can trying to make meals appetizing for him…I don't get it…I have been with this kid for eight years. And I still don't get it" (Suarez et al., 2014; p. 105).

Some families provided insight into the understanding they already had of what was influencing their child's feeding difficulty, like a concurrent condition the children had (i.e., anxiety, gut issues, intolerances, food sensitivities, etc.) (Estrem et al., 2018; Glasson et al., 2020; Rogers et al., 2012).

> "He was on medications three times a day, and that was all going down orally…I think he actually just became aversive to anything going in his mouth" (Glasson et al., 2020; p. 971).

Other understandings related to sensory reactions to food and the feeding difficulties being related to characteristics of autism, like inflexibility and showing a preference for consistency (Lazaro et al., 2016; Rogers et al., 2012). Some parents in Rogers et al. (2012) also reported that the challenging mealtime behaviour their children exhibited may have been influenced by aversions to food, difficulties with communication, and difficulties sitting. Other understandings related to the children engaging in behaviours to obtain their preferred foods, having oral-motor or chewing difficulties, or not feeling hunger or being able to respond to hunger cues (Lazaro et al., 2016; Rogers et al., 2012). Some families noted how understanding their child’s feeding difficulty helped them accept and support their children in meaningful ways. Adams et al. (2021) described how diagnoses helped parents understand their child’s feeding difficulty, accept the situation and the ways in which they might be able to support their child. Accepting their child’s difficulties also changed the expectations parents had of their children and changed the ways that they supported them (Curtiss & Ebata, 2021). Curtiss and Ebata (2021) described how parents were able to see past the presenting difficulties and support their children when their expectations aligned with what the children were able to do, and the parents faced difficulties with this when their expectations were misaligned. Ultimately, parents were navigating understanding and accepting their child’s limitations and finding ways to work with these, rather than against these.

> “I mean I think it’s…it’s a long-term process. You have to be patient. You know every new day comes with its own opportunities. … It’s kind of like the stock market, you know it, if you follow it too closely, every day, you’re going to be on a huge roller coaster. … you have to take a long-term approach to it” (Estrem et al., 2016; p. 4).

> “It came sort of as a whole epiphany. …He was about five and I realized nothing that I was doing was working. …So from there I made a very conscientious effort throughout the day whether it was mealtime…to try to figure out what worked best for him” (Curtiss & Ebata, 2021; p. 6).

Discussion

This study was a systematic review that aimed to identify and synthesise existing research related to families' experiences of behavioural feeding difficulties exhibited by their children with IDD. Meta-ethnography was used for a secondary analysis of the identified literature.

Considering that estimates of the prevalence of feeding difficulties exhibited by children with IDD are as high as 89% (Ledford & Gast, 2006), there is not much research that explores families' experiences of their child's behavioural feeding difficulty. Interestingly, this research found that there is very recent interest or research in this area, with the earliest included study in this systematic review being published in 2012. The lived experience of feeding difficulties of families of children with IDD has only recently been explored, relative to some of the early studies implementing interventions for feeding difficulties (e.g., Schmidt, 1976; Riordan et al., 1980; White, 1982). This finding is significant as it indicates that much of the research on interventions for feeding difficulties was developed or carried out before research explored and understood the family experience. It is possible that the interventions that have been developed may need to be adapted given new information about family experience to ensure they are appropriate for family contexts. For example, this systematic review (along with a previous chapter; Chapter Two) showed the clear impact of feeding difficulties on families. It would be important to ensure that current and future intervention research on feeding difficulties factors this into the assessment and intervention development or support process.

Interestingly, this study showed that carers' experiences were largely congruent, meaning that across studies the family members brought up similar concerns, and general experiences. While there was variation in the *specific* experiences that families described, the undertone of impacts, coping, support, and understanding was largely congruent. Generally, mealtimes were difficult to manage and required families to adapt in many ways. Importantly, despite the difficulties managing mealtimes and the adaptations that were required of families to have mealtimes, it was clear that these adaptations became part of their family routines, and part of their child's daily life as an eater (Estrem et al., 2018). That mealtimes were difficult to manage was not surprising, given that this is directly implied as part of having a child with a behavioural feeding difficulty. The finding that the adaptations become part of families' routines was aligned with Winson et al.'s (2015) finding that mothers who participated in their study commented on how they simply adapted to their daily routines and occupations when they had a child with a feeding difficulty. This may be important for clinicians or healthcare professionals to consider. Families of children with feeding difficulties experience a 'new normal' during mealtimes; they have often adapted to their child's needs, and this has become a part of their mealtime routine. This means that families that reach out for feeding support may need to be supported as a whole (i.e., not a direct intervention solely on the child). Interventions for families of children with feeding difficulties may need to target systemic change to address the 'new normal' that families experience, which often involves going to lengths to get their children to eat and has been described as draining for families.

This study supported current literature by demonstrating that families face difficulties to receiving support yet. This study added to this by describing these challenges as a whole, and describing what families reported might help. A key finding from this study relates to the clear importance of having an explanation for their child's feeding difficulty and understanding their child's feeding difficulty, and how this may lead to acceptance of their child's situation and may allow families to support their children in more meaningful ways. This was aligned with the findings from Chapter Two that also found that families needed and looked for ways to understand their child's feeding difficulties, and this had the potential to change the way they supported their children.

It is important to note that the perspectives of family members that are carers is paramount to understanding how services are experienced by the individuals that receive them (Cheak-Zamora & Teti, 2015). As such, this meta-synthesis has identified multiple areas of clinical implications for those who provide support for feeding difficulties, as determined by the family experience reported in the literature. Primarily, there were findings related to parents' suggestions about what might help and what had helped and what had not helped in terms of receiving support or intervention for their child's feeding difficulty. Professionals may consider using this information to inform the supports they deliver. For example, families described how it is important for parents themselves to be supported. This is significant as much of the literature on interventions for feeding difficulties focuses on a direct intervention component on the child themselves (e.g., Seiverling et al., 2018; Sharp et al., 2016, etc.). It would be important going forth for research to consider how to support parents when their child has a feeding difficulty. It is clear from interviews with parents (Chapter Two) and from this study that feeding difficulties impact the family system, and caregivers are significantly impacted by feeding difficulties, thus it would be important to focus intervention efforts around supporting parents. Targeted support for parents has previously been demonstrated to be effective in supporting parents of children with IDD exhibiting challenging behaviours to understand their children and develop more effective behavioural management strategies, and experience more positive relationships with their children (Thompson-James et al., 2016). Parents may need to be supported themselves to be able to provide a supportive mealtime environment for their children.

This synthesis also found that families suggested that it would help them if clinicians took the time to explain things to them and provided them with information. It was also clear that understanding their child's feeding difficulty was important for families and that this led them to accepting their children and the ways in which they needed to be supported. These findings suggest that it may be beneficial for clinicians to work with families to develop an explanation of what is influencing their child's feeding difficulty and how to support them given that information. It may be beneficial to work with families on understanding and acceptance and support them through navigating the balance between acceptance and action geared towards trying to change their child's feeding situation as this may be challenging for families on their own. Importantly, these findings indicate that families need support and validation from those providing support, as it was clear from this review that many professionals do not provide this, and it has been reported to have a detrimental impact on caregivers. This feeling of battling with professions for access to services and support has been detailed in previous literature (Ryan & Quinlan, 2017; Wodehouse & McGill, 2009). The need for validation of a feeding issue was also prominent in Chapter Two, indicating that this finding is also shared across other qualitative research in the area and should be considered by clinicians that encounter families with young children but may not necessarily provide feeding specific support (e.g., GPs, etc.).

There are also some systemic issues identified in this study that made it difficult for families to access support for their child's feeding difficulties. These related to having to act as the care coordinators and carry all their child's information to all professionals involved, experiencing difficulties with referrals and long waiting lists, and ultimately not knowing who to turn to for support. Previous research (Ryan & Quinlan, 2017) also found that parents of children with disabilities felt there was a lack of accessible information about the supports and services available for their children. This indicates that this may be a wider issue, and one that is not unique to feeding difficulties. While some of these are systemic issues that are more challenging to resolve (i.e., long waiting lists), others provide suggestions that would support the delivery of services for families of children with feeding difficulties. It would likely support families if there was better information available about the healthcare professionals that provide support for feeding difficulties, so families could know who to turn to for this support. This might also help with the difficulties families reported experiencing related to obtaining referrals for their child's feeding difficulty. If this was clearer not just for families, but also for healthcare professionals, then referrals may be easier to obtain.

This chapter has provided an overview of the current state of the research in this area, and implications for future research. Considerations for future qualitative research in this area would be for qualitative researchers to state their philosophical perspective, so the congruity with the research methodology can be evaluated properly. Similarly, statements locating the researcher culturally or theoretically (i.e., positionality) should also be prioritised, as that information is important for readers to interpret the findings. Future studies should seek to continue to be very transparent with qualitative research. Qualitative research contributes significant and unique information to an understanding of phenomena, it is important that it is carried out with sufficient rigour and transparency to enable others to be confident in the findings of the reported research.

Research related to understanding families' experiences of their child's feeding difficulty has been carried out in very limited areas or ways. The focus has been primarily on mothers, with a very limited number of fathers or male caregivers participating. This is a wider problem in research, however one that is ultimately important to actively address when trying to develop an understanding of families' experiences of their child's feeding difficulty, as fathers or male caregivers are important and active participants in their children's mealtimes and should be specifically focused on to understand the impact of the situation on them, and what their experiences may be.

For the studies that reported data related to race or ethnicity, most of the participants included were White. This is a significant limitation of the literature as it fails to capture the nuances of experiences that caregivers from diverse racial or ethnic backgrounds may encounter. For qualitative research, it would be important to ensure that going forth, the experiences of diverse individuals are specifically considered and recruited as participants, as they may experience unique mealtimes challenges that would not be well represented in the current literature. Problematically, many studies failed to report the race or ethnicity of the family members that took part in the research or the race or ethnicity of the children with feeding difficulties they were discussing. It is important to report on both as separate sets of information, as the children discussed may be living in multi-ethic, multi-racial, or multi-cultural households, and obtaining demographic information solely related to the parent in terms of their race and ethnicity would limit the understanding of the child's mealtime cultural context.

Most of the child participants discussed were autistic. Future research should seek to explore families experience of feeding difficulties exhibited by children specifically with intellectual disabilities, that are not autistic, as the understanding of feeding difficulties and subsequent support needs in children with intellectual disabilities that are not autistic may be different and important to explore. Most of the studies included were carried out in developed countries, and of these the majority were carried out in the United States. Clinicians and health care professionals should interpret these results with this understanding, and those working in developing countries, or developed countries outside of the United States (such as the UK, Australia, New Zealand, etc.) should consider that the experiences of families may vary due to different systems of support and different levels of focus on support for individuals with intellectual disabilities or autistic individuals.

Strengths

A strength of this review was the methodical process that was taken with respect to data analysis and the identification and creation of 'master' themes. Meta-ethnography requires multiple steps to ensure that the identified qualitative studies translate into each other in a way that pulls together the existing literature meaningfully. These steps were followed carefully, and a rigorous approach was taken to ensure that the translations of the studies into each other to derive findings was representative of the state of the literature on this topic. This is a strength of this review as there is confidence that the 'master' themes identified illustrate the relationships in the data across studies.

Limitations

There are some important limitations of this study to consider. For example, the data presented in relation to demographic information was skewed by an outlier (i.e., Hillman et al., 2017) and difficult to interpret. There was an attempt to account for this by presenting demographic information with and without the outlier throughout, however this is still a limitation of the research as it meant that the demographic information was more challenging to interpret accurately. Another limitation of this study was the omission of grey literature from inclusion. This meant that the studies included only reflected published research in this area and may have resulted in publication bias. In relation to qualitative research, this means that studies with findings that are clearer, striking, or more easily described are published, while qualitative studies with less clear, striking or easily describable findings are not (Petticrew et al., 2008). Additionally, this review did not exclude studies based on quality. This decision was made due to the limited number of studies yielded from the searches, and the intention to capture as much available literature as possible in the analysis. However, there were two studies included that did not meet 50% of the JBI quality indicators (Hillman et al., 2017; Lazaro & Ponde, 2017), and which were deemed to be low-quality studies. As such, this review did not only include articles deemed to be high-quality and the results should be considered with this in mind.

Conclusion

In conclusion, the findings from this meta-synthesis show that families report facing a variety of impacts as a result of their child's feeding difficulties. Families report developing lots of ways of coping and this becomes their 'new normal'. Families report experiencing difficulties obtaining support and report things that help or might help, which included having support for parents themselves and having more information about feeding difficulties. It was clearly important for families to understand why their child's feeding difficulty was happening as they reported that this led them to accept their children and the ways in which their children needed to be supported with their feeding. This echoes findings from Chapter Two that emphasised the importance of understanding having the potential to mitigate the impacts of feeding difficulties, as parents understood their child's feeding difficulties, and this changed their attributions about their child's feeding difficulty and their behaviours in supporting their children.

Further research should seek to explore the specific context of the UK and in particular the National Health Service (NHS) as the way in which support is provided through the NHS may be different to the ways support is provided in countries with different models of service delivery (i.e., the United States), and in which most family experience research has been carried out. Future research should also seek to explore the perspectives of those who deliver support for feeding difficulties, as the literature has focused strongly on parent or family perspectives, and there is not much known about the experiences of those who provide this support. One of the research questions guiding this thesis was to explore stakeholders' experiences and understandings of behavioural feeding difficulties amongst children with IDD, and their experiences of related supports for these. Thus far, the experiences of parents have been thoroughly examined (Chapters Two and Three), and it is clear there are many difficulties experienced by families of children with feeding difficulties, and there continue to be difficulties highlighted in relation to the support they receive. The next step in addressing the research questions guiding this thesis will be to explore professional's perspectives of delivering support for children with feeding difficulties and their families in the NHS to fill the gap in the literature that exists in relation to professionals' experiences of delivering this support. This will also provide an understanding of the experience of delivering support for children with IDD exhibiting behavioural feeding difficulties in the specific context of the NHS.

Chapter Four NHS Clinician's Experience of Supporting Children with Intellectual and Developmental Disabilities exhibiting Behavioural Feeding Difficulties and their Families

Chapter Overview

Chapters Two and Three explored the lived experience of parents and families of children with intellectual and developmental disabilities (IDD) exhibiting behavioural feeding difficulties. Chapter Three used a systematic review and meta-synthesis, guided by meta-ethnographic methods (Noblit & Hare, 1988) and found that while there appeared to be individual differences in experiences of behavioural feeding difficulties, there did appear to be congruence in the literature, with participants across studies in this body of literature reporting similar difficulties. The only area where family members reported incongruence was in experiences of support, with most reporting difficulties (e.g., feeling like they were fighting with services, etc.), and some reporting that the support they received was helpful and attuned to their child's feeding struggle. Chapter One also highlighted a difficulty reported by parents in England of receiving support for their child's behavioural feeding difficulty. Clearly, support for behavioural feeding difficulties is important, yet it appears that many families struggle to obtain good support for these.

One of the research questions guiding this thesis is to explore stakeholders' experiences and understandings of behavioural feeding difficulties amongst children with IDD, and their experiences of related supports for these. Previous chapters in this thesis (Chapters Two and Three) have provided a comprehensive and in-depth exploration of parent experiences of behavioural feeding difficulties amongst children with IDD along with their experiences of receiving supports. The current chapter seeks to explore the lived experiences of National Health Service (NHS) Clinicians that deliver support for behavioural feeding difficulties in NHS Trusts in England, with the aim of understanding the complexity of the support they provide, their working models (i.e., how they understand behavioural feeding difficulties and how this informs their interventions), and some of the challenges they face in their roles. As such, this chapter will contribute to the aims of this thesis by exploring the clinician perspective and experience of behavioural feeding difficulties and related supports.

Introduction

Feeding difficulties can have a serious impact on the lives of children with an intellectual or developmental disability (IDD), including nutritional deficits, social impacts, and long-term health risks (Cornish, 1998; Ledford & Gast, 2006; Patel, 2013). One of the most serious complications of feeding difficulties is failure to thrive (Romano et al., 2015), and in some cases feeding difficulties can lead to hospitalization (Milnes & Piazza, 2013). As such, there are usually many clinicians involved in supporting feeding difficulties. The clinicians supporting children with feeding difficulties can include occupational therapists, nutritionists, dietitians, physicians, psychologists, speech and language therapists, psychologists, social workers, nurses, and behaviour analysts (Gosa et al., 2020; Junquiera et al., 2015; Kuhn & Matson, 2004; Taylor et al., 2021a). It is generally understood that a multidisciplinary approach is the best way to support children with feeding difficulties due to the heterogeneous presentation of these difficulties for this population (Beaudry-Bellefeuille et al., 2021; Gosa et al., 2020). Clinicians can play a unique role in the assessment and intervention process for feeding difficulties, and important issues related to feeding may be missed if approached solely from one perspective (Beaudry-Bellefeuille et al., 2021). As such, healthcare clinicians are integral to supporting children with feeding difficulties and their families, as each brings their own knowledge and expertise to the understanding of the presenting feeding difficulty.

Most of the research surrounding feeding difficulties has focused on caregiver experiences, the development and validation of assessment tools, the development of interventions, and identifying effective interventions (e.g., Gosa et al., 2017; Ibañez et al., 2021; Kivilclim et al., 2019; Lukens & Linscheid, 2008; Rogers et al., 2012; Tan et al., 2021). The experiences and roles of clinicians delivering interventions within specified settings have not been well represented in the literature. However, some literature exists about: clinicians' awareness of family situations; their personal experiences of delivering support for feeding difficulties (Jakcson et al., 2022a; Jackson et al., 2022b; Luscombe et al., 2021; Miles et al., 2021); the bespoke and person-centred support they provide for these (Taylor et al., 2021b); best practice when supporting feeding difficulties (Jackson et al., 2022a; Jackson et al., 2022b; Miles et al., 2021; Taylor et al., 2021b); and barriers faced by clinicians when supporting this population (Fujino & Ikeda, 2022; Harrison, 2021; Miles et al., 2021).

Clinicians supporting these children and families are typically reported to be aware of the challenges faced by parents and families. This includes awareness of physical, emotional and financial burdens, increased parental stress when there is a child with a feeding difficulty, difficulties families encounter to receiving support, and family anxiety (Jackson et al., 2022a; Jackson et al., 2022b; Luscombe et al., 2021; Miles et al., 2021). Clinicians also note how family anxiety can be alleviated by accessing specialist paediatric support (Luscombe et al., 2021).

Providing support for this population can personally affect those who support children and families with feeding difficulties. The literature reports clinicians feeling pressured to try to get the children to eat as much as possible, feeling exhausted and unappreciated for their efforts dealing with individual feeding needs of the children they support, being uncertain in their approaches, and lacking confidence (Fujino & Ikeda, 2022; Harrison, 2021; Miles et al., 2021). Clinicians have previously highlighted how receiving clinical supervision for support with high-risk cases and ongoing skills development were important for reassurance and feeling part of a clinical feeding team (Jackson et al., 2022b; Luscombe et al., 2021).

Research involving these clinicians has highlighted key areas that are needed for best practice supporting feeding difficulties. This includes working with families to ensure feeding plans are appropriate to families' cultures and meet families' needs, designing services that address the impact of feeding difficulties on the family, and working collaboratively with families in a way that ensures each party's involvement is clear (Jackson et al., 2022a; Jackson et al., 2022b; Miles et al., 2021). A person-centred approach is also recognised by clinicians as being key to delivering support for feeding difficulties (Taylor et al., 2021b). Clinicians also describe difficulties encountered while working with families. They have reported experiencing difficulties working with families when there are differing perspectives; where they rely on parents to provide medical information; where there are concerns about families' understandings of their child's feeding difficulties and the risks of feeding; where they may feel it is difficult to ask parents for their cooperation; and where there are difficulties to collaborative decision-making (Fujino & Ikeda, 2022; Jackson et al., 2022b; Miles et al., 2021).

The difficulties described related to collaborative decision-making relate to situations where parents and clinicians' views do not agree (Jackson et al., 2022b; Miles et al., 2021). The difference of opinion between parents and clinicians has been described as causing conflict in the working relationship between parents and clinicians and resulting in the children receiving disjointed and possibly less than optimal support for their feeding (Miles et al., 2021). Relying on parents to provide medical information meant that when the children being supported had medical appointments, the information from these appointments was not shared, whereas a model of support where information was shared would be considered more supportive or coordinated (Miles et al., 2021). This suggests that sharing information between clinicians is important and valued, and it may be important for families to see the benefit of this to encourage information sharing, as families may be the ones bringing information from one clinician to another, though it would be important to consider the parent experience here as parents have previously described difficulties with having to co-ordinate care (Chapter Three). Fujino and Ikeda (2022) described cases where there was significant potential for breakdown in the relationship between the parents and the clinician, with clinicians attempting to navigate the situation sensitively while preventing the deterioration of the relationship. The intricacies involved in working with families has only been briefly described to date in the literature for clinicians supporting children with feeding difficulties and their families. A further understanding of the working models of clinicians when supporting this population would help with furthering the understanding of the intricacies of carrying out this work.

Further to difficulties faced when working with families, clinicians can also encounter a lack of resources and services, limited access to a multidisciplinary team, lack of support for families, and insufficient knowledge by relevant clinicians (Jackson et al., 2022a; Jackson et al., 2022b). Those supporting these children may struggle to know what to advise when delivering support or intervention for children with behavioural feeding difficulties rather than organic/ mechanical/ physical feeding difficulties (i.e., dysphagia; e.g., Miles et al., 2021), highlighting a further gap in the knowledge of those supporting these children and families.

In the United Kingdom (UK), support for feeding difficulties is generally available either through the National Health Service (NHS) or through accessing private services. In a recent study (Taylor et al., 2021b), healthcare professionals supporting children with eating and swallowing difficulties (including behavioural feeding difficulties) in the UK responded to a questionnaire about the types of interventions they use and their perceptions of important outcomes for feeding and swallowing interventions. Four-hundred and twenty-one health professionals responded to the questionnaire. Most of the respondents worked in the NHS (86.9%) and only 3.6% of respondents identified as being independent practitioners. Of all the respondents, 71.5% identified as working within community services, and 36.1% identified as working in secondary and tertiary services. This suggests that most support for feeding difficulties delivered in the UK is likely to be through the NHS, and more specifically through community services, rather than increasingly specialist secondary or tertiary services.

Recently, Harrison (2021) investigated the barriers to effective healthcare for children diagnosed with Avoidant and Restrictive Food Intake Disorder (ARFID) in the UK. There are likely to be some significant overlaps between ARFID and behavioural feeding difficulties primarily due to the topographical nature of the current working definition of behavioural feeding difficulties in this thesis. It is also likely that some clinicians that support children with behavioural feeding difficulties may also support children with ARFID (e.g., clinical psychologists). Harrison (2021) disseminated a mixed methods online survey, with open ended questions specifically collecting information about barriers to effectively diagnosing and supporting children with ARFID. The findings from this research suggest that the support needs of children with ARFID are not currently being met, as health care clinicians face difficulties with identifying children with ARFID, knowing who to refer them to for assessment and support, lack of knowledge and training around ARFID, and the lack of a clear pathway of support in services for these children. There was a worry that clinicians were providing families with uniform, non-individualised advice, or inappropriate advice. Clinicians also encountered systemic barriers such as no clear pathway of care for children with ARFID and no specific services for this population, meaning children with ARFID were potentially falling through the cracks because they did not fit easily into any specific service. Similar concerns may also apply to children exhibiting behavioural feeding difficulties.

There is a notable lack of literature exploring clinicians' perspectives and experiences of delivering support or intervention for this population. This is important as those delivering support for feeding difficulties are usually not just working with the children themselves, but with their families, and being aware of family contexts is important, as well as considering the additional challenges that working with families of children with IDD might pose. Recently, Parr et al. (2021) provided insight into current clinical practice in the UK for treating children with feeding and swallowing difficulties, however the rich lived experience of professionals providing this support was not carried out with an in-depth exploratory focus. Thus, further theoretical exploration of the lived experiences of clinicians providing support for children with feeding difficulties and IDD in NHS settings is needed to comprehensively understand their experiences, including barriers and their perspectives of key aspects of support.

The aim of this study was to understand clinician experiences of delivering support or intervention for children with IDD exhibiting behavioural feeding difficulties in NHS settings in England. The aim was also to use grounded theory methodology and analysis to allow for an understanding the current scope of service delivery for feeding difficulties in the NHS from clinicians' perspectives. The objective was to understand the working models of clinicians who support this population and their experiences of providing support or intervention for behavioural feeding difficulties. The research questions guiding this research were as follows:

- What are the supports or interventions provided to children with IDD exhibiting behavioural feeding difficulties and their families by clinicians?
- What working models do clinicians have about the development and maintenance of behavioural feeding difficulties and how do these working models influence the support or intervention provided to children with IDD and their families?
- What are clinicians' perspectives about what constitutes a good support or intervention for behavioural feeding difficulties and the barriers to providing this?

Methodology

Research Design

Qualitative research was selected as the methodology for this study as the intention was to carry out exploratory research of NHS clinician's experiences of providing support for children with IDD exhibiting behavioural feeding difficulties and their families. Qualitative methods can capture intricacies related to feelings, emotions, thoughts, and processes that are difficult to learn about in the same way through other research methods (Strauss & Corbin, 1998). It was deemed that qualitative methods would yield rich data that would allow for a deeper exploration of clinicians' experiences and allow them to explain their working models in more detail and would therefore be the most appropriate methodology to address the research questions. An exploratory approach was also appropriate as there is limited research with this population (i.e., clinicians supporting children with behavioural feeding difficulties and IDD).

Interviews

Semi-structured interviews were selected as these allow for the gathering of information from stakeholders who have personal experience, perceptions, and beliefs about a topic of interest (DeJonckheere & Vaughn, 2019). The flexibility of the semi-structured approach was an appropriate methodology given that the research questions aimed to learn about clinicians' experiences of supporting behavioural feeding difficulties in children with IDD and this methodology allowed for the deep exploration of the topic (DeJonckheere & Vaughn, 2019), while still ensuring that information related to the research questions was being asked. This ensured that participants' leads could be followed and probed further, while also ensuring the interview covered questions designed to obtain data related to the research questions. The use of semi-structured interviews allowed for richer data to be obtained as participants were able to provide elaborate responses and helped establish rapport with participants. A final reason semi-structured interviews were selected was that these would allow for more focused interviews, which was important as it was anticipated that NHS clinicians would have limited time that they could participate. Additionally, interviews were selected over surveys as surveys can sometimes be lengthy and take a significant amount of time to complete, and interviews were expected to yield richer data as clinicians would be able to elaborate.

Interview Schedule

An interview schedule (Appendix T) was developed along with probes. Interview schedule questions corresponded to the research questions. The questions on the interview schedule were developed as a guide to obtain specific information related to the research questions, and probes were available to follow up on topics or areas which participants might talk about. These questions were developed along with supervisors. The questions on the interview schedule were broadly about how children were referred to their service, the process from referral to intervention, the supports or intervention provided and what influences this support, their perspectives of what makes for a good support or intervention for feeding difficulties and barriers to providing this, their professional working models of why and how behavioural feeding difficulties emerge in children, and how these working models influence the support or intervention they provide. These areas were all included as they related directly to the research questions.

Participants

Ten interviews were carried out. Participants were ten clinicians working in a NHS Trust in England and currently providing support or intervention for children with IDD exhibiting behavioural feeding difficulties The accepted age range for the children supported was between 1.5-18 years old (exclusive). This age range was selected based on the World Health Organisation guidelines for starting babies on solid foods around six months of age and the estimation that refining the new skill of feeding can take between 6-12 months (Rappaport, 2015). The upper age range was selected as according to the Children's Act (2004) a child is anyone who has not yet reached their 18th birthday.

Participants in this study were included if they were over 18 years old. It was anticipated that participants would be clinical psychologists, speech and language therapists, dietitians, occupational therapists, and behaviour analysts. Demographic information for the participants can be seen below in Table 10. All participants reported having received some form of training for behavioural feeding difficulties, with only one (10%) reporting not having received informal training and three (30%) reporting not having received formal training.

Table 10

NHS Clinician Study Participant Demographic Information.

Characteristic	**Category**	**Number of participants (%) (*n* = 10)**
Gender	Female	10 (100%)
Race/ethnicity	White	8 (80%)
	Black	1 (10%)
	Indian	1 (10%)

Characteristic	Category	Number of participants (%) (*n* = 10)
Age (in years)	20-29	5 (50%)
	30-39	1 (10%)
	40-49	2 (20%)
	50-59	2 (20%)
Occupation	Clinical psychologist	2 (20%)
	Outreach worker	1 (10%)
	Speech and language therapist	2 (20%)
	Behaviour analyst	1 (10%)
	Learning disability nurse	1 (10%)
	Occupational therapist	1 (10%)
	Assistant psychologist	2 (20%)
Length of employment in current role (in years)	> 1	2 (20%)
	1-5	4 (40%)
	6-10	1 (10%)
	10+	3 (30%)
Formal training for feeding difficulties received	Yes	7 (70%)
	No	3 (30%)
Informal training for feeding difficulties received	Yes	9 (90%)
	No	1 (10%)

Ethical Considerations

Ethical issues were considered in the development of this study. It was considered likely that there would be some power imbalance due to the researcher/participant nature of the exchange. This was addressed by ensuring it was clear to participants that they could withdraw without giving a reason before data analysis occurred, and that their participation as not assumed because they had been in contact requesting information about the study (i.e., consent was not assumed), and their decision to participate was completely their own.

No payment was offered for participation as participation was entirely voluntary. As PhD research, this project was not funded, so there were no funds to pay participants. This was discussed with supervisors, and it was considered that paying participants would establish a new layer of a power differential between the researcher and participants that might impact the data collected (i.e., the researcher viewed in a powerful position, when the intention was to gather data from participants as experts on their lived experience of working in their roles and their views). It was also considered that this additional layer of a power differential could mean that participants might not feel confident in withdrawing from the research.

It was considered that throughout the course of the interview participants might feel as though their job performance or services delivered were being assessed, evaluated, targeted, or judged. This was addressed by ensuring that the interview schedule questions were worded sensitively and that these questions were delivered in a sensitive way. It was considered highly unlikely that participants would become upset by discussing some of the topics raised in their interviews, however it was decided that should this occur, participants would be referred to Project 5, an online system which gives NHS employees access to free 1:1 support from a team of volunteer coaches and mental health practitioners (Appendix U).

Given that this study was carried out during the ongoing COVID-19 context and the increased pressures on the NHS during this period, it was considered that participating could pose an additional burden on clinicians. This was minimised by being as flexible as possible when scheduling interviews and ensuring the shortest amount of time possible was taken to complete the interviews. All these issues were considered on the ethics application.

Procedure

This study was granted Tizard Centre Ethics Committee approval on July 28th, 2021. An Integrated Research Application System (IRAS) form was completed and submitted, and this project received Health Research Authority approval on July 16th, 2021.

Recruitment

Research information was disseminated through social media, mailing lists, and through the participating NHS Trusts starting in July 2021 and concluding in November 2021 (see research poster in Appendix V). The intention was to reach localised community services and national services, however no participants from national services were recruited, thus the focus of the study was on clinicians providing support in community services.

Each participating NHS Trust was liaised with to distribute recruitment materials. Purposive sampling was used as participants needed to be grouped and recruited according to pre-determined criteria (i.e., NHS clinicians providing support or intervention for children with IDD and behavioural feeding difficulties). Upon receiving inquiries about participation, a preliminary conversation through email occurred to confirm inclusion requirements and answer any questions. Upon confirming inclusion requirements, they were sent a Participant Information Sheet (PIS; Appendix W). A total of 15 clinicians expressed an interest in participating, and a total of ten interviews were carried out, with ten participants. Not all those who came forward for participation met the inclusion criteria (*n* = 2, not in England), some did not return study forms providing consent (*n* = 2), and one interview could not be rescheduled due to the individual going on maternity leave. All these were thus excluded from participation.

Consent and Demographic Information

Informed consent was obtained from participants through the completion of a consent form prior to the interview (Appendix X). Demographic information was obtained from participants either through the completion of a form (Appendix Y) prior to the interview or recorded verbally at the start of the interview.

Pilot Interviews

An interview schedule was used in all interviews. The interview was piloted with a fellow PhD student and with a PhD supervisor (PB) who had experience of working in the NHS. The pilots were meaningful to this research as they enabled a variety of situations to be considered and feedback from various sources to be obtained and applied to the subsequent research interviews. This allowed the researcher to be prepared for multiple possible scenarios and to practice navigating the delivery of questions prior to undertaking interviews with research participants.

Research Interviews

It was anticipated that interviews would last 1 hour, however interviews lasted between 1-1.75 hours. A short demographic questionnaire was also used to capture additional information about clinicians' roles within the NHS and the kinds of training they had received about feeding difficulties. Interviews were conducted online and video-recorded via MS Teams. All recorded interviews were stored on Stream. All interviews were transcribed verbatim and anonymised. All names and identifiable information (including names of cities, counties, Trusts, clinicians) mentioned were redacted from the transcripts. Participants were assigned different names from their own to ensure that participants' real names or identities were kept confidential. Pseudonyms are used throughout this report. Data collection ceased when theoretical saturation was reached.

Following the conclusion of each interview, all participants were sent a follow-up email thanking them for participating which included a comments form (Appendix Z) if they wished to provide any feedback to the researcher. Only one participant provided feedback following the interview, and this was provided via email (Appendix Z).

Data Analysis

Grounded theory was used to analyse the data.

Grounded Theory Selection

Data analysis used a grounded theory approach. Grounded theory was selected as the most appropriate data analysis method as data from this study will contribute to a new theory of the experiences of NHS clinicians supporting this population, which will emerge from the data gathered and analysed (Howard-Payne, 2016). The type of grounded theory used was Straussian grounded theory, as Strauss' approach is applied within a contextualistic epistemological positioning that acknowledges the inter-subjective interpretation and understanding of the topic (Howard-Payne, 2016).

Concurrent Data Collection and Analysis

The interviews were scheduled and carried out between August 2021 and December 2021. Data collection and data analysis were carried out at the same time; this is a hallmark of Straussian grounded theory. All interviews were carried out by the PhD researcher, as well as transcribed and reviewed, as the data was being collected. An open coding framework (described below) was developed as the data was being collected and the data was coded into this framework.

Member Checking

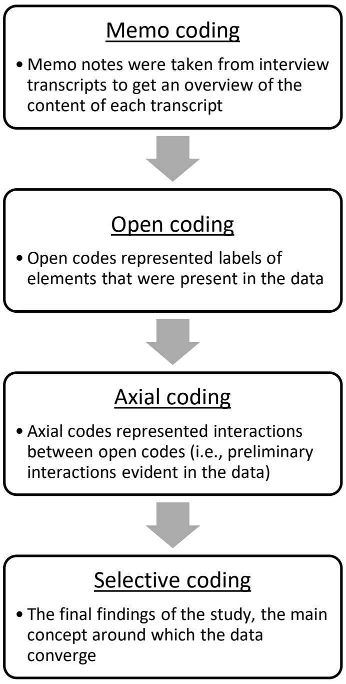
As ideas about the recurrent themes and connections between the data emerged, these were tested with participants through an element of member checking. Member checking involved presenting participants with prominent preliminary themes and asking them how those interpretations sounded to them, and whether there was anything they would add to the presented interpretation. This allowed participants to confirm some of the interactions between the data and confirm preliminary results to a degree (Birt et al., 2016). This process also allowed for theoretical sampling by enabling the focus of interviews to be guided by the data that had already been collected, in the form of the interview questions asked and the widened scope of the existing interview questions (Ligita et al., 2019).

Memo Coding and Open Coding

An overview of the stages involved in analysis and how the analysis process changes across these is evident in Figure 7. While the data was being collected, the transcripts were reviewed and coded into memos. Memos were reviewed and grouped, outlining a preliminary set of 13 open codes (as seen in Appendix AA). The memo codes and groupings were also reviewed by a supervisor (NG), who provided feedback about rewording some codes and refining some concepts out further. The preliminary set of open codes was then examined and grouped based on common themes, as per supervisor feedback, resulting in six main open codes, each with subcategories of specific elements which were present in the data. The final open coding framework was input to NVivo and can be found in Appendix BB.

Figure 7

Overview of the Stages Involved in Straussian Grounded Theory Analysis.



Axial Coding

After coding the raw data into the open coding framework, relationships between codes were examined in NVivo by running matrix queries. The relationships between open codes were examined individually rather than by categories to allow for the interaction of all the codes to be captured. This was adopted to ensure that the data relates back to itself naturally rather than at a pre-determined category level. Matrix queries were run comparing all codes to each other, resulting in a 14x14 grid, as seen in Appendix CC. This allowed the researcher to obtain an overview of the relationships between all codes. This also ensured the data was being related back to itself in an objective way, in keeping with a Straussian grounded theory approach. Appendix CC also shows the relationships between code categories that were selected for further exploration (i.e., those marked as significant).

The criteria for deciding if a relationship between codes should be explored further were:

1. There were many interactions between the categories (it was presumed that this would be a strong demonstration of the data relating back to itself)
2. The interactions between the code categories represented powerful lived experience

After running matrix queries, memos were taken to explore the relationships between open codes; these were extracted and examined for patterns, identifying nine key interactions in the data. The data interactions were explored in detail, and these were drawn together into nine categories which exemplified nuanced interactions between the codes in the data. These categories became the axial codes; they are listed in Appendix DD, along with an interpretation of each axial code.

Selective Coding

Following the development of the axial coding framework, the raw transcripts were coded into this framework. Following this, the same systematic matrix query process described above was repeated. The relationships between all axial codes were checked and displayed as a 9x9 grid in Appendix EE. This systematic process provided an overview of the interaction between axial codes. The relationships between codes were then explored and memos were created. These memos were then analysed for patterns, and selective codes emerged, along with the findings of the study.

The criteria for deciding if an interaction between axial codes exists was as follows:

- The interactions between the axial codes represent an important contribution to the research questions
- The interactions between the axial codes capture a rich and powerful lived experience
- There are many interactions between the axial codes (it was presumed that this would be a strong demonstration of the data relating back to itself)

Each of these criteria were included as they ensured that the analysis was tailored around the research questions and allowed for the consideration of rich lived experience as well as repeated interactions, highlighting the inductive nature of the analysis process selected for this research. An interaction was identified as representing an important contribution to the research questions if the content of the interaction was related to any of the research questions. An interaction was identified as capturing a rich and powerful lived experience if the information within an interaction was not common or repeated amongst many participants but represented a unique perspective or contribution that was important to consider in the analysis. An interaction was identified as having many interactions if there were ten or more excerpts within that interaction.

Results

This study sought to understand NHS clinicians' experiences of providing support or intervention for behavioural feeding difficulties in children with IDD and their families and the working models which inform the support or intervention they provide. From this study, it was evident that their working models are influenced by their understanding of why the presenting feeding difficulty is occurring. Individualised supports and parents as intervention agents for systems change were key parts of the work delivered. Finally, NHS clinicians face many barriers to providing effective support for this population. The four main themes and the relevant subthemes can be seen on Table 11.

Table 11

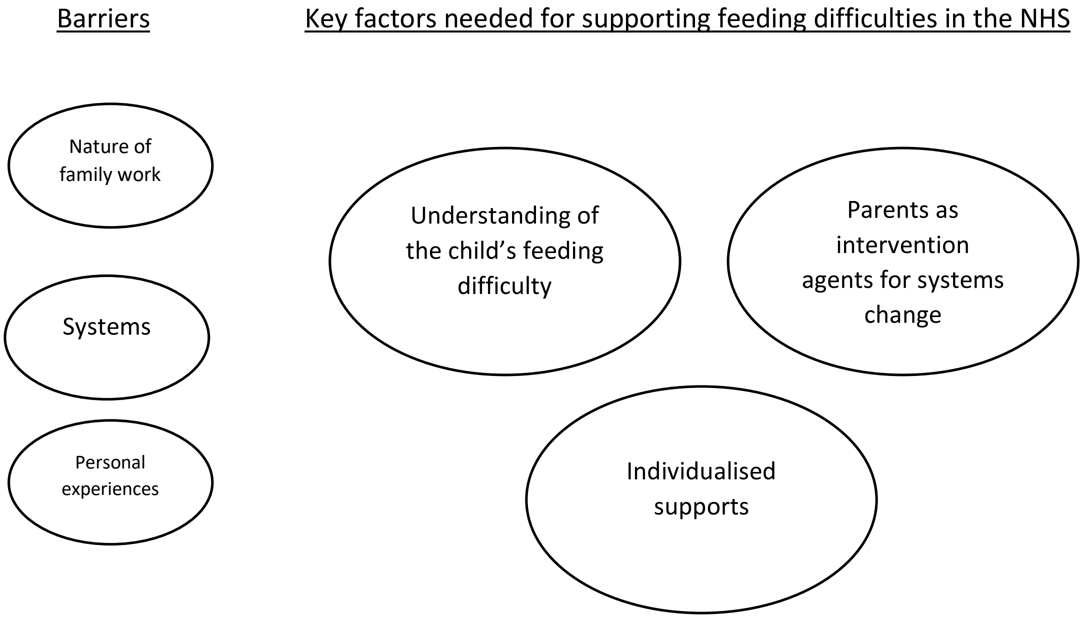
NHS Clinician Study Themes Identified along with Subthemes.

Themes	Subthemes
Understanding why the feeding difficulty occurs	Meaning optimises management and intervention approach Shared understanding and family work
Individualised supports	Unique presentation means tailored support Family-centred support as best practice
Parents as intervention agents for systems change	Collaborative approach: ‘Do with’ rather than ‘do to’ Families can play a role in maintenance of feeding difficulties, but are also integral to the solution
Things that make it difficult to provide support	Systems Nature of family work Personal experiences

The main themes identified in this study work together to explain how clinicians deliver support for feeding difficulties in England and the main difficulties that they face (Figure 8). This interaction will be detailed first, followed by an in-depth exploration of each of the individual themes.

Figure 8

Grounded Theory Model of the Experiences of Clinicians Providing Support for Children with IDD Exhibiting Feeding Difficulties in the NHS.



Grounded Theory of Clinicians' Experiences when Supporting Children with Behavioural Feeding Difficulties in the NHS

There were three main points described by participants as being key to their work (key factors noted on Figure 8). Clinicians described that it was important to understand why the child's feeding difficulty was happening and having this understanding be shared with families. This helped them have a starting point for supporting families in their efforts to improve their child's feeding difficulty.

> "That's the importance of coming to shared understandings… that's what you refer back to as a building block." (Interview 1)

Clinicians spoke extensively about families’ need to have individualised supports. This individualised approach was consistent in the support described through from the decision to admit families to services, assessment, intervention, and discharge; it was individualised down to its core. Clearly, an individualised approach was recognised as the gold standard approach to feeding difficulties. Participants described tailoring the individual supports based on the understanding they formed and shared with families about the child’s feeding difficulty.

> “You can adjust and adapt the way that you approach the parents as well, so you might need to take it a bit more slow with them…use strategies in a bit more of a sort of a graded way with them as well.” (Interview 10)

> “If there are underlying gastrointestinal issues…that needs to be sorted out before we focus on the feeding… When you look at the impact of anxiety…that could include sensory overstimulation but could also include you know negative interactions with parents … it depends on the individual formulation… the sort of dominant underlying factors, as well as the ones that are most easily changed. And then obviously, you have to make a clinical judgment and collaborate with parents to consider where you’re gonna start.” (Interview 7)

Participants also noted that families played a key role as they are the ones that put in place intervention strategies in the home setting, and that families’ involvement was key to facilitating a change in the family system to support children’s feeding difficulties. Thus, families played an integral role, however, their ability to be involved in the interventions also varied and needed to be considered on an individual basis. This reflected the space and resources families were able to dedicate to implementing any intervention strategies in the home setting for their child’s feeding difficulty. The interventions or strategies that families were asked to implement were informed by clinicians’ expertise or experience supporting feeding difficulties and their understanding of each individual families’ situation and context.

> “I think ultimately what we're trying to do is empower them…I suppose in a way when we try to provide feedback, it's almost trying to help them get to that place themselves as well…and kind of trying to have them, see that for themselves almost.” (Interview 2)

> “It could be that their child is particularly distressed or challenging around mealtimes, so people are nervous about making those changes.” (Interview 5)

Altogether, the working models of clinicians highlight these three areas as intertwined, essential parts of supporting families and children with feeding difficulties. Unfortunately, clinicians providing this support in NHS settings in England face many barriers to this work. These barriers relate to the nature of family work, systemic challenges, and personal experiences that make it difficult for these key components to come together cohesively.

> “A parent might want a child to finish all their meal …and the child has…said, ‘I'm finished’ and parent might want to keep forcing them. But what we try to teach them actually is that they are communicating to you that they've had enough…so really the work can be sometimes with parents around…accepting this boundary…from the child and learning to respect that….As long as they’ve eaten, that is important.” (Interview 10)

> “In the initial crisis it's really worrying, and you’re…leaning a lot on your kind of physical health colleagues for support, and making sure those relationships work, cause that can be difficult in terms of like, ‘oh it’s behavioural, you do it’, yeah, OK, but you know their iron levels are so low that they're very physically unwell, so you manage that bit and it's like making sure those, yeah, the services are joining up, makes it easier I guess.” (Interview 4)

> “it's really hard because…I just want to help all the time. That is why I'm in this profession and it does make you feel less confident sometimes, and sometimes it can be like, OK I've tried everything and it's just not working, but then…that is quite reflective of what the

> parents are also experiencing with the child where they've tried everything, and I guess then it can give you a new perspective on the situation as well.” (Interview 10)

Theme One: Understanding Why the Feeding Difficulty Occurs – “The First Steps”

Clinicians in this study emphasised the importance of understanding why the feeding difficulties were occurring. Having meaning for why the feeding difficulty was occurring meant that the management of the feeding difficulty and the implementation of interventions were optimised. They discussed the importance of developing a shared understanding with relation to family work and established shared understanding as the foundation from which to build on when developing interventions or approaching support for feeding difficulties.

Meaning Optimises Management and Intervention Implementation

Having meaning for why the feeding difficulty was occurring meant that clinicians could support families in breaking down mealtime patterns, so families were not so controlled by their child’s feeding difficulty. An experienced clinical psychologist discussed their perspective of how supporting families with understanding why their child’s feeding difficulty is occurring was the first step in providing support:

> “So the important message is around…understanding what we're doing here. Before I suppose we start doing anything tangible, that kind of understanding what's going on here…so they’re the first steps.” (Interview 1)

There was a suggestion amongst participants that supporting families in understanding is also part of supporting them with breaking down the patterns identified, as having meaning gives families context for what is going on. An outreach worker in a tertiary NHS service discussed how helping families understand and providing meaning for them was the first step before moving onto more interactive support for their child’s feeding difficulty:

> “Acknowledging what they're saying…like normalise it in a way…So kind of often reflecting a lot back to them and then helping them to understand.” (Interview 2)

There was a recognition amongst clinicians that unpicking each individual situation helped set the context for the support being provided. A speech and language therapist in community services emphasised the value of this when families are asked to implement certain strategies:

> “They know why they're doing it…they've had a think about it, and you know decided that it actually is something that's practical and will work within their family.” (Interview 6)

Shared Understanding and Family Work

Many clinicians in this study discussed the importance of arriving at a shared understanding with families about their child and family situation in relation to the feeding difficulty. This formed the building blocks of the beginning stages of providing support or intervention. It was also emphasised how working together in the process of developing a shared understanding meant that sometimes it was necessary to hold back clinical interpretations and align with families with what they believed to facilitate work with families.

Formulation is a key part of the work carried out by clinical psychologists. One clinical psychologist in this study discussed their perspective, that developing a shared understanding was key to ascertaining whether the clinician and family agreed that intervention was necessary for the child’s feeding difficulty, and what that might look like:

> “I would then do a quick formulation…that…enables the sort of building blocks to that shared understanding of…what the difficulty is …if we agreed that…this would be a child or young person requiring intervention… we would discuss what that might look like, where that might be.” (Interview 1)

One participant provided their perspective that understanding feeding difficulties was important to ensure that they were able to facilitate family work in the most appropriate way and not damage working relationships with families by placing any blame:

> "Understanding…some of the root causes… I think it's really important… to explain those, to have… [an] understanding of the lived experience of the parent and of the child and making sure that there's kind of no blame, no pointing fingers." (Interview 8)

Comments from participants also suggested that they were aware that developing shared understanding can take work, and one behaviour analyst emphasised that it was important for clinicians to know when to stop pushing families to understand things from their clinical interpretation of the situation, and to validate families' experiences:

> "You might have video footage and we can kind of sensitively, say, 'OK, this is what I observed…would you agree that this is what was going on here? … Are you seeing what I'm seeing?'...And if not just really listening to that, 'cause actually they're living it and that's really important that they feel validated and understood rather than us coming in as professionals being like, 'oh, I think you should do this, I think this is why', and actually that needs to be sensitive and match up otherwise it's not going to work." (Interview 4)

Theme Two: Individualised Supports – "You Gotta Tailor Your Approach"

The notion of providing individualised supports to families is not a new one, however in this study, clinicians described recognising the unique presentation of each child and family, and how this influences the way they address formulations and the approach or intervention strategies used with each family. They explicitly discussed person- or family-centred approaches to support as best practice when supporting families of children with feeding difficulties.

Unique Presentation Means Tailored Support

Participants in this study described recognising that all the families and children that they supported for feeding difficulties had a presentation of the difficulty that was unique to their situation. One clinical psychologist described how her work involved identifying those unique interactions between all the factors that could be influencing the presenting feeding situation:

> “That's part of the work I do, the interaction between the child and the parent and the diagnosis and the context, and you know, God knows what else.” (Interview 1)

An assistant psychologist discussed how from her perspective considering all the unique elements was vital to providing support for families. She described how she considered all contributing elements and the contextual information to be aspects of people’s identities that needed to be incorporated into family support in order for the intervention to be effective and meaningful:

> “It's just so important…to hold those things in mind because they're a part of that person… when they leave the feeding clinic, when they leave your session, they carry on being that person with all those things involved, so keeping it in mind and making sure that whatever it is that you are trying to intervene with, or give them support with, it kind of tallies up with that.” (Interview 10)

Clinicians in this study described how their understanding of the unique presentations of each child and family influenced the way that they delivered support. The support discussed varied, and there were varying levels of individualisation described, often limited by other factors (explored in Theme 4). However, participants described the importance of individualised approaches and incorporating this into their practice in their respective services.

The importance of formulation, and the individualised understanding of the presenting situation, was highlighted by many clinicians. One clinical psychologist described how to them formulation meant “gauging the relative impacts of [the] individual factors” that may be contributing to the presenting child’s feeding difficulty (Interview 7). There was a general understanding from clinicians that this process involves developing a unique understanding of each family’s situation, highlighting the individualised nature of this approach. Another clinical psychologist discussed how in their work formulation completely guides interventions and the approach taken when working with individual families:

> “It is totally about the understanding of the feeding problem and what's gone into it, and that so dictates…the thruft [sic] of your intervention…And then there's a whole range of stuff around working with individual parents… you gotta tailor your approach.” (Interview 1)

Participants also described how these formulations gave them important information about the level of support that they need to provide. Some clinicians discussed how for families of children with feeding difficulties that are and are not at risk of inpatient, the level of support offered would reflect the current risk factors associated with the feeding difficulty:

> “It depends…[on] the complexities of it…when we have other children that are…going into hospital those kind of things, and that's probably more complex, long term, heavier package of interventions, so can look very different.” (Interview 2)

> “Dependent on the severity we might think about how intense our package of support needs to be… so kind of if parents themselves, they might have a learning disability…or like they might be really stressed and overwhelmed and just not able to take on board what we're saying and put it into a live environment. So those kind of cases…actually a systemic practitioner might be really helpful.” (Interview 4)

As noted in the quote above, one participant described how understanding the wider context and situation also provided information about additional support parents might need when engaging in family work. Many clinicians highlighted that support needed to be delivered in a way that was appropriate for families, thereby tailoring approaches with parents based on their needs:

> “It's on a 1:1 with the parent carers where the psychoeducation would be delivered at a pitch that's appropriate for the parent carer...So it's important that we consider the needs of them…to make sure it's a level they understand.” (Interview 5)

> “So is the webinar gonna be helpful? Is that too wordy? Do I need to give you that information in a clearer way?... What can they access? What do they feel able to do? And then how can I sort of grade my therapeutic approach really to provide what I can within the remit of my service.” (Interview 8)

Another way clinicians described doing this was to grade the way they delivered support based on what families could receive:

> “Also the fine grainedness [sic]…about how you might provide behavioural advice or structure to people. Some people go home with…written programmes, and I will check in with them. Some people, we just discuss it. We're clear what we're gonna do and then they go home and do it.” (Interview 1)

When referring to the children with feeding difficulties themselves, participants also spoke about having to individualise the strategies that they used or suggested, tailoring these around the children’s individual presentations and needs:

> “Even with a child of eight, for example, depending on the formulation, I might see them on their own and do hypnosis with them on their own, with another child of eight, I wouldn't. It would be something completely different because it's so led by the strengths, needs, difficulties of the child and the parents.” (Interview 1)

> “If I give you an example of working with somebody that has Prader Willi, that would be very different to somebody with limited choices.” (Interview 5)

Participants also recognised that their overall approach with different children and families needed to vary depending on what the child or family could cope with:

> "If a child isn't going to cope in a group…we would then perhaps offer some 1:1 therapy block instead…For some children that isn't even possible because even 1:1 therapy is all really tough. So in those approaches for those children, I would probably offer like video consultation with the parents…and use…a coaching approach… And kind of trying to skill the parent up and help them problem solve how to expand their child's diet." (Interview 8)

Finally, there was also an acknowledgement from participants that individualising the approach needed based on the presenting situation meant that sometimes clinicians needed to start somewhere else (i.e., physical health colleagues) or advocate for other health professionals to be involved:

> "If there is a sense of a child might be malnourished, if they're not already under dietetics…if they haven't had their weights and heights done…if they haven't had bloods done, if there is, you know if there's any indication that there might be deficiencies, I will chase that up and obviously the focus …that is prioritised." (Interview 7)

Family-Centred Support as Best Practice

Although it was clear from the interviews that the supports clinicians spoke about were geared towards optimising individual support, it is important to highlight that they explicitly referred to this approach as family- or person-centred and identified this as best practice. One assistant psychologist considered that it was important to adapt the way clinicians work clinically to ways that will support the children they work with in the most appropriate way:

> "Where I am in the children's service, [children] are literally the core of everything…you can be guided by parents and…the theory, I think at the end of the day, the child is what's most important and working with children with disabilities, autism, whatever it is, you have to

> really sort of adapt…the way that you work and really have their needs in mind when you're working in that way.” (Interview 10)

Another assistant psychologist gave an example of working in this way with a child who had feeding difficulties, and being led by the child’s needs, adapting their feeding intervention approach to ensure it was most appropriate for the child:

> “He is someone that…wants fun…so I wanted to take that fun approach…And that was really my guiding factor, because the article that I read on the [intervention approach], they didn't have a lot of fun elements involved in it, so I really had to bring that in 'cause I knew that if it was just do this step and then this step he just wouldn't, he does not like that…so yeah, that was my guiding factor and thinking also of like, what are his reinforcements? … what's highly reinforcing to him at that moment? And then use that as the reinforcer. So yeah, really person-centred. Like what does he need? What does he like?” (Interview 9)

Theme Three: Parents as Intervention Agents for Systems Change – “You Need the Parents Totally 100% on Board”

A prominent theme throughout all the interviews was the way participants in this study described the involvement of parents in the intervention delivered. They discussed using primarily a collaborative approach and explained the rationale for this. It was clear that from their perspectives, families were integral to the resolution of children’s feeding difficulties.

Collaborative Approach: ‘Do With’ Rather Than ‘Do To’

Clinicians in this study recognised parents as key players in the formulation, assessment, and intervention process. Interventions often involved families heavily, using coaching, modelling, in-home support, parent-led goals, and strategies being delivered through parents. There was an emphasis and recognition from participants that the intensive parent involvement in their feeding interventions was aimed at empowering parents to continue to progress on their own at home.

As discussed earlier (Theme 2), participants in this study considered that parents play a key role in the formulation process, with the goal being to develop a shared understanding, and involving parents are in a collaborative way. In this study, clinicians described checking for families' agreement with their formulations before proceeding with intervention, highlighting the collaborative nature of the formulation stage of feeding interventions:

> "I think it's really important…to reflect like our formulation or understanding back to the parents … we're a third party like this is our understanding, but is this actually, you know, does this align with what the family believe?" (Interview 4)

> "We…share our formulation with families before we then conclude our recommendations." (Interview 5)

> "We don't just throw strategies at it…it's about a reasoned formulation, taking parents with us." (Interview 1)

> "Why is this person presenting with this feeding difficulty at this moment in time? What might be keeping it going?... I'll share with [parents] an initial psychological understanding of how I see things, get their…response to that to gauge if that resonates. If it does, then I will think about the parent's goals, the child's goals and I'll start thinking about how realistic those goals are given how I see the problem and give them what I know about that particular problem." (Interview 7)

Unsurprisingly, clinicians also described parents as key contributors to their assessments for feeding difficulties. Importantly, however was the description provided about the depth of the information in the assessment process that parents provided, and which other professionals supporting families and children should be aware of.

> "We go over the child's feeding history… medical history…current circumstances of any family, relevant family and circumstances, school, friendships, all these, etc. And just to get a

> more complete picture. And obviously when we talk about the feeding difficulty…I tap into the details… the severity, the frequency…we'll have a bit of discussion about what the feeding difficulty appears to be driven by." (Interview 7)

Families were also described as being involved collaboratively when defining intervention goals for children's feeding difficulties.

> "Really start to think about goals for the family, and it's very much parent led, so it's what they sort of want to work on, what they feel is most helpful." (Interview 10)

While participants described considering families' wishes in terms of goal selection, they also highlighted supporting families to recognise the limits of their child's eating when outlining these goals:

> "What the family would like to achieve with the young person and are those realistic goals? And like having conversations around that as well." (Interview 4)

In terms of the interventions themselves, they mostly described parents as being the primary interventionists, carrying out most of the intervention work themselves. One clinical psychologist discussed how in their service the entire intervention might be carried out through parents:

> "You know I might be delivering the entire therapy through them…so the whole session could be, you know, with a parent or carer, absolutely." (Interview 1)

Clinicians described a range of reasons for taking a collaborative approach. A behaviour analyst working in a specialist tertiary service discussed how their approach was targeted at facilitating systems change at the family level:

> "We call it a parent as therapist model… it's systems change…supporting the systems around the child to facilitate what they need to." (Interview 4)

Other participants discussed promoting effective and long-lasting change, cohesively balancing, and bringing together parents' contribution with clinicians' intervention knowledge and promoting parent involvement as a means of empowerment. It was generally understood that taking a collaborative approach would help with promoting effective and long-lasting change:

> "We kind of aim for like a do with approach, rather than a do to approach… involving them in their own plans… I think if we just presented a plan and said this was it, probably wouldn't be as effective as kind of that collaborative work…it just helps with buy in and motivation for the families too." (Interview 4)

The same clinician suggested how the goal with a collaborative approach might be to give parents the tools to apply the same principles if similar challenges occurred in future. Participants suggested that the goal of this was to empower families:

> "If similar things come up, they can kind of look back on their learning throughout their support from us, and then hopefully be able to kind of apply that as well kind of moving forward, so they're feeling kind of ready with the toolkit…and involving the system rather than just that direct intervention to the child and those specific situations. (Interview 4)

> "I think…our remit is to empower and skill up parents to carry this out with their child day-to-day everyday rather than kind of perhaps working a more private therapy way where you would kind of work with them weekly for months." (Interview 8)

Another clinician emphasised how from their perspective it was important to respect the parents' role as experts on their children and their families, and apply their intervention knowledge in a way that allowed for this to be recognised and respected, for the work to be truly collaborative:

> "They are the expert in their child and their family and we're just coming in with our like knowledge of kind of interventions and behavioural stuff. And you know, seeing how that marries up really…collaborative I think is the word." (Interview 2)

Families can Play a Role in Maintenance of Behavioural Feeding Difficulties, but are Integral to the Solution

Clinicians described how in their experience parents were often not the reason why their children’s feeding difficulties may have started, yet there was a sense of possibility that parents might play a role in why their children’s feeding difficulties were continuing to occur. This highlighted how parents were integral to the solution, needing to be on board with the support provided to make a difference in their child’s feeding difficulty.

Some participants discussed how from their perspective some feeding difficulty behaviours could have been accidentally modelled by the children’s families:

> “Sometimes the parent doesn't like getting messy themselves…I think people don't necessarily realize how much children pick up on these things from their parents’ behaviour.” (Interview 3)

> “Mum saying, ‘oh, I need to get him to eat better’, but she won't sit there and eat it herself, or sibling going ‘ew, no!’ So actually…family response to food and mealtimes.” (Interview 5)

One participant also discussed how they thought it was possible that some children did not have models in their families of what mealtimes and eating should look like:

> “I think for some children perhaps eating isn't modelled so well within some families, so family mealtimes can be really chaotic, and maybe they don't sit down together. Maybe they do just get given a packet of crisps for tea or go into the cupboard and get what you want, so that kind of family dynamic is really key to modelling eating.” (Interview 8)

Further to this, clinicians also discussed their opinions about the role of the family mealtime environment. These descriptions were primarily related to the parents’ anxiety around mealtimes and the environment that was created for the children that were eating in that environment:

> “I had one mom actually, who the little chap …there's no sort of reason why he might have a difficulty…and mum’s quite anxious around mealtimes and choking risks and things, and that's obviously having an impact on him…and not that it's their fault, but it is impacting on that.” (Interview 3)

> “I wonder too if…that eating environment of the child, parents, siblings, whatever if they're struggling with foods, or if they're quite negative to the child, whether that's going to again increase the anxiety increase the stress around mealtimes, making eating just generally not nice into the future.” (Interview 8)

Some participants also discussed how they thought parents may have avoided pushing their children outside of their comfort zones to avoid any challenging mealtime behaviours or feeding difficulty behaviour, and how this may have played a role in their children’s limited eating:

> “They kind of… were stuck in…that neophobic… they're not wanting to try anything and do anything. And again, obviously I think then parents fall into that pattern themselves…avoiding that behaviour, so they’re just sort of allowing that to happen perhaps.” (Interview 4)

> “I think it could keep happening because parents don't keep pushing it…it leads to challenging behaviour and it's difficult to manage and it impacts the mealtimes, it impacts everyone around them, other siblings…maybe the child then has these five items, they just go along with the five items…it's…them being afraid of challenging behaviours, so not wanting to take the risk, then they go into just providing these food items.” (Interview 9)

Another clinician described how they thought that negative cycles may have been established during mealtimes, whereby parents reacted in ways following instances of their children’s feeding difficulties, and this may have exacerbated the situation:

> “So sometimes certain children who…they're not able to communicate when they're full or when they want food or whatever it is, and sometimes the communication then comes out as a behaviour, and then parents don't always understand that part and then it leads to this vicious cycle of ‘Oh no, they're doing that behaviour again, they're just being naughty.’ They don't get it, and the parent then reacts to that and respond in a negative way and then yeah cycle.” (Interview 10)

Ultimately, it was clear from the level of parental involvement described by most clinicians that parents were considered to be the key agents of change. One participant described how in their experience parents needed to be fully on board for these interventions to make a real difference to their children’s feeding difficulties, continuing to highlight the integral role of parents in interventions for feeding difficulties:

> “I guess to make a real difference with it you need the parents totally 100% on board.” (Interview 3)

Clinicians in this study described many ways that they considered parents might contribute to why their child’s feeding difficulty may continue to happen. From the interviews, there was a sense that this understanding, along with the focus on collaborative working described earlier, meant that the main agents of change of the interventions recommended were parents themselves. Altogether, it was evident that parents were considered to be the key agents of change in interventions for feeding difficulties.

Theme Four: Things that Make it Difficult to Provide Support – “Unless You’re in Crisis, We Can’t Offer that Gold Standard Package”

Participants discussed many factors they perceived to hold them back from being able to carry out their work. These centred primarily around the systemic difficulties, the nature of family work, and personal experiences they had when supporting these children and their families.

Systems

There were systemic difficulties described by clinicians. Participants described struggling with accessing the relevant professionals to work together to provide appropriate supports. They also described limitations imposed on them due to their services' design and commissioning. Notably, they highlighted that clarity in service provision was needed, and that it was their perception that there was a clear gap in the NHS related to supporting children with IDD exhibiting feeding difficulties. Some participants also described struggling to implement well-known models of support that they described as difficult to adapt to implement in the UK context, as they were developed in the US, in a very different health system context.

One of the most prominent difficulties described by participants was the ability to access the relevant professionals. When describing her work, a clinical psychologist discussed how she felt it was necessary to involve dietitians to ensure the children were receiving adequate nutrition, however she could not do this given that dietitians were not located in her Trust:

> "When the food diary comes back, I try desperately to get it looked at by a dietician. It's not always successful because they belong to a different trust. Because I quite like to…think about if there's anything glaringly obvious missing from the food groups on there, and I'm not a dietitian so I don't know." (Interview 1)

Clinicians discussed how in an ideal world, they would like to work closely with other professionals to allow them to link up with the other relevant and necessary services appropriately to improve supports. They discussed how they did not believe it was possible to work collaboratively with professionals from other disciplines with the current systemic limitations that they found inhibited them from accessing the necessary and relevant professionals:

> "The services tend to be…like one's over here, one's over here, one's over here, and linking everybody up is really difficult…if we were able to sit more closely with some of the other

> teams, such as social care or physical health…that would probably make a huge, huge difference to that collaborative working.” (Interview 2)

> “So in my ideal head, we'd all be in one place… and we'd all be doing joint assessments…We need to [make decisions] as a multidisciplinary team, but by the time you kind of contact people…it just takes so long, and it just feels like there's so many barriers up to good communication and inter disciplinary working.” (Interview 3)

One experienced clinical psychologist believed the multidisciplinary nature of the feeding clinic setting increased her confidence because it reassured her that the children were receiving appropriate supports that were outside of her clinical remit:

> “Dietitian is right there…where there’s any doubts, there will always be follow-up investigations or supplements prescribed…I feel a lot more confidence when I know that the dietary side is being looked at.” (Interview 7)

Participants also described limitations to the support or intervention they could provide that they perceived to be imposed on them due to the design and commissioning of their service. They described feeling limited in the amount of support they could provide due to time and resource constraints. One assistant psychologist discussed how she did not believe this was conducive to providing good and effective family work:

> “Three sessions is just not enough… once you get to the third session, which is the last session, you're just getting going, parents are really just starting to open up and feel a bit more confident and comfortable and then you have to close.” (Interview 10)

Another participant described frustration at feeling like they could only provide a gold standard package of support when families reached breaking points:

> “Working for an NHS service, I'd like to offer a lot more intervention…and it not just be…this family’s at risk of breakdown, or…they're at risk of in-patient, to be able to provide that

> more intensive package. Like I'd like that to be more available…unless you're in crisis, we can't offer that kind of gold standard package because there aren't enough hours or there aren't enough people or money to be able to do that." (Interview 4)

A speech and language therapist described feeling like working in her service was relentless, likening it to being on a hamster wheel. She felt that this systemic challenge prevented her and her team from being able to ensure families fully understood what they were recommending, resulting in not preparing families appropriately for implementing the strategies they recommended:

> "I think 'oh the parents understood' and then they come back, and you realise they haven't understood anything you've said… with time constraints and things like that… it sounds awful, you kind of don't have that time to kind of keep going over things and keep saying do you understand? Can you explain it to me?...You've got the next one in 10 minutes and have to…be on that hamster kind of wheel." (Interview 3)

Another speech and language therapist describe experiencing challenges related to the commissioning. She discussed how in her service they were unable to provide Sequential Oral Sensory (SOR) intervention until their service received new commissioning to provide it, due to their current capacity limitations.

> "We are hoping to be able to offer the SOS program…we would really like to be able to offer that, but it would take new commissioning 'cause we don't have capacity at the moment." (Interview 6)

Importantly, clinicians described needing clarity in terms of service provision for children with feeding difficulties. One clinical psychologist emphasised how she believed service provision needed not only to be clearer, but also more nuanced to include clinicians and relevant professionals that were trained to manage the complexities usually observed with this population: "We need clarity in terms of service provision. We need clarity in terms of who's doing what, and…service configuration perhaps needs to be…a bit more nuanced.” (Interview 7)

A specialist speech and language therapist noted how children with behavioural feeding difficulties should not have been seen in her service as it meant that they were unable to prioritise cases of children with dysphagia, which they were commissioned to support. She described being generally unclear about who was supposed to support children with behavioural feeding difficulties, rather than physical/mechanical feeding difficulties:

> “I don't necessarily know if it's us…but I do think there should be a service that provides support for these kinds of children…in a way it would really give priority and time to the children with dysphagia and actually kind of make it easier for us to prioritise those cases, for other professionals to prioritise their cases…it's a really difficult one because in a way I don't really see it as our area. But then you kind of think well whose area is it?” (Interview 3)

It was also clear from participants in this study that they felt there was a clear gap in the NHS related to supporting children with these feeding difficulties:

> “It does kind of feel like a gap…in the NHS…Because it’s not necessarily speech therapists’ bag as such if we’re looking more at dysphagia or a dietician…so they kind of feel like sometimes they get missed out a bit.” (Interview 3)

Another speech and language therapist reiterated the difficulty around not being commissioned to support children with behavioural feeding difficulties, yet recognising that there was nowhere else for these children to receive support:

> “We really do try to weed [them] out… but we don't always successfully do that…we're not actually commissioned to see anything except the organic dysphagia, but we can't not see them 'cause once they've come in…there's nobody else to pick them up really.” (Interview 6)

A final systemic challenge that participants described facing was wanting to implement a sequential-oral-sensory (SOS) approach but feeling unable to do so as the SOS approach was developed in the US, which meant that they felt it did not fit the current model of service provision in the UK.

> “We have to make it realistic for the service, but also realistic for the families, and I think 13 weeks…it's very much, it's an American model. It's, you know, parents who are paying for it, and you do get a very different approach…than what we have in the NHS here.” (Interview 6)

Clinicians navigating adapting a US model of service delivery to the UK context described struggling to do so. One occupational therapist discussed how she believed it would be important to either merge the US models of support to the UK context, or develop UK-centred approaches to support:

> “It’s such a great approach and…as a clinician you can really see the benefit of it…but it's almost as though we need to develop a…what works in the UK based kind of approach…I guess it's lovely having these tools. It's just finding the most effective way that they can work within a very different kind of like model of provision.” (Interview 8)

Nature of Family Work

Clinicians in this study described their experiences of how working with families came with its own challenges. From their perspectives, families needed to be able to implement the interventions recommended to see changes in their child’s feeding difficulty. They also described experiencing difficulties when the nature of the work centred around changing family narratives. Finally, participants discussed challenges they experienced when families came to feeding services with an expectation of a medical model of service delivery.

Clinicians described understanding that it could be difficult for families to implement the interventions and strategies they were asked to implement. There was a sense of awareness of high-pressure situations families might be in, and needing to tread carefully with how they approached difficult conversations:

> “I think it's hard for parents…to have the time to do all of that and to take that forward, I can appreciate it’s really difficult.” (Interview 3)

> “Obviously you’re working in real life situations where families are burned out, they're not supported by other services…sometimes it's really dangerous, sometimes the children are really unwell and that's quite a high-pressure situation and…the family stress is very high, the child stress is very high and you're trying to come in and also have like a sensitive conversation…you have to be very careful.” (Interview 4)

However, as discussed previously (Theme 3), there was an understanding that parents play a significant role as the primary agents of change, and clinicians described how parents are expected to implement strategies and interventions at home. Participants discussed how this was difficult for them because they relied on parents to implement these strategies and interventions and described a sense of helplessness that there was nothing they could do if parents and families had not implemented them:

> “You're relying on parents you know doing it outside and reporting back that they've done it because…we're not Big Brother, we haven't got a camera and seeing what they're doing so that makes it harder sometimes, because if parents haven't followed it up, they haven't followed up.” (Interview 3)

> “I'd say probably one of one of the big barriers…whether parents…are able to consistently make the changes at home…to feed them three times a day, maybe, and offer them snacks, it's hard work when every one of those mealtimes or snack times is tricky, and so sometimes

> parents can find it hard to be consistent with our approach, and it's quite difficult for us because we can kind of provide the advice, but we can't be with them every mealtime to implement that.” (Interview 8)

Participants also described how they perceived it to be important for parents to be resilient, patient, and dedicated to implementing the strategies recommended, as well as engaging appropriately with those delivering support:

> “Often it's just whether or not the families have got the resilience to do what's required, or…the patience.” (Interview 5)

> “People not attending, not picking up the phone…People don't treat virtual appointments in the same way as they treat face to face appointments. Especially over summer holidays, it's really difficult to have a therapeutic conversation in a therapy session when there's four other children, all of whom are under seven in the background.” (Interview 1)

> “They can understand and they can do it, but I think sometimes the motivation to change…can be a sticking point because realising then ‘oh, I actually have to now do this and change this and do it every day and put this in place’.” (Interview 2)

> “We really struggled to get families that could commit to a big block of therapy, and there's no point coming if you don't come to all or nearly all of it…attendance was quite poor.” (Interview 6)

Clinicians also described experiencing difficulties navigating changes to families’ narratives. This related to dealing with families’ belief systems around food, mismatches of narratives between families and clinicians, and helping to manage families’ expectations. One clinical psychologist described her experience dealing with families’ belief systems around food and the challenge it posed when families drifted away from the shared understanding that it appeared they had agreed on:

> “Sometimes…there are still old, fixed beliefs that mean that… [parents] might turn around to me after three sessions and say, ‘I don't think we're doing the right thing…we need to get him eating roast dinners’, so there's always that drift of the individual psychology of parents and carers that drag them back again to what they think is the right approach. That's quite tough.” (Interview 1)

An assistant psychologist discussed how from her perspective, a key aspect of effective feeding work was working with parents to accept their child’s boundaries around food, and how she thought this could be difficult for parents as it is a way of viewing food that most families are unfamiliar with:

> “Parents acceptance of the child's difficulty as well is really key…we have these ideas and beliefs about food and how we should be eating…‘we should be having our veggies’…and a lot of parents, that is the belief system that they've grown up with and it's very hard to strip that all back, so I think sometimes they need a lot more time to come to terms with this new way of thinking, this new way of looking at food.” (Interview 10)

Other clinicians described experiencing challenges to delivering interventions when they experienced a mismatch of narratives between the family and the clinician about why the child’s feeding difficulty was occurring. One outreach worker working in a tertiary service suggested that supporting families through viewing their child’s feeding difficulty through a different perspective meant that this could cause anxiety for families and impact on their proposed interventions:

> “What parents think is going on versus what we think might be going on, and that mismatch of narratives sometimes I think can be quite difficult…maybe we're suggesting sort of a slightly different way to think about it…but that anxiety that could bring can maybe impact on that intervention too.” (Interview 2)

A behaviour analyst also working in a tertiary service highlighted how to access their service, families need to be referred, however they had encountered situations where the person referring the family had presented the family with an understanding of their child's feeding difficulty that the clinicians in the tertiary service did not agree with. She discussed how she believed these situations were challenging as it might be difficult for families to know who to listen to (i.e., the referrer that they first encountered, or the clinicians in the tertiary service). She also considered that it could be more difficult for families to engage with their tertiary service appropriately if they were confused about having different understandings of their child's feeding difficulty presented to them by different health professionals.

> "I think also it's tricky like if the referrer doesn't have as much expertise…then they might present an understanding of the difficulties that we actually might not agree with, but the family have heard that first, and they're like, 'oh well, the paediatrician said they're manipulative and they just want this', and we're thinking, 'oh, actually, that's interesting that that's… what's been said, but how about we think about it in a different way?' So I think it's really confusing for families sometimes, a lot of families have a lot of professionals involved and not always saying the same thing… don't know who to listen to, or like whose …ideas make most sense to them…And that's hard 'cause…then you kind of have to undo some stuff…it's complicated." (Interview 4)

Participants discussed their experiences of encountering families that had unrealistic goals or expectations from their children about the progress that could made, and from services about the kind of support that could be provided. A clinical psychologist highlighted how she considered that managing families' expectations around the work that they will be providing was helpful in setting boundaries:

> "Manag[ing] goals, I think it's helpful… to set some boundaries around the work we're doing, and to offer the family a framework as much as myself." (Interview 7)

Another difficulty that participants described was their experience of encountering some families that expected the feeding support to follow a medical model. Clinicians described that their understanding of feeding service delivery was not aligned with a medical model. They suggested that families' expectations of a medical model of service delivery was frequent and unrealistic, yet unsurprising given that families access this medical models more frequently:

> "I think the old historical view of input is that they bring them to a clinic, we therapy them, and then they're cured, so I guess it's changing kind of years of misconceptions about what service provides." (Interview 3)

> "It's that medical model…we come along, you fix the problem, you know, not the case necessarily with feeding problems. You come along and we enable you to move forward, inch forward…to eat more normally, more typically…and that's really hard and I don't say…'well, I can't fix this'. I do say 'it's slow, it's long, and that's normal'." (Interview 1)

> "Most of the time parents come into the service thinking there's like a magic wand, it's going to be fixed in like a day and it's all gonna be great." (Interview 2)

> "I guess it doesn't help necessarily where you know the medical model is used so much in places that they probably access more, like the GP or, you know your paediatrician...but for us, it's different, but we're not seen as frequently as maybe they are" (Interview 3)

One speech and language therapist discussed how in her experience, families expecting a medical model of service delivery could experience disappointment and difficulties accessing the ongoing work, as families that expect that model of service delivery appeared to be less prepared to work cooperatively:

> "Some families want an instant answer. Other families are much more prepared to work at it and do the slow change…some families really sort of like the medical model…and are really disappointed if that doesn't happen. Whereas other families come with a much more sort of

> co-operational model where they come for me for advice and they're willing to go away and try it. And then they'll come back and say, well, this didn't work, what do you think if I do this? And then we can work on it more cooperatively.” (Interview 6)

There was also a sense of difficulty experienced by clinicians in balancing the work delivered when families expect them to take the expert role, particularly when that is not aligned with the model of service delivery that their service provides:

> “Some families do really want you to say ‘do this and it will work’, and that's quite difficult because you don't know if it's gonna work or not like 100%…they want like you to take an expert role, whereas we don't often take the expert role.” (Interview 4)

Interestingly, clinicians in this study reported experiencing difficulties engaging parents in implementing the interventions they suggested. This appeared to juxtapose with earlier themes of the key role of shared understanding, as well as the recognition of the role of parents as agents of change for interventions in earlier themes. There is a sense of tension between these themes, whereby clinicians described being aware of the vital nature of shared understandings, working collaboratively, and parents as agents of change, but described difficulties navigating working with parents and engaging them in the proposed interventions effectively. Although it was recognised that collaborative working and family-centred approaches to support were the best practices, there was a sense that participants found this to be challenging, despite this being a part of the work described. The sense from this juxtaposition was of a rising duality between clinicians and parents.

Personal Experiences

Another difficulty participants described was in relation to personal experiences they encountered in their roles while carrying out this work. This related to the confidence clinicians felt when supporting children and families with feeding difficulties, and the importance of the development of clinical skills. Interestingly while all participants reported having received *some* training on behavioural feeding difficulties, 30% of participants did not report having received any formal training and 10% did not report having received any informal training.

From the interviews it was clear that confidence was important for clinicians supporting families of children with feeding difficulties. One participant that had less experience and had attended some training for behavioural feeding difficulties noted that she considered it could be difficult working with some parents, which she felt affected her confidence in her clinical abilities despite her doing her best:

> “Whatever you say to them is just not ever good enough…you just don't feel like you're doing a very good job as a clinician…sometimes they might even complain because they feel like you've not helped them in the way that they want you to help them.” (Interview 10)

Another clinician with less experience and some training for behavioural feeding difficulties reported that she personally found this work anxiety provoking due to the severity of some of the children’s feeding difficulties:

> “It’s actually quite anxiety provoking, which I hope doesn't rub off on the families cause I do work really hard on that. I think because it's not my area of expertise…I think it's just maybe a confidence thing and…children become very ill and it’s sometimes… really high pressure.” (Interview 4)

It was clear that the development of clinical skills for clinicians when supporting feeding difficulties was important, particularly for those with less experience and training, and participants described these as supporting them to carry out their family work. The same participant as above discussed how she felt her confidence has developed over the years in her role, and she felt her clinical skills have been supported by working with other professionals:

> "I guess you just like gradually build those skills…and become more confident… through shadowing…other professionals like psychologist and systemic therapists…so it's been really helpful to kind of been able to do that and joint work as well." (Interview 4)

Other participants described how they perceived working with different families helped develop their clinical skills, as well as having regular supervision:

> "The more cases you come across, the more parents and children you deal with, the better you become at sort of managing that…we do have access to kind of regular supervision as well. So if I wasn't sure about what to do or I was concerned, I would bring it to supervision and…ask my colleagues what they thought." (Interview 3)

> "Supervision is one of them…and I guess just being able to work with different clients really because every case I've had in the feeding clinic so far, they've all been different…and each parent is different, each family context is different, so you do have to find ways to…adapt the way that you utilise the strategies with families." (Interview 10)

Discussion

This study explored NHS clinicians' working models when providing support or intervention for children with feeding difficulties, and their experiences of providing this support. This study showed that clinicians perceive there to be three key elements of support that are required for optimal support of feeding difficulties: developing an understanding of the feeding difficulty alongside the family, parents participating in the support or intervention process to allow for systemic change, and providing supports that are individualised, including the assessment and formulation process. While these factors are recognised as being key components, there were barriers described by clinicians which relate to systemic difficulties, the nature of family work, and personal experiences delivering this support.

Systemic barriers were detailed by participants in this study. Previous literature shows that those who support children with feeding difficulties and their families are aware of the challenges faced by families, namely increased parental stress, family anxiety and the difficulties families face when trying to access support (Jackson et al., 2022a; Jackson et al., 2022b; Luscombe et al., 2021; Miles et al., 2021). Those who provide support also report noting how family anxiety can be alleviated by accessing specialist paediatric support (Luscombe et al., 2021), though as described previously (Chapter Two) parents have experiencing significant difficulties accessing support for their child's feeding difficulty. This study found that clinicians working in community services perceived there to be a gap in the service provision within the NHS for this population. While the literature shows that accessing specialist paediatric support is important for alleviating family anxiety, it would appear that it is difficult to access this support for children with behavioural feeding difficulties in the NHS, as clinicians reported lack of clarity around who should support this population and general lack of service provision for this population.

The difficulties faced by clinicians providing support for feeding difficulties in the UK are unique to the healthcare system in which that support is being delivered. Participants in this study spoke about being unable to support this population, not due to lack of skill, but due to lack of commissioning. This was notably different to previous research that has outlined that some healthcare professionals may lack the knowledge to support children with feeding difficulties (Jackson et al., 2022a). This is perhaps due to the differences in the professions included in Jackson et al. (2022a) which included dietitians and medical professionals, which may not have as robust intervention or support knowledge as allied health professionals, which was the primary target population in the current study.

Many participants in this study had extensive experience of supporting children with feeding difficulties, and those who did not described being supported well through clinical supervision, through support making clinical decisions, and general clinical guidance. Previous research has also highlighted how receiving clinical supervision for support with high-risk cases and ongoing skills development has been perceived to be important to clinicians, providing reassurance and supporting them to feel a part of a clinical feeding team (Jackson et al., 2022b; Luscombe et al., 2021). This study showed that clinicians who were supported in their clinical work reported experiencing more confidence, as this is work that can be anxiety provoking and difficult for those with less experience. However, it is important to note that even those with more experience discussed feeling more confident when they had additional clinical support, indicating even highly experienced and specialised clinicians can be affected by personal confidence in their clinical work.

An important finding of this study related to the juxtaposition between parents as intervention agents for systems change and the emphasis on individualisation, and the difficulties clinicians reportedly faced due to the nature of family work. This study found that clinicians described parents as intervention agents for systems change to be one of the key factors needed for supporting feeding difficulties in the NHS. It was clear that they commended collaborative working, and often described the significant role of parents as the key to obtaining systems change. This study also demonstrated that participants described person centred approaches as best practice when supporting this population. This supports previous research that indicates that best practice for supporting feeding difficulties includes working in collaboration with families (Jackson et al., 2022a; Jackson et al., 2022b; Miles et al., 2021). Previous research also indicates that professionals recognise person-centred approaches as being key to delivering support for feeding difficulties (Taylor et al., 2021b). Interestingly, one of the key barriers reported by participants to effectively being able to deliver support for feeding difficulties was related to the nature of family work itself. Previous research also indicates that clinicians have reported experiencing difficulties working with families when: there are differing perspectives between clinicians and parents, where clinicians rely on parents to share their child’s medical information; where there are concerns about families’ understandings of their child’s feeding difficulties and the risks associated with feeding; where it may be difficult to ask parents for their cooperation; and where there are difficulties collaborating to engage in shared decision-making (Fujino & Ikeda, 2022; Jackson et al., 2022b; Miles et al., 2021). Clinicians in this study reported experiencing difficulties providing support when families did not carry out the interventions they recommended, when there were challenges related to changing family narratives, and expectations of families of a medical model of service delivery. There appears to be a circular phenomenon occurring, where a main component of the work delivered relies on parents, yet working with families themselves can sometimes be seen as a challenge given the interaction between family characteristics and systemic issues described. A significant portion of the work carried out is delivered in family contexts, illustrating that this is a core component of their work. While clinicians may experience difficulties as part of working with families, which may be compounded by additional barriers like systemic challenges, these should be considered to be part of the nature of the work delivered, rather than an additional challenge above and beyond what supporting families entails. Those working with families may benefit from additional training or clinical supervision specifically targeted at resolving difficulties encountered in clinical family work, to continue to develop these skills, and to minimise feelings of difficulties working with families that may create a narrative of ‘us’ and them’ and affect their ability to work with families collaboratively and effectively. There is a risk in recognising families as essential yet viewing the nature of work as a challenge that a feeling of duality may arise, where clinicians and parents are not working together, and ultimately the child would be affected by not receiving adequate or sufficient support. It is important going forth to continue to seek families’ perspectives on their healthcare provision related to their child’s feeding difficulties, and to develop approaches to support that are collaborative and transparent in nature with families. Further research should also be carried out with professionals to explore the nature of this issue in more depth (i.e., are families seen as an inconvenience, or are the systemic issues acting as a barrier to the collaborative work).

A final key factor described by clinicians as being essential to carrying out feeding work was developing a shared understanding with families about why their child’s feeding difficulty was occurring. This was described as being central to the work as this factor ensured that families and clinicians were on the same page about the approach to take to address the child's feeding difficulty. As noted above, clinicians have discussed difficulties related to collaborative decision making when parents and clinicians do not agree (Jackson et al., 2022b; Miles et al., 2021). It is clear from this study that developing a shared understanding may help to abate this difficulty, as this would ensure that both parties are on the same page from the start. However, as described in this study, even after a shared understanding is established, parents may still drift away from this when there are individual beliefs that predate the shared understanding. This is important for clinicians to be aware of when supporting this population, as establishing a shared understanding is a cyclical and ongoing process that should continue to be developed and expanded on throughout the work.

Strengths

While previous research (Parr et al., 2021) has demonstrated what support by clinicians in the UK for feeding difficulties looks like topographically (i.e., strategies recommended, settings professionals work in, how long interventions last, etc.), this study followed an exploratory approach which allowed for in-depth discussions with clinicians about their perspectives on ideal supports and the things they encountered which prevented them from being able to carry these out. This exploratory nature of this work was a strength, as in-depth explorations of clinicians' experiences and perspectives supporting children with IDD and feeding difficulties in the UK have not yet been detailed. Using a grounded theory process to data collection as well as analysis allowed for the in-depth exploration of the key factors in supporting families of children with feeding difficulties and the many barriers which clinicians face in these roles. Further to the use of grounded theory, the selected Straussian grounded theory was also a strength of this work as it enabled a systematic and methodical approach to data analysis that was rigorous and deemed to be of high integrity by one of the PhD researcher's supervisors (NG). This rigorous process ensured that the findings stayed close to the data and reflected what participants were saying, while allowing for sophisticated identifications of patterns in the data. A notable strength of this study was that some of the necessary modifications to a grounded theory approach that were undertaken in Chapter Two (i.e., implicit rather than explicit concurrent data collection and analysis) were not used in this study, as the need for these modifications was identified from that experience and addressed in this study. This has shown growth in the use of grounded theory from the first empirical study in this PhD and this second empirical study.

Another strength was that the participants represented a variety of professions and had different levels of experience. This was significant as it enabled confidence that the grounded theory that emerged from this research is representative of the difficulties faced by clinicians from different allied health fields, with varying years of experience, and those working in different services within the NHS. This is important as grounded theory seeks to generate a theory that is representative and captures and considers varying perspectives.

Limitations

There are some limitations that are important to highlight. Unfortunately, like much existing research, this study did not recruit a racially or ethnically diverse sample. Only 20% of participants in this study were of diverse racial or ethnic backgrounds. This could be representative of the racial and ethnic diversity in certain professions, or the difficulties to entry for some professions (i.e., requiring masters' level education, or bachelor's degrees, and membership fees to national and international societies; Royal College of Speech and Language Therapists, Behaviour Analyst Certification Board). Despite this, it is still important to highlight as a limitation as the perspectives of clinicians that are racially and ethnically diverse have not been explored in depth, and these clinicians could have a perspective on supporting families and barriers faced that may not have been captured in depth here.

Another limitation of this study is that all the participants were women. Like above, this may be representative of the breakdown of gender representation in certain professions (speech and language therapists, board certified behaviour analysts, occupational therapists, etc.). However, this is important to highlight as the key factors and barriers to supporting families with children with feeding difficulties have all come from the perspectives of women, which may have a different perspective to supporting families than men in these professions, due to the differences in their lived experiences.

Conclusion

In conclusion, the findings from this study show that clinicians supporting children with feeding difficulties in NHS settings face many barriers to carrying out this work effectively. Clinicians report there to be three main key factors which contribute to effectively supporting this population: having a shared understanding of the feeding difficulty to guide their work; individualised supports for feeding difficulties at all levels; and parents as intervention agents for systems change. Clearly, the role of parents in interventions for feeding difficulties is paramount, however clinicians reported experiencing difficulties with the nature of family work. This juxtaposition is important – clinicians are the ones that guide parents and ultimately support them in making changes to their child’s feeding. There is potential for a breakdown in the relationship between parents and clinicians if an “us” and “them” narrative is experienced over the course of the family work, rather than a “we” narrative. Participants in this study acknowledged the significance of collaborative working, and while clinicians may experience difficulties due to the nature of family work, it is important that these difficulties be conceptualised as part of the journey of collaborative working and the ongoing process of maintaining a shared understanding. Clinicians in this study noted that having a shared understanding with families about why their child’s feeding difficulty was occurring was essential for this work, however it is important that this is an ongoing, iterative process. Further training should be provided for those working with families to address their child’s feeding difficulty on the nuances of family work and navigating situations when drifts occur away from a shared understanding. This should include ways to incorporate families’ beliefs and values, even if these contradict with the original shared understanding, as it is clear from previous work (Chapter Two) that families value feeling heard and understood and their feeding struggles recognised. Additionally, it is possible that the systematic challenges described could have exacerbated the challenge participants described about working with families or prevented the conditions necessary for optimal delivery of support, however further research should explore this in more depth.

Further research should also examine the systemic barriers in the current service provision for children with IDD and feeding difficulties in the NHS and explore ways to break those down to increase access to relevant professionals, address commissioning difficulties, and discover ways to continue to provide adequate support for clinicians that support families and children with feeding difficulties. New feeding services (where this may be occurring) should be designed with consideration of the key factors to providing effective support for feeding difficulties explored in this study, so that some systemic barriers can be addressed pre-emptively. Finally, it would be helpful for families to receive more information about the nature of the work that is delivered by those supporting feeding difficulties, so their expectations about services are clear from the start. This may also help families learn about what is involved in this therapeutic environment and be prepared to implement interventions or strategies. Having more transparency about what this support involves and direct illustrations of the differences between allied health professionals' approach versus medical professionals' approach may also help families know what to expect when they receive these services.

One of the aims of this thesis was to explore stakeholders' experiences and understanding of behavioural feeding difficulties amongst children with IDD, and their experiences of related supports for these. Thus far, parent (Chapters Two and Three) and clinician (Chapter Four) perspectives and experiences of behavioural feeding difficulties and related supports have been explored. The next chapter will build on these findings to address another aim of this thesis, to explore interventions for behavioural feeding difficulties that are informed by stakeholder perspectives. Chapter Five will report on the development of a logic model for an intervention approach to feeding difficulties, integrating data gathered from the studies in this thesis (Chapters Two, Three, and Four) with existing literature.

Chapter Five Developing an Early Logic Model for an Intervention for Behavioural Feeding Difficulties amongst Children with Intellectual and Developmental Disabilities

Chapter Overview

Chapter One described a range of factors that influence the development of behavioural feeding difficulties and argued that a comprehensive and contextual theory, like the biopsychosocial theory (Berlin et al., 2009) that considered this range of factors that influence the development and continued occurrence of behavioural feeding difficulties was important for the development of interventions. Chapters Two, Three and Four gathered data related to the lived experience of parents and those who support children with intellectual and developmental disabilities (IDD) exhibiting behavioural feeding difficulties. The findings from these studies will be used to inform the development of an initial logic model for an intervention approach for behavioural feeding difficulties amongst children with IDD.

One of the aims of this thesis is to explore approaches to interventions for behavioural feeding difficulties amongst children with IDD. As such, this chapter will introduce logic models and describe how a logic model for an intervention approach for behavioural feeding difficulties amongst children with IDD was developed to guide the development of the Family Feeding Intervention Study (Chapter Six). The core underpinning theories or conceptual areas of this initial logic model will be described (a biopsychosocial theory, behavioural underpinnings, a guiding values base, collaborative working, an iterative coaching approach, and a bespoke approach). The data from relevant sources (i.e., the wider feeding literature, Chapters One, Two, Three and Four) that led to the inclusion of these six influencing factors will be presented, then the logic model will be presented.

Logic Models

Logic models are visual representations of theory or logic that guide the way in which programmes or policies are designed and implemented (Shakman & Rodriguez, 2015). Logic models have been described as illustrating the relationship between the resources used in these, activities undertaken, and outputs produced, as well as identifying outcomes in the short, medium, and long-term (Scott et al., 2018).

Logic models have been used previously in the intellectual and developmental disability (IDD) literature (i.e., La Valle, 2016; Scott et al., 2018). In the case of this thesis, a logic model refers to the visual representation of the theoretical and other core underpinnings of an intervention approach for behavioural feeding difficulties amongst children with IDD. This was deemed necessary, as it became clear throughout this PhD that there needed to be a logical, rational, and pragmatic approach taken to the development of an intervention approach that brought together and synthesised relevant data sources. A brief description of how the logic model was developed will be presented to provide an overview of this process and an understanding of how this came together, followed by a more in-depth exploration of the underpinnings to the logic model.

An Early Logic Model for an Intervention for Behavioural Feeding Difficulties amongst Children with Intellectual and Developmental Disabilities

For the development of this initial logic model there was a range of relevant information that was gathered and reviewed. Firstly, the perspectives of key stakeholders (i.e., parents and clinicians) were considered in relation to their experiences of behavioural feeding difficulties and related supports (see Chapter Two, Three and Four). The intervention literature around behavioural feeding difficulties was also reviewed to identify the current best practice around interventions for these, and some limitations of these interventions were identified. Additionally, the wider literature around Positive Behaviour Support (PBS), parent involvement in interventions for behavioural feeding difficulties, and considerations of working in family contexts were considered. These, along with their contribution to the logic model, will be explored in this chapter. See Figure 9 for a visual representation of the logic model for an intervention approach for behavioural feeding difficulties amongst children with IDD. There were six core influencing factors to the logic model which will be described in the following section.

Figure 9

Logic Model of an Intervention Approach for Behavioural Feeding Difficulties amongst Children with IDD.

Context and assumptions:

- Children with IDD commonly exhibit behavioural feeding difficulties
- Behavioural feeding difficulties in children with IDD are often complex and require tailored support
- Families are highly affected by their children's behavioural feeding difficulties
- Families are generally not receiving appropriate supports for behavioural feeding difficulties in the UK
- The intervention literature for behavioural feeding difficulties has demonstrated that behavioural interventions are the most effective for reducing these
- Behavioural interventions reported are often conducted outside of natural environments
- Behavioural interventions reported have generally not been developed with families and do not usually report social validity measures about the intervention procedures used

Aims and mechanism:

- A family-centred evidence-based practice & contextual approach to behavioural feeding difficulties will promote wellbeing and skills of parents/carers who have a child with IDD exhibiting behavioural feeding difficulties and increase positive mealtime experiences in a family context.
- This provides a basis for improving the child's eating behaviours by breaking reinforcement cycles and improving the parent/carer's experience of the child's behavioural feeding difficulty.
- Positive changes in these areas will improve the health of the child with IDD and the family's ability to cope with the child's behavioural feeding difficulty, which will reduce long-term support costs.

Logic model of an intervention approach to behavioural feeding difficulties

Inputs:

Information provided

- General knowledge about behavioural feeding difficulties
- Information about core behavioural principles
- Training on collecting data
- Functional assessment

Evidence-based practices

- Strategies informed by EBPs in ABA/PBS literature

Partnership working

- Strategies developed with families

Iterative coaching approach

- Families implement strategies and receive support through that process
- Space to problem solve collaboratively and receive social and emotional support

Data-based & contextual decision making

- Any changes in intervention are guided by the data and by the family's report of their experiences & abilities to implement the intervention

Outputs:

Resources produced with families

- Operational definitions of specific target mealtime behaviours
- Feeding strategies plan produced together

Resources provided to families

- Data sheets
- Graphs of progress along with explanations/interpretations
- Training materials for data collection training
- Information packet with general knowledge about feeding difficulties
- Information packet with general information about strategies informed by EBPs in ABA/PBS literature
- Information packet on how to collect data
- Information packet on how to use MS Teams to record mealtimes

Processes:

Changing mealtime perceptions & behaviours

- Family active contributions to development of intervention plan
- Family support through implementation of intervention plan
- Individualisation of support plan to needs and circumstances of families
- Increased parent skills to manage their child's feeding difficulty
- Flexible but systematic decision making that synthesises families' needs & circumstances (contextual factors) and EBPs
- Emotional and social support through the intervention process

Outcomes (& how measured):

Parents/carers

- Changed perspective of their family's mealtime situation (qual & quant)
- Increased confidence and ability to manage their child's feeding difficulty (qual & SCD)

Child

- Increased food consumption (SCD)
- Decreased challenging mealtime behaviours (SCD)
- Supported in their feeding difficulty – improved child/parent mealtime relationship (qual)

Intervention

- Intervention deemed socially valid by parents (SV measure)
- Intervention having contextual fit with family's lives (qual & procedural fidelity)

Note. ABA = Applied behaviour analysis. EBP = Evidence based practice. IDD = Intellectual and developmental disabilities. MS = Microsoft. PBS = Positive behaviour support. SCD = Single-case design. SV = Social validity. UK = United Kingdom.

Underpinning Theories or Conceptual Areas of the Current Logic Model

There were six main underpinning theories or conceptual areas that guided the development of this logic model and influenced the components of the current logic model. These will be described below and a summary of this information can be seen in Table 12.

Table 12

Summary of Main Underpinnings to the Logic Model.

Key components	Rationale	Relevant data source	Presence in logic model
1) Biopsychosocial theory	Comprehensive theory	Berlin et al. (2009); Engel, (1977) Hastings et al. (2013)	• Psychosocial support for parents (emotional and social support • Identifying relevant influencing factors
2) Behavioural underpinnings in the process	Efficacy in the literature, evidence-based practices for behavioural feeding difficulties	Cooper et al. (2020); Gosa et al. (2017); Piazza et al. (2003); & wider behavioural feeding research (see in text for examples)	• Functional assessment • Function-based intervention • Behavioural strategies • Operational definitions • Data collection methods • Outcome measurements
3) A guiding values base	Guiding ethical principles and values-base	Gore et al. (2013)	• Prevention and reduction of challenging behaviour and improved quality of life • Constructional approaches and avoiding restrictive and aversive practices • Stakeholder participation

Key components	Rationale	Relevant data source	Presence in logic model
4) Collaborative working with parents	Active participation of families in the whole process	Study 1; Study 2; Meta-synthesis	• Develop strategies & problem solve together • Provide resources so families can participate • Social validity and contextual fit
5) Iterative coaching approach	Provide ongoing support in implementation of strategies and involvement in intervention	Study 2; Aponte et al. (2019)	• Families implement strategies & are supported through this; space for ongoing coaching • Increased confidence and ability to manage their child's behavioural feeding difficulty
6) Bespoke approach	Ensure contextual fit for families and individualised support for their family needs	Study 2; Berlin et al. (2009); Heinemann (2015); & wider behavioural feeding research (see in text for examples)	• Evidence-based practice & contextual approach • Individualised feeding plan, strategies, and training materials • Social validity & contextual fit

Underpinning One: Biopsychosocial Theory

The biopsychosocial approach for understanding conditions or disorders is one that allows for the consideration of the range of relevant factors (Engel, 1977). As discussed previously (Chapter One), Berlin et al. (2009) proposed a biopsychosocial model of feeding difficulties which considers that the development of feeding requires a complex interaction of multiple factors (e.g., psychosocial, biological, behavioural). The strength of the biopsychosocial model is the comprehensive and contextual nature of this approach, which proposes that the development of a behavioural feeding difficulty is not attributed to a single factor, but rather to a multitude of factors, and the ways in which these factors interact with one another. It is also widely agreed in the field that behavioural feeding difficulties are multidimensional and that the biopsychosocial model is well placed to describe the development of these (van Dijk, 2021). As highlighted previously, there are many risk factors for the development of behavioural feeding difficulties amongst children with IDD (see Risk Factors for Behavioural Feeding Difficulties in IDD Section in Chapter One). This means that interventions guided by a biopsychosocial approach to understanding behavioural feeding difficulties are likely to be more comprehensive and contextual and consider the range of influencing factors, thus encouraging multicomponent interventions which have the flexibility to incorporate different elements which may be relevant to the presenting situation (Martin et al., 2008). Importantly, using a biopsychosocial approach as a conceptual framework to understand why behaviour occurs is not a new approach, and this has been used widely in the challenging behaviour literature (Hastings et al., 2013).

There are two main areas in which the biopsychosocial model was influential in the current logic model: a psychosocial focus in the form of emotional and social support for parents, and a focus on identifying all the relevant influencing factors to the presenting behavioural feeding difficulty.

Psychosocial Support for Parents

Parents are part of the mealtime environment, and their behaviour can contribute to why their child's behavioural feeding difficulty continues to occur. Hastings et al. (2013) highlight the significant role that carers play in maintaining challenging behaviours. In relation to behavioural feeding difficulties, functional analyses of maintaining contingencies show that these are most likely to be maintained by negative and positive reinforcement contingencies (Piazza et al., 2003). This indicates reinforcement that is likely to be facilitated by someone else (i.e., parent removes a spoonful of food after the child turns their head away, parent presents a preferred food after the child has refused a non-preferred food). As parents are part of the environment that might influence why their child's feeding difficulty is continuing to occur, providing psychosocial support for parents to enable them to change their own mealtime behaviours is an important consideration in interventions. Additionally, it is clear from existing research that parents experience significant impacts because of their children's behavioural feeding difficulties (see Chapter Two and Chapter Three for a review of the literature), thus considering parent support in interventions for behavioural feeding difficulties is paramount.

Identifying Influencing Factors

As discussed previously, identification of the influencing factors for behavioural feeding difficulties is important in order to have a comprehensive understanding of why a behavioural feeding difficulty is occurring. Functional assessments (O'Neill et al., 1997) aim to identify why behaviours are occurring. Functional assessments have been used in the literature to identify functions of challenging behaviours and also behavioural feeding difficulties (e.g., Fettig et al., 2016; Gale et al., 2011; Galensky et al., 2001; Wood et al., 2011). The functional assessment process focuses on identifying things that occur before and after the behaviour that may be influencing why the behavioural feeding difficulty is continuing to occur.

Underpinning Two: Behaviour Analysis

Strong behaviour analytic underpinnings united the logic model across a range of components. This was the case because the most common interventions in the literature for feeding difficulties are behavioural interventions. Gosa et al. (2017) carried out a systematic review exploring interventions for feeding difficulties and found that the behavioural interventions were the most effective interventions identified for the treatment of behavioural feeding difficulties.

As described previously, the use of a functional assessment allowed for a range of factors that influenced the presenting behavioural feeding difficulty to be identified. This information is then used to develop a function-based intervention. Function-based interventions have been used widely in the literature to successfully reduce or increase behaviours, depending on the behaviour and intervention aims (e.g., Drew et al., 2022). This approach has also been used in the behavioural intervention literature (e.g., Piazza et al., 2003). These interventions use common behavioural strategies like antecedent approaches, reinforcement, extinction and punishment.

Finally, it was considered that a behavioural approach would focus on breaking negative reinforcement cycles to improve the child's eating behaviours and the parents' experience of their child's behavioural feeding difficulty. It would also likely include a focus on the use of positive reinforcement to increase food consumption by the children.

Underpinning Three: A Guiding Values Base

There were core guiding values similar to those seen in PBS that informed this logic model. As outlined in Gore et al. (2013), the guiding values adopted in PBS are: prevention and reduction of challenging behaviour in the context of increased quality of life, participation, and upheld valued social roles of people with IDD; constructional approaches that aim to build skills of stakeholders and do not condone aversive or restrictive practices; and a focus on participation of stakeholders to inform the assessment and intervention process, as well as implement and validate these. .

Increased Quality of Life Through Prevention and Reduction of Challenging Behaviour

The value of prevention and reduction of challenging behaviour in the form of a behavioural feeding difficulty and increased quality of life were central in the current logic model. This was considered important to focus on as it was considered that positive changes in the child's behavioural feeding difficulty would improve the child's health and the family's ability to cope with their child's behavioural feeding difficulty, and conversely that supporting a family with coping with their child's behavioural feeding difficulty would also support their child to increase their food consumption and reduce their behavioural feeding difficulty. This indicates a clear focus on increasing the quality of life for the child exhibiting the behavioural feeding difficulty as well as their parent(s).

Constructional Approaches and Avoiding Restrictive and Aversive Practices

A constructional approach is one in which practitioners focus on building behavioural repertoires in order to address a presenting difficulty (Delprato, 1981; Goldiamond, 1974). This is conceptualised as a value as it guided by an understanding that increasing skills can support individuals with IDD in a different way than taking a solely eliminative approach (i.e., reducing behaviours that challenge). Taking a constructional approach and avoiding the use of restrictive and aversive practices was also central in the current logic model in the context of increasing skills of parents and carers.

Avoiding the use of restrictive and aversive practices was implicit in the logic model, with a strong focus on the intervention being deemed socially valid by parents. This meant that while behavioural strategies would be used, as they were considered to be evidence-based interventions for behavioural feeding difficulties (see section above), it was important that the procedures like extinction and punishment, which use restrictive and aversive practices, and are often found in the behavioural intervention literature (e.g., Haney et al., 2021; Kirkwood et al., 2021; Panerai et al., 2018) would be eschewed.

Stakeholder Participation

Stakeholder participation throughout the entire assessment and intervention process was embedded in the current logic model in various ways. It was clear that parents are highly affected by their children's behavioural feeding difficulties (see Chapters Two and Three). Despite this, interventions for these do not often consider parent perspectives or report social validity measures, which could provide an understanding of how appropriate parents felt the goals, strategies and outcomes of an intervention were (see Ahearn et al., 1996 for an example of considering parent perspectives and social validity).

Underpinning Four: Collaborative Working with Parents

Collaborative working was deemed to be important as a key finding from Chapter Two indicated that parents reported experiencing a reduced impact of their child's behavioural feeding difficulty when they understood why it was occurring and were able to change their attributions about this or their behaviours during mealtimes to better support their children's eating needs. It was considered that working collaboratively with parents throughout the intervention process would support them in understanding why their child's behavioural feeding difficulty was occurring. Collaborative working with families was also something that National Health Service (NHS) clinicians noted as being a central factor to delivering good interventions for behavioural feeding difficulties exhibited by children with IDD (Chapter Four). It was also considered that collaborative working would foster feelings of 'togetherness' rather than a feeling of 'us' versus 'them' (Chapter Four). It was also clear from existing research (see Chapter Three) that families had clear ideas of what had helped them or would help them if they were to receive support, so working together with families collaboratively was considered to be instrumental.

Underpinning Five: Iterative Coaching Approach

The current logic model was also grounded in the use of an iterative coaching approach. Chapter Four found that parents were often the interventionists that implemented the strategies suggested by clinicians. It was considered that parents would need to be coached on an ongoing basis in order to be equipped to be the interventionists themselves. A recent systematic review (Aponte et al., 2019) found that approaches to parent training in the literature notably lack an ongoing approach and are often described as occurring at certain points in time, rather than on an ongoing basis (e.g., an observation behind a one-way mirror and then being taught to implement the procedures (i.e., Pizzo et al., 2019). As parents clearly play a critical role in implementing interventions (Chapter Four), it was considered important to ensure that they are not only trained, but also coached throughout the implementation of intervention strategies, as these may be challenging for parents. Additionally, Chapter Four found that the involvement of parents was important for allowing systemic family change, further illustrating the critical role of parents in interventions for behavioural feeding difficulties, and the need for them to be well supported through carrying these out.

Underpinning Six: Bespoke Approach

Finally, a bespoke approach was at the core of the current logic model. As described in previous sections, a guiding values base (similar to that of PBS), biopsychosocial theory, and behavioural underpinnings were influential in the development of this logic model. Inherent in these three areas is the need for a bespoke approach, as PBS is recognised as being an individualised process (Hienemann, 2015), a biopsychosocial theory (Berlin et al., 2009) allows for the identification of the range of influencing factors for a child’s behavioural feeding difficulty, and behavioural interventions have illustrated the need for individualising interventions to each child’s presenting feeding situation (e.g., Berth et al., 2019; Rubio et al., 2020; Seiverling et al., 2018). Chapter Four also found that individualising interventions was one of the key factors for clinicians to be able to deliver effective interventions for behavioural feeding difficulties. Importantly, it was considered that using a bespoke approach would allow for increased contextual fit (Albin et al., 1996) of the interventions.

Conclusion

This chapter presented the development of a logic model for an intervention approach for behavioural feeding difficulties amongst children with IDD, and the underpinnings that guided its development. The result of the process described was a preliminary intervention approach for behavioural feeding difficulties that was contextual, functional, values driven, family-centred, and individualised. This intervention approach was arrived at by exploring the literature and including parent and clinician perspectives about supports for behavioural feeding difficulties. One of the aims of this thesis is to explore approaches to interventions for behavioural feeding difficulties amongst children with IDD. This chapter introduced a preliminary intervention approach for behavioural feeding difficulties guided by the presented logic model. In the next chapter, the Family Feeding Intervention Study will be presented, and this logic model will be referenced in relation to how this influenced the development of the intervention approach used in the study.

Chapter Six Pilot of a Family Intervention for Children with Intellectual and Developmental Disabilities Exhibiting Behavioural Feeding Difficulties

Chapter Overview

Chapter Five presented the development of a logic model for an intervention approach for behavioural feeding difficulties exhibited by children with intellectual and developmental disabilities (IDD). The underpinnings that guided the development of the logic model were described along with the relevant data source (i.e., wider literature, Chapters One, Two, Three and Four). The logic model outlined that an intervention approach for behavioural feeding difficulties amongst children with IDD needs to be contextual, functional, values-drive, family-centred, and individualised. One of the research questions guiding this thesis is how can a biopsychosocial approach to behavioural feeding difficulties be used to inform interventions for these amongst children with IDD. The logic model guided the development of an intervention that was guided by a biopsychosocial approach, amongst others, for behavioural feeding difficulties in this population. The current study will describe this intervention and the effectiveness of this intervention on behavioural feeding difficulties exhibited by two children with IDD will be tested using a single-case design (Kazdin, 2011). Results and considerations for research and clinical practice in relation to intervention approaches for behavioural feeding difficulties will be discussed.

Introduction

As described previously in this thesis, behavioural feeding difficulties can have a range of different impacts, including on the child’s health (e.g., increased prevalence of obesity, nutritional deficiencies, etc.; Bandini et al., 2017; Levin et al., 2014), parental well-being (e.g., increased caregiver stress, feeling personally responsible for their child’s difficulties, etc.; Bui et al., 2013; Curtin et al., 2015; Greer et al., 2008), and social exclusion of families and children (Hagekull & Dahl, 1987; Ledford & Gast, 2006), amongst others. As such, research into interventions for behavioural feeding difficulties is highly relevant. To date, the most common interventions in the literature for feeding difficulties are behavioural interventions (e.g., Ahearn et al., 2001; Patel et al., 2002). Gosa et al. (2017) carried out a systematic review exploring interventions for feeding difficulties and found that the behavioural interventions were the most effective interventions identified for the treatment of behavioural feeding difficulties. However, the current scope of behaviour-analytic interventions for behavioural feeding difficulties has several limitations. First, most of this research and interventions are carried out clinic settings, in the United States (US), and they are often implemented by interventionists, experienced clinicians, or researchers (e.g., Borrero et al., 2013; Johnson & Babbitt, 1993). Sometimes parents are involved, however this is not common and the procedures for involving parents in interventions have not been well delineated in the literature, and in fact, parent training in interventions for behavioural feeding difficulties has been described as being experimental, given the current state of the literature (Aponte et al., 2019). Additionally, most interventions are carried out in clinic settings, meaning they are being carried out in controlled settings (Tereshko et al., 2021b) and it may be more difficult for these interventions to generalise to natural settings. That the extant literature is mostly carried out in the US is important as the US has a different medical and health-care system to the UK, and models of support or interventions that are acceptable and applicable in the US may not translate well to the current systems of support in the UK. The lack of parent involvement in the current literature is surprising, given that parents are the ones most likely to provide support for their children during mealtimes, and as such, their involvement in interventions is paramount.

Additionally, these interventions usually involve using behaviour analytic procedures like escape extinction (EE; e.g., Hoch et al., 1994 LaRue et al., 2011; Voulgarakis & Forte, 2015), differential reinforcement of alternative behaviour (DRA; e.g., Berth et al., 2019; de los Santos & Silbaugh, 2020; Valdimarsdottir et al., 2010), and sometimes involve some punishment procedures (e.g., response cost, physical prompts; e.g., Buckley & Newchok, 2005; Clawson & Elliott, 2014; Murphy & Zlomke, 2016). Of these, EE and punishment involve the use of aversive procedures.

Tereshko et al. (2021b) provided some guidelines of ethical considerations of behavioural feeding interventions and highlighted how EE should be used with caution.

Importantly, the intervention strategies described previously focus heavily on a consequence-based intervention approach for feeding difficulties. There is limited research into using antecedent-based interventions for behavioural feeding difficulties, however, there have been some approaches outlined in the literature which have used antecedent-based approaches. For example, Penrod et al. (2013) examined the effects of the high-probability instructional sequence in the treatment of selective eating exhibited by two nine and ten-year-old autistic boys. They found that this antecedent-based intervention was effective in increasing the consumption of food for both participants.

Recently, Tereshko et al. (2021a) conducted a systematic review of antecedent-based and non-aversive consequence-based procedures (i.e., reinforcement procedures) and their effects on feeding behaviour. They identified 21 articles and concluded that positive practices (like reinforcement and antecedent-based approaches) may be effective in treating behavioural feeding difficulties, however, the authors note that it is important to highlight the minimal number of articles that have used reinforcement and antecedent-based approaches without the use of EE, in comparison to the number of articles that have used EE. They conclude that further research is needed to understand the effectiveness of interventions that do not use EE.

There is also limited research that considers broader contextual interventions like Positive Behaviour Support (PBS) as a framework for supporting behavioural feeding difficulties. Binnendyk and Lucyshyn (2008) evaluated the effectiveness of a family-centred PBS approach for food refusal in an autistic child. They found that this approach resulted in high levels of child food acceptance, child participation in a pre-selected household routine, and high parent ratings of social validity and contextual fit. The results were maintained 26 months after the intervention had terminated. Additionally, Curtiss et al. (2008) also describe the implementation of a PBS approach to support a child with their feeding difficulty. They highlight the use of a functional assessment to support and monitor an individualised intervention plan that was implemented by caregivers in the family's natural context, and crucially, the training and coaching of parents to implement intervention techniques as being the key to success with a PBS approach. They found that this approach resulted in the child increasing their food consumption, reducing their food refusals, achieving stabilised growth, and eliminating the need for enteral feeding.

As such, the current intervention approach for behavioural feeding difficulties amongst children with IDD that will be explored in this study was influenced by PBS and guided by the logic model described in the previous chapter. The current intervention approach prioritised the involvement of family members throughout the assessment and intervention process, and there was a focus on a collaborative and coaching approach. There was also a strong awareness that the current intervention approach needed to focus on antecedent and reinforcement-based interventions in efforts to reduce restrictive and aversive practices, and to ensure that the intervention approach was aligned with the recognised values-base of behavioural practitioners in the UK. There were also considerations like the extent of support that can be provided within the UK's health-care system, the National Health Service (NHS; i.e., number of sessions, coaching approach rather than direct intervention, etc.), which differed drastically from many behavioural interventions in the literature that are carried out across months and in clinic settings.

As such, the aim of this study was to work with family carers to develop bespoke strategies and coach them through the implementation of these, as part of a behavioural intervention approach for behavioural feeding difficulties amongst their child with an IDD. The objective of this study was to pilot an intervention approach that matched the amount of service delivery that might be feasible within the NHS context and was guided by the logic model (see Chapter Five), involving a behavioural and collaborative approach via telehealth. The research questions guiding this study were:

- Is an intervention approach of this nature effective in improving the child’s behavioural feeding difficulty?
- What are family experiences of participating in this type of intervention approach?
- Can this intervention approach be delivered as intended?

Methodology

Study Design

This study used single-case design methodology (Baer et al., 1968) to evaluate the effectiveness of this intervention with the participants. Specifically, a delayed multiple baseline design (MBD) was used to evaluate any changes to the dependent variables (described below) that occurred as a result of the implementation of the intervention. A delayed MBD was selected as it was deemed that it would not be likely to recruit families to the study at the same time to be able to start simultaneous data collection. Quantitative data from a questionnaire about parents’ perceptions of their children’s behaviour and their own behaviour during mealtimes pre- and post-intervention was also collected to evaluate the effectiveness of this intervention. Qualitative data about parents’ experiences of this intervention and their perceptions about social validity was also collected to learn about parents’ experiences of participating in this intervention. Finally, quantitative data related to parental implementation of strategies, researcher fidelity, and interobserver agreement (IOA) was collected to determine if this intervention could be delivered as intended.

Participants

Participant Inclusion Criteria

Participants were required to be family carers (biological parents/primary carers/foster parents) of a child with an IDD that currently engaged in a behavioural feeding difficulty. Family carers also needed to be at least 18 years old, have capacity to consent, and speak and write English well enough to engage with an intervention to ensure that they could meaningfully participate in the sessions in real time. They also needed to be able to commit to engaging with the intervention for the outlined intervention period (i.e., about two to three months). Family carers needed to have access to a video-recording device to use for mealtime observation videos (i.e., smart phone, tablet, video-recorder, laptop, etc.) as this project had no funding and this technology would not be able to be provided for families. Additionally, the goal of the families needed to be to increase their child's consumption of foods, as this would be the dependent variable monitored throughout the course of this intervention.

The focal child with an IDD that exhibited a behavioural feeding difficulty was required to be between 1.5-7 years old (inclusive). This age range was selected based on the World Health Organisation guidelines for starting babies on solid foods around 6 months of age and the estimation that refining the new skill of feeding can take between 6-12 months (Rappaport, 2015). The upper age range was selected as previous research in this PhD has indicated that families and NHS staff members believe early intervention is particularly important for behavioural feeding difficulties. For inclusion, participants also needed to be living in England. Up to two family carers per family could participate.

Participant Exclusion Criteria

To reduce threats to internal validity, any child that was currently receiving any other intervention for their behavioural feeding difficulty would be excluded. The focal children in this study also needed to exhibit feeding behaviours that could safely be addressed given the researcher's clinical competence and the very limited resources for this research. This meant that:

- The children could not be on the verge of hospitalisation
- They could not exhibit feeding situations that required significant input from other professionals that are not behaviour analytic

- The range/quantities of food that they consumed must not have significantly reduced in the month leading up to study as this would have indicated a review by the child's medical team was needed.
- The child needed to have been previously assessed for a safe swallow to ensure that they could safely increase the amount or range of food consumed.

Participant Recruitment

Participants were recruited through social media and mailing lists. Research information was disseminated through social media and mailing lists and contained the researcher's contact details. (see research poster in Appendix FF). Twenty-two families reached out about participating in this research. After families reached out, they were sent a Participant Information Sheet (PIS; Appendix GG) to learn more about the research. Following this, there was a preliminary conversation through email, telephone, or video-call to confirm inclusion requirements and answer any questions. Then, families that met the inclusion criteria were provided with the demographic form and the consent form.

Of the 22 families that contacted the research about participating, 20 were excluded due to: not responding to further emails (*n* = 7), reaching out after the study was full (*n* = 4), not being in England (*n* = 3), the focal child not having been assessed for a safe swallow (*n* = 3), the focal child not having a diagnosis of IDD (*n* = 1), the focal child was currently receiving feeding support (*n* = 1), or explicitly saying they would not participate (*n* = 1). The three families that were not in England were located in the United Arab Emirates, Russia, and Wales. Two families were included in this study; these were the first two families that fit the inclusion criteria.

Participant Characteristics

Participants were two families of children with IDD who were currently exhibiting a behavioural feeding difficulty. For Family One, there was one family carer that participated. For Family Two, there were two family carers that participated. In the case of both families, the family carers that participated were the biological parents of the children. Family carer and child participants are described below. Pseudonyms have been assigned to all participants in this study to protect their confidentiality, and all identifiable information has been removed.

Family One

Max, a 4-year-old White British male, was diagnosed autistic with no medical concerns. Max had experienced inconsistencies with the food he accepted throughout most of his life (e.g., dropping foods that he previously enjoyed), and he was currently exhibiting food refusal and selective eating. Max would engage in challenging mealtime behaviours (e.g., kicking) if during a mealtime he was pushed too far to try a food he did not want to try. Max had seen a community paediatrician and a dietitian, but the family reported they did not receive any substantial support for Max’s food refusal or expanding his diet. He also exhibited sensory preferences that his family reported also extended to foods (i.e., Max liked crunchy foods). During lunch, Max was spoon-fed mostly, though he would also self-feed occasionally. Max’s mother, Molly, a 37-year-old White British female, participated in this study.

Family Two

Adina was a 2 year and 9 months old, mixed race (White/Chinese) female, with learning disabilities, severe developmental delays, and her parents identified her to be autistic. She was also referred by professionals for an autism diagnosis but had not been diagnosed at the time of the study. Adina had feeding difficulties frequently, and it was reported that there were some inconsistencies with what she accepted, for instance she would occasionally eat cheese but other times she would refuse. Adina was currently exhibiting food refusal and selective eating. She would also occasionally engage in challenging mealtime behaviours (e.g., tantrums). She had seen a paediatrician who referred her to the dietitian, who reported that Adina was not getting enough nutrients from food and gave her Pediasure, a supplemental nutritional drink. Adina initially drank the Pediasure and then refused. She was given a laxative daily and parents reported that she experienced some constipation, which they attributed to her diet and the lack of vegetables. During dinner, Adina mostly self-fed though occasionally she was fed by either her mother or her father. Adina's mother, Viviana, a 36-year-old White European female, and Adina's father, Jiang, a 38-year-old Chinese male both participated in this study.

Setting and Materials

This study was carried out online in England due to the ongoing COVID-19 pandemic, and all study procedures were carried out in participants' homes. Materials were laptops (provided by the researcher and the family carers), MS Teams application or software, paper data sheets, paper activity sheets, and a pen or pencil. A detailed study manual was used by the researcher to guide each session (Appendix HH), and this included a detailed description of each session to guide all procedures consistently across families.

Procedure

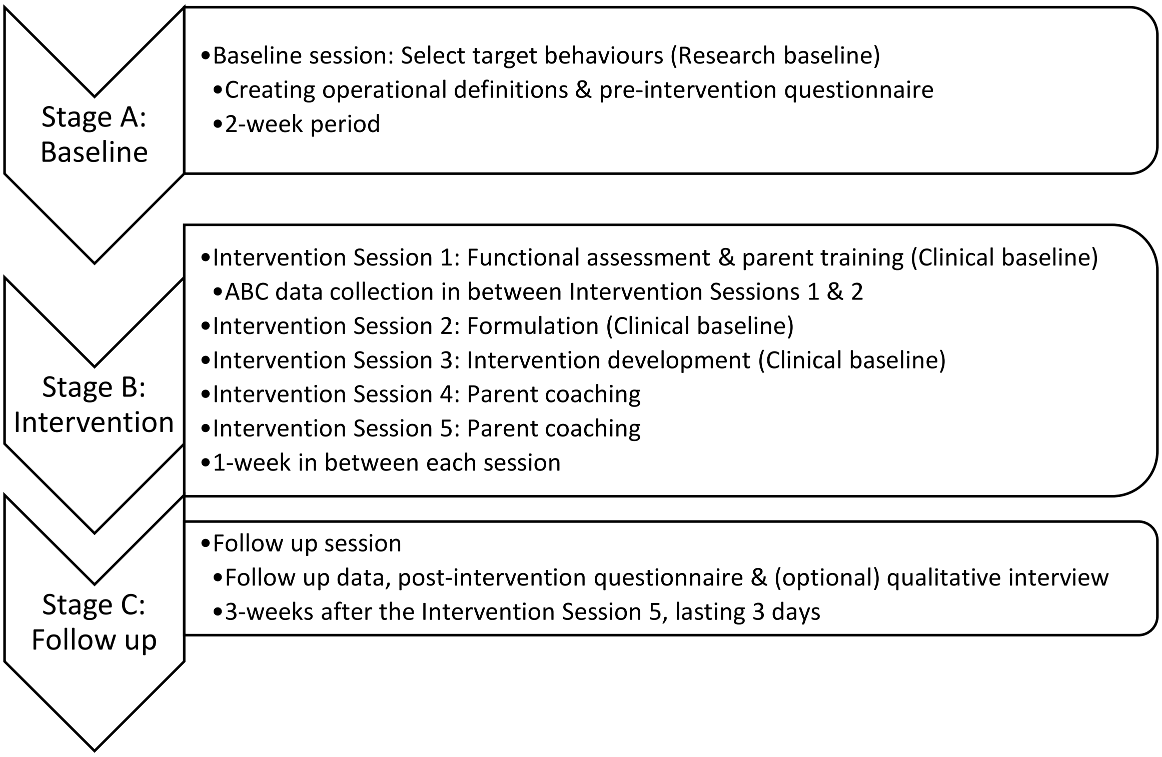
When participants provided consent (see consent form in Appendix II and Participant Recruitment above) and returned their demographic information (see demographic form in Appendix JJ), a date was set at a mutually convenient time to start the study.

This research was carried out virtually, through MS Teams (recording procedures described below), and this study involved 3 stages: 1) baseline, 2) intervention, and 3) follow-up. The procedure was consistent across participants. Figure 10 below provides an overview of the study and the goals of the sessions in each stage, and Appendix KK provides a detailed overview of the sessions in this study.

Following the conclusion of each family's involvement in the study, all participants were sent a follow-up email thanking them for participating and which included a comments form (Appendix LL) if they wished to provide any feedback to the researcher. Only one participant provided feedback following the interview, and this was provided via email (Appendix LL).

Figure 10

Overview of the Stages of the Study and the Goals of Each Session.



Stage A: Baseline

- Baseline session: Select target behaviours (Research baseline)
  - Creating operational definitions & pre-intervention questionnaire
  - 2-week period

Stage B: Intervention

- Intervention Session 1: Functional assessment & parent training (Clinical baseline)
  - ABC data collection in between Intervention Sessions 1 & 2
- Intervention Session 2: Formulation (Clinical baseline)
- Intervention Session 3: Intervention development (Clinical baseline)
- Intervention Session 4: Parent coaching
- Intervention Session 5: Parent coaching
- 1-week in between each session

Stage C: Follow up

- Follow up session
  - Follow up data, post-intervention questionnaire & (optional) qualitative interview
  - 3-weeks after the Intervention Session 5, lasting 3 days

Baseline (Stage A)

This was a *research baseline* stage in which the family and researcher met once to select target behaviours, create preliminary operational definitions, and complete the pre-intervention questionnaire. Families had no further contact with the researcher during this stage other than meeting to start the video-recordings of their mealtimes. During this stage, families implemented their mealtimes as normal over a two-week period, which started after the initial baseline meeting. The researcher video-recorded the target mealtimes (lunch for Max and dinner for Adina) during this period and collected baseline observational data during this period.

Intervention (Stage B)

This intervention stage consisted of a *clinical baseline* period and a period where there was active implementation of feeding strategies. The intervention stage lasted for a total of five sessions, carried out over five weeks (i.e., one session per week). The intervention in this study was conceptualised as the period where the assessment and implementation of strategies took place. As such, the intervention in this study consisted of carrying out a functional assessment of Max and Adina's mealtime behaviours with their parents, training parents to collect frequency data, going through a formulation process with families to guide collaborative working and to develop strategies to support their child with their eating, and coaching while families implemented these strategies. These components are described in further detail below.

Functional Assessment.

The functional assessment was carried out in one intervention session (Intervention Session 1) and between the first and second intervention sessions. An adapted Functional Assessment Interview was completed with families during the first intervention session. The Functional Assessment Interview (FAI; O'Neill et all., 2015) is a structured interview that is primarily used to collect information from key people in an individual's life about the variables that may be or are likely to be relevant influences on their behaviours (i.e., things that make it more likely for the behaviours to happen, and things that usually happen after the behaviour). The FAI has been used widely in the challenging behaviour literature to identify functions of behaviours that challenge (e.g., Fettig et al., 2016; Wood et al., 2011), and has also been used in the behavioural feeding intervention literature as part of the assessment process for behavioural feeding difficulties to identify the function of the behavioural feeding difficulty (e.g., Gale et al., 2011; Galensky et al., 2001; Sprague et al., 1998).

The FAI was modified for this study in several ways. First, a supervisor (NG) had already adapted the FAI for clinical use with children, and this modification was built on for the purposes of this study. All further modifications to the FAI were made in collaboration with a supervisor (NG). This included some questions being taken out as they were not relevant for feeding difficulties and it was deemed important to reduce the length of the questionnaire to reduce overall burden on families. For example, the original FAI queries about the pattern of staffing support that the person receives, however given the target demographic and the inclusion criteria, it was deemed that this question would not be relevant and was removed. It also included changes to the wording of some questions so these more clearly related to feeding difficulties (i.e., changing: ‘briefly describe how the person’s behaviour would be affected if *you asked him or her to perform a difficult task*’ to ‘*you asked your child to complete a task (take a bite, try a new food, etc.*’). Finally, a section related to ‘History and Context of the Behaviour’ was added to specifically obtain wider contextual information about feeding history, developmental history, family and cultural context, and other contextual information. The modified FAI can be seen in Appendix MM. The FAI was completed in full with each family, and this took between 2.25-2.5 hours to administer.

In this session, preliminary operational definitions were reviewed, and final operational definitions were developed together and confirmed with families. After the administration of the FAI, the researcher fed back to families the specific antecedent conditions that appeared to increase the likelihood that their child would refuse food, and the common events after food refusal. This provided the information necessary for Antecedent-Behaviour-Consequence (ABC) data collection. Following this, the researcher collected ABC data to gather information about the potential function of the child’s food refusal. ABC data was collected by the researcher from three mealtime videos (recorded after Intervention Session 1, and before Intervention Session 2). The specific antecedents and consequences that data was collected on was individualised for each family and was informed by the information obtained by the FAI and some common antecedents and consequences that the researcher and a PhD supervisor (NG) identified, guided by the literature and clinical experience using behavioural approaches. This led to the identification of the presumed function of Max and Adina’s behaviour, and the factors that were likely to increase their food refusal.

Formulation.

Formulation was carried out during one intervention session (Intervention Session 2). The information obtained from the modified FAI and the findings of the functional assessment was used to develop a shared understanding of Max and Adina's food refusal behaviours. In this session, the researcher and the parents developed an understanding about the unique and individual factors that made mealtime more aversive to Max and Adina, and this was an initial step towards collaborative working on the development of strategies for each child. Formulation maps were developed for Max and Adina and can be seen in Appendices NN and OO, respectively.

Parent Training.

Parent training was carried out during one intervention session (Intervention Session 1) and reviewed across the rest of the intervention sessions as needed. Families were trained on how to collect frequency data using behavioural skills teaching (BST), which has been used successfully to train parents (Shaefer & Andzik, 2021). This involved delivering instructions on how to collect data, modelling what this would look like, practicing with families, and providing positive and corrective feedback where necessary. Families' own mealtime videos from the baseline recordings were used to complete this training, to ensure that the videos were appropriate and relevant for families given the bespoke operational definitions that were developed.

Intervention Development.

Intervention development occurred in one session (Intervention Session 3). This session involved developing an action plan with participants. The goal was to collaboratively develop a plan based on antecedent strategies, avoiding the use of aversive procedures. Discussion in this session centred around identifying ways to break down identified patterns between environmental event and the child's feeding difficulty, such that mealtimes would be less aversive for Max and Adina. The parents and the researcher completed a worksheet tailored around identifying strategies that would break down the patterns identified in the formulation stage. The strategies recommended by parents and the researcher were then discussed in the context of the formulation for each child, thus ensuring that each strategy was specifically addressing the assumed function of each child's feeding difficulty. The strategies were then synthesised and put together into an action plan. Some strategies were put on hold to review later, as the child's feeding difficulty progressed. This resulted in the development of an action plan for strategies that families would implement (see Appendices PP and QQ for Max and Adina's action plans, respectively). Families were asked to identify whether a strategy was something they felt able to implement daily or occasionally, to differentiate between strategies that would be easy to implement daily and others that required more preparation or planning and could not be implemented daily.

Parent Coaching.

Parent coaching occurring during two intervention sessions (Intervention Sessions 4 and 5). The goals of these sessions were to review parents' implementations of the feeding strategies, the frequency data, and the parent-self-checklist. Families were provided with a self-checklist consisting of a list of the strategies that were discussed and asked to tally how many days each strategy was implemented throughout the week.

Primarily, discussions centred around families' experiences of implementing this action plan, and whether what families were implementing had contextual fit for them (i.e., if they felt able to cope with what they were doing). The coaching element of the intervention was also centred around continuing to support families emotionally through understanding why their children struggled with eating and providing support for them while they implemented strategies to support their children with their eating.

Follow-up (Stage C)

This follow-up stage consisted of one session that occurred three weeks after the conclusion of Intervention Session 5. This also consisted of the collection of frequency data and IOA data for three days before the follow-up meeting. During this stage, the goal was to collect further data about the children's behavioural feeding difficulties, and families continued to implement the strategies on their action plans and collect data. The researcher video-recorded the target mealtimes during this stage and collected follow-up behavioural data. This stage occurred about three-weeks after the conclusion of the intervention stage and lasted three consecutive days. At the follow-up meeting, a questionnaire was administered post-intervention, and participants were offered the opportunity to participate in a qualitative interview of their experiences of going through this intervention.

Data collection

The data collected in this study will be described in relation to data related to direct measures and indirect measures, qualitative data, and data related to strategy implementation, researcher fidelity, and interobserver agreement.

Direct Measures

The primary data that was collected throughout this study was observational behavioural data. This data was collected on food refusal, food acceptance, and challenging mealtime behaviours (e.g., kicking for Max, and tantrum for Adina). The dependent variables were frequency of acceptance/refusal of target food and other food, and other challenging mealtime behaviours. These will be described below. Data was also collected on acceptance/refusal of preferred foods, however a separate report for Max and Adina in relation to this dependent variable can be found in Appendix RR as this data was supplementary to the main objective of data collection.

Operational Definitions.

Operational definitions for target behaviours were developed in consultation with each family to ensure the definitions were complete and the terminology was appropriate to them. The behaviour definitions related to food acceptance and refusal were individualised for each child and can be seen in Table 13.

Table 13

Operational Definitions for Dependent Variables for Max and Adina.

	Participant	
	Max	**Adina**
Acceptance	Brings food to the mouth and places a bolus of at least a pea size in mouth and consumes the food, or when presented with food, the bite is accepted and consumed.	
Refusal	When presented with a spoon of food. Max turns his face away, pushes away the spoon, moves to a different part of the room or walks away from the food, this may also be accompanied by negative expressions or 'eww' 'blech' noises. When self-feeding, Max moves a piece of food off his plate or away from him or pushes the plate of food away from him.	When presented with food, Adina turns her face away, pushes the food away or shakes her head. When self-feeding, when Adina has a piece of food or bowl or utensils in front of her, she throws this, so it is no longer in front of her (with each individual throw as an instance of refusal, i.e., if she throws 3 raspberries individually then this would be counted as 3 throws), she pushes the food away or moves the food off her tray.
Other challenging mealtime behaviour	When his food refusal escalated it could result in *kicking*. This was defined as Max sticking his leg out and making contact with any part of a family member.	She sometimes exhibited self-injurious behaviour, which the family referred to as a *tantrum*. Tantrum was defined as Adina hitting her head with her hand with an open fist, and also included

	Participant	
	Max	**Adina**
		instances where Adina arched her back and banged her head on the back of the high seat, this may also be accompanied by swinging her feet forward.

Each child's preferred foods (i.e., the most consistent ones that they usually ate during the specified mealtime, as identified by parents) were identified for the study. There were also target foods selected for this study in consultation with each family, and foods that did not fall into either of these categories were also tracked. An overview of Max and Adina's preferred, other, and target foods can be seen on Table 14.

Table 14

Dependent Variable Food Categories for Max and Adina.

	Participant	
	Max	**Adina**
Preferred foods	Beans on toast (or any variation: beans only, toast only)	Pasta, couscous, orzo, chicken nuggets, ham, soup
Target foods	Courgette, spaghetti Bolognese, peas, carrots	Cucumber, tomato, pepper, broccoli
Other foods	Any other food not listed under preferred or target foods	

Response Measurement.

Frequency data was collected throughout the study for food acceptance and refusal of target and other foods for both Max and Adina, and other challenging mealtime behaviours. Frequency data was collected as the number of times food was refused per lunch or dinner divided by the total amount of time that the mealtime lasted (i.e., number of minutes). This provided information about the rate per minute (i.e., frequency) at which Max and Adina were accepting food, rejecting food, or engaging in other challenging mealtime behaviours as outlined previously. The researcher collected this frequency data during the baseline stage, and parents collected this frequency data during the intervention and follow-up stages. Parents were provided with instructions and co-developed operational definitions for this.

Indirect Measures

Family carers completed a questionnaire pre-intervention and post-intervention. This questionnaire was modified to a Word document with checklists (see Appendix SS), and this was administered by the researcher sharing her screen and filling in the corresponding tick boxes as participants provided their responses. For Family Two, Jiang and Viviana completed this at the same time, though their answers were recorded independently of each other, resulting in scores produced for each parent (i.e., two questionnaire score reports were produced for Adina from information provided by Jiang and Viviana). Only one report was produced for Max as Molly's responses. This took about 15-30 minutes to complete.

Behavioral Pediatrics Feeding Assessment Scale (BPFAS).

The BPFAS (Crist & Napier-Phillips, 2001; Crist et al., 1994) is a 35-item parent-report measure. The first 25 questions provide a description of the child's behaviour and the next 10 provide descriptions of the parent's feelings about the child's feeding difficulty or strategies for dealing with this. These items are phrased both positively and negatively and parents are asked to rate how often the behaviour occurs on a five-point Likert scale from 'never' to 'always'. Some items are reverse scored. For each item, parents are also asked to identify whether the behaviour is a problem for them, by circling ‘yes’ or ‘no’. This scale generates scores for both parent and child sections, in the form of frequency ratings from the Likert scale responses and from the number of behaviours identified as challenging for parents. This results in two scores that reflect the frequency of child behaviours and number of challenging child behaviours, and two scores that reflect the frequency of parent behaviours and number of problematic parent behaviours (e.g., I get frustrated and/or anxious when feeding my child, I use threats to get my child to eat, I feel confident my child gets enough to eat, etc.). The BPFAS has been used with children with feeding difficulties and autistic children (e.g., Allen et al., 2015; Dovey et al., 2019; Kang et al., 2022). This measure is sensitive to differences between children with clinical-level feeding difficulties and nonclinical samples. It is classified as a 'well-established’ parent-report measure for paediatric mealtime assessments (Poppert et al., 2015). The BPFAS is used for children between 6-months and 12-years.

Qualitative Data

After participating in the intervention, family carers were asked if they were willing to complete an optional qualitative interview about their experiences of working together to develop strategies to address their child’s feeding difficulty throughout the study and implementing these. This qualitative interview also focused on obtaining information about social validity (i.e., the appropriateness of the goals, of the intervention, and the outcomes obtained from the intervention). Both families consented to participating in this qualitative interview.

Family carers were asked open-ended questions that followed a semi-structured interview approach (see Appendix TT). A semi-structured interview approach was adopted to ensure that the data obtained related to the specific experiences of going through this process and social validity, but that would provide sufficient flexibility to follow participants’ leads if they brought up something that would have been important to explore. The interviews lasted 30-60 minutes and were video-and audio-recorded through Teams. The data were transcribed, anonymised, and the data was analysed (see Data Analysis).

Strategy Implementation

Families were provided with a self-completion checklist of a list of the strategies that were discussed and asked to tally how many days each strategy was implemented throughout the week. This data was then graphed in relation to percentage of occurrence throughout the week.

Researcher Fidelity

Fidelity data was recorded by the researcher for her implementation of the procedures outlined for each session using a task analysis of procedures (see study manual, Appendix HH). Data was collected by scoring each step in the task analysis for each session as either having occurred or not having occurred. This was devised and included to ensure that the intervention components in each session with families was being delivered consistently to all families in the study. This was calculated as an average of percentage of steps implemented correctly across the baseline session, intervention sessions, and follow-up session, across both families.

Interobserver Agreement

A second rater independently collected behavioural data across 36.4% of baseline lunches for Family One and 30.8% of baseline dinners for Family Two, to calculate interobserver agreement (IOA) between the primary and secondary data collectors. The primary data collector for the baseline data was the researcher and the second rater was a colleague at the Tizard Centre, at the University of Kent who was considered to be a member of the research team. For data collected during the intervention stage and the follow-up stage, the primary data collectors were family carers. The researcher was the secondary data collector who collected data across 50% of lunches for Family One and 41.7% of dinners for Family Two during the intervention stage. For the follow-up stage, the researcher collected data for 100% of target meals during this stage for both families.

As data was collected on frequency of behaviour, total count IOA was calculated by dividing the smaller count observed by the larger count and multiplying this figure by 100. This yielded a percentage of agreement between both observers. Agreement of about 80% or above is usually the accepted range for IOA (Cooper et al., 2020); this was the standard that was accepted for IOA of baseline data collection, where both observers were collecting data from the same videos. However, IOA range of acceptance was lowered to 70% for IOA calculated for data collected by the researcher and the family carers, as there were challenges associated with obtaining the same values when collecting data in person, rather than from a video. For example, if the child moved off the screen and took a bite, the family carers would have observed this and scored it, but the researcher would have been unable to, therefore the range of acceptance of IOA between the researcher and family carers was lowered. Anything lower than 70% indicated that a reminder needed to be provided to family carers about the parameters of the operational definitions outlined in the data sheets. Inter-observer agreement lower than 80% can be accepted when multiple behaviours are being observed in a complex environment (Cooper et al., 2020).

Table 15 below provides information about the number of sessions in which IOA data was collected for across families and stages, the average IOA across observers, and the range of this IOA, all in relation to food acceptance data. Table 16 below provides the same information about food refusal data, and Table 17 about other challenging mealtime behaviour data.

Table 15

IOA Information about Food Acceptance.

			Other food		**Target food**	
		Number of sessions (%)	**Average IOA %**	**Range of IOA**	**Average IOA %**	**Range of IOA**
	Stage					
Family 1	**Baseline**	4/11 (36.4%)	97.7%	90.9-100	-	-

			Other food		Target food	
		Number of sessions (%)	**Average IOA %**	**Range of IOA**	**Average IOA %**	**Range of IOA**
	Intervention	11 / 22 (50%)	92.1%	80-100	100%	-
	Follow-up	3/3 (100%)	87%	76.7-93.1	100%	-
Family 2	**Baseline**	4/13 (30.8%)	83.5%	68.4-97.5	-	-
	Intervention	10 / 24 (41.7%)	91.47%	75-100	100%	-
	Follow-up	3/3 (100%)	92%	81.8-100	67%*	0-100

* Indicates IOA that was lower than the outlined standards.

Table 16

IOA Information about Food Refusal.

			Other food		Target food	
		Number of sessions (%)	**Average IOA %**	**Range of IOA**	**Average IOA %**	**Range of IOA**
	Stage					
Family 1	**Baseline**	4/11 (36.4%)	87.5%	50-100	-	-
	Intervention	11 / 22 (50%)	95.45%	50-100	93.56%	62.5-100
	Follow-up	3/3 (100%)	100%	-	100%	-
Family 2	**Baseline**	4/13 (30.8%)	74.7%*	50-95.8	-	-
	Intervention	10 / 24 (41.7%)	93.57%	50-100	100%	-
	Follow-up	3/3 (100%)	100%	-	100%	-

* Indicates IOA that was lower than the outlined standards.

Table 17

IOA Information about Other Challenging Mealtime Behaviour.

			Kicking		Tantrum	
		Number of sessions (%)	**Average IOA %**	**Range of IOA**	**Average IOA %**	**Range of IOA**
	Stage					
Family 1	**Baseline**	4/11 (36.4%)	100%	-	-	-
	Intervention	11 / 22 (50%)	100%	-	-	-
	Follow-up	3/3 (100%)	100%	-	-	-
Family 2	**Baseline**	4/13 (30.8%)	-	-	93.8%	75-100
	Intervention	10 / 24 (41.7%)	-	-	78.89%	0-100
	Follow-up	3/3 (100%)	-	-	100%	-

Data Analysis

As is the convention with behavioural data (Cooper et al., 2020), these were graphed and analysed through visual analysis to track any changes in the frequency of the behaviours. The behavioural data was graphed per day as the researcher was collecting data from daily mealtimes during the baseline period, and family carers were collecting data daily during the intervention and follow-up periods.

BPFAS data was calculated to obtain total scores. Changes in scores for all family carers were examined from pre- to post-intervention. It was not possible to calculate if there was statistical significance from pre- to post-intervention as there were only three family carer participants. It was not possible to use thematic analysis for analysis of the qualitative data collected as there were only two interviews conducted, with three participants. As such, qualitative data of participants' experiences of going through this process was described. Qualitative data that related to participants' perceptions of social validity was also analysed descriptively in relation to the three components of social validity (i.e., goals, intervention, outcomes; Wolf, 1978).

Recording Procedures

For all mealtime recordings, families were sent Teams links. The researcher started the Teams meeting and families joined the meeting. The researcher started the recording and then left the meeting and the recording continued after the researcher left the meeting. Once families finished their mealtimes, they left the meeting and the recording saved automatically in the researcher's Stream account. This placed the burden on the researcher and reduced families having to transfer data to the researcher.

During the baseline period, 84.6% lunches were recorded for Family One, and 100% of dinners were recorded for Family Two. Family One missed two mealtime recordings during the baseline period due to Molly being out of town. During the intervention period, on average three mealtimes were recorded per week for both families, for IOA data collection. During the follow-up period, 100% of mealtimes were recorded for both families for three mealtimes on three days.

Ethical Considerations

Ethical approval was obtained from Tizard Centre Ethics Committee on April 4, 2022. There were many ethical considerations that were considered in the development and design of this study. Firstly, no payment was offered as there was no funding for participants. It was also considered that paying participants could establish a power differential where participants might not feel confident in withdrawing from the research.

Secondly, it was considered that a limit to confidentiality would occur where any safeguarding or welfare concerns arose in relation to either concern for a child or disclosure of a potentially harmful practice. In these cases, anonymity could not be guaranteed as the necessary steps would need to be taken to address the situation. This would have involved discussions with supervisors in the first instance, and reporting to the necessary child protection services if necessary. Participants were made aware of this on the informed consent form and the PIS. These instances were not encountered. Another limit to confidentiality was that the research team would know the participants' identities and personal details. Participants were made aware of this on the informed consent form and the PIS.

Thirdly, it was considered possible that family carers could become upset when discussing the impact of their child's feeding difficulty on themselves or their family, or lack of progress throughout the intervention. If this occurred, the researcher would stop the session and ask the participant if they would like a break, end the session, continue at a later date, or end their involvement in the study. If participants experienced distress at any time, they would have been signposted to support resources by Feeding Matters (an international organisation for families of children with feeding difficulties) or the Challenging Behaviour Foundation. Neither family became distressed at any point in the study.

It was considered that burdens to participants could be high as this study involved family carers heavily, however all attempts possible were made to keep burden to participants minimal (e.g., providing all materials, keeping the sessions as short as possible, providing electronic access via Teams, arranging sessions at times convenient to participants and being flexible about these, etc.). While the burden to participants may have been high, family carers were supported through supporting their child with their feeding difficulty, which was presumed to have benefits for participants, therefore it was considered that time burdens were balanced by the potential benefits of participating. To ensure that the clinical portion of the work was being carried out appropriately, there was contact with a supervisor (NG) following all sessions with families for ongoing ‘check ins’ of the progress of the sessions. Finally, it was identified that there were risks involved when trying to increase the amount of food a child consumes, however, this was addressed by identifying clear parameters around the feeding situations that could safely be addressed in this research (see Participant exclusion criteria). There was an instance with Family Two where it was identified that supporting the family through reducing Adina’s milk intake would support her to consume more food, however it was felt that this was outside of the researcher’s scope of competence and clinical experience, therefore it was agreed with a supervisor (NG) and the family that this would not be addressed in this study.

Results

Findings will initially be presented for data relating to child outcomes (observational data and indirect assessments via BPFAS results), followed by qualitative data relating to social validity and parental experiences, and finally data relating to delivery of the intervention.

Food Results

Target Foods

Figure 11 illustrates the way in which Max’s and Adina’s acceptance and refusal of target food progressed throughout the study. The target foods for intervention were selected at Intervention Session 1, therefore there was no baseline data collected in relation to these during the research baseline phase of this study. There was, however, a clinical baseline period where the intervention with the family had started (i.e., Intervention Session 1), but no strategies were being implemented to target Max or Adina’s food refusal. These strategies started being implemented after Intervention Session 3, therefore a phase change line can be seen at this stage in Figure 11, illustrating when the clinical baseline period ended, and the intervention for food refusal of target foods started.

Figure 11 shows that there was no change throughout this study in the acceptance of the target foods for either Max or Adina. For both, acceptance of the target foods remained at zero rates throughout the study. Refusal of the target food for Max during the clinical baseline stage was variable, with no trend, and had high rates compared to the rest of the conditions. In the intervention stage, Max’s refusal was variable, with no trend, and in the follow-up stage, this was stable, with no trend and at low rates. This is likely to be representative of less bites of the target foods being presented to Max as the study progressed. Refusal of the target food for Adina during the clinical baseline stage was variable, with no trend, and had high rates compared to the rest of the conditions. In the intervention stage, Adina’s refusal was stable with no trend, and in the follow-up stage, this was stable with no trend and at low rates. This is also likely to be representative of the fact that Jiang and Viviana presented Adina with less target foods as the study progressed. Table 18 provides an overview of the changes in level (mean) across conditions for Max and Adina.

Figure 11

Frequency of Acceptance and Refusal or Target Foods.

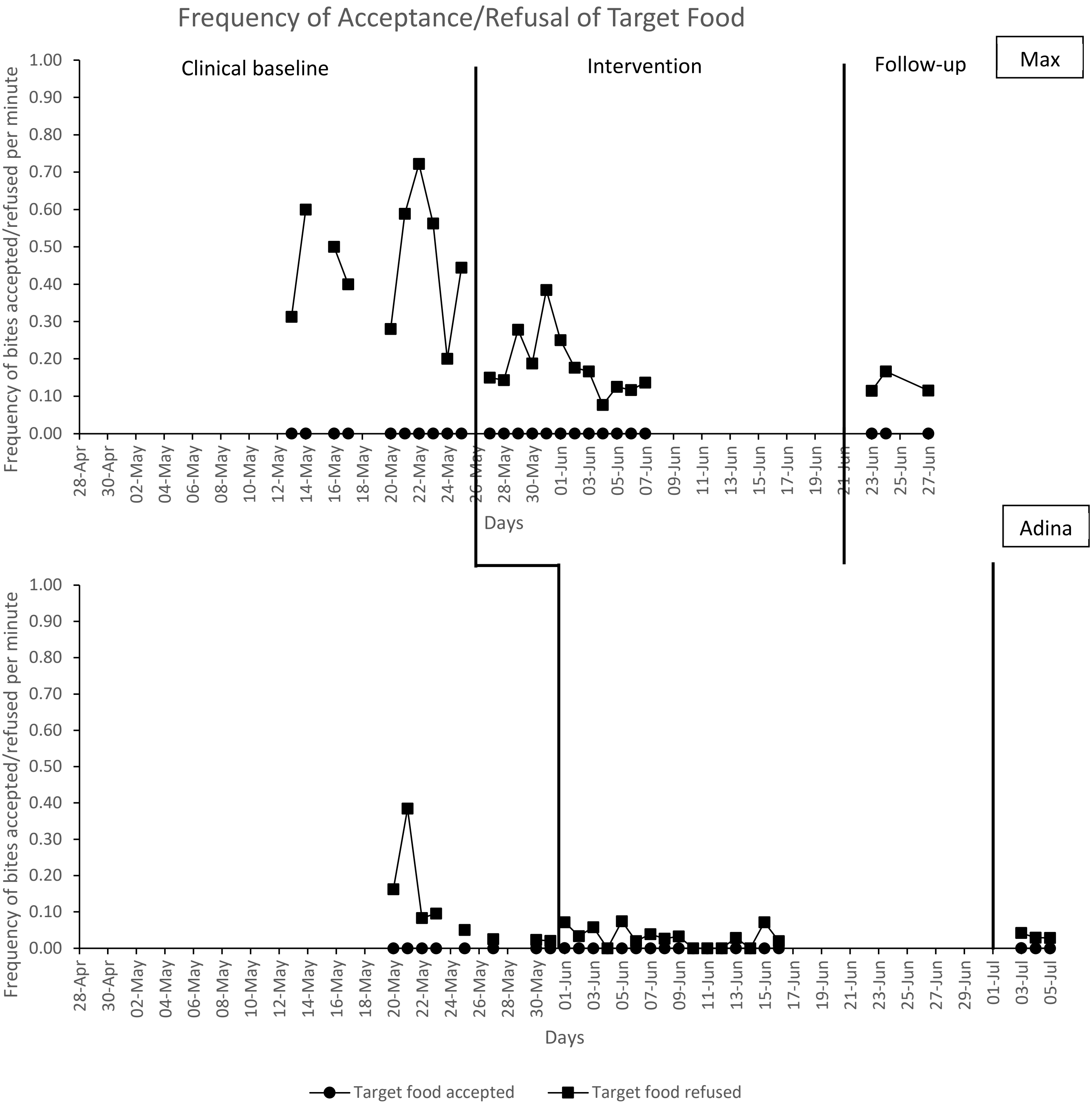


Table 18

Level of Acceptance and Refusal per Minute of Target Foods for Max and Adina Across Conditions.

		Clinical Baseline	Intervention	Follow-up
			Mean (Range)	
Acceptance				
	Max	0	0	0
	Adina	0	0	0
Refusal				
	Max	0.46 (0.2-0.72)	0.18 (0.08-0.38)	0.13 (0.11-0.17)
	Adina	0.11 (0.02-0.38)	0.03 (0-0.07)	0.03 (0.03-0.04)

Other Foods

Figure 12 illustrates how Max’s and Adina’s acceptance and refusal of other foods progressed throughout the study. These foods were identified at the baseline session; thus they were tracked throughout the baseline, intervention, and follow-up stage of this research. There is a phase change line that can be seen between the baseline and follow-up stages, indicating where the clinical baseline period ended, and the implementation of strategies began (i.e., the families were implementing the strategies outlined in their action plans).

Figure 12 shows how Max’s acceptance of other foods relatively stayed the same throughout the study, but increased at the follow-up stage. Adina’s acceptance of other foods decreased on average steadily throughout the study. Acceptance of other foods for Max during the research baseline stage was variable, with low rates and no trend, and during the clinical baseline stage this was the same. During the intervention stage, Max’s acceptance was variable, with low rates and a slight decreasing trend, and in the follow-up stage, this was variable, with high rates and no trend. Acceptance of other foods for Adina during the research baseline stage was variable with high rates and no trend, with the exception of an increasing trend at the end of this stage. In the clinical baseline stage, this was variable, with high rates, though these were lower in comparison to the previous stage, and no trend. During the intervention stage, Adina’s acceptance was variable, with similar rates to the previous stage and no trend, and in the follow-up, this was stable, with low rates and a decreasing trend.

Max’s refusal of other foods stayed on average the same throughout the study, with a slight increase during the follow-up stage. Adina’s refusal of other foods had a slight decrease in level across the stages of the study. Refusal of other foods for Max during the research baseline stage was variable, with low rates and no trend, and during the clinical baseline stage this was the same with the exception that there was stability in the data. During the intervention stage, Max’s refusal of other foods was stable with low rates and no trend, and this was the same in the follow-up stage. Refusal of other foods for Adina during the baseline stage was variable, with low rates and no trend, and during the clinical baseline stage this was the same with the exception that there was stability in the data. During the intervention stage, Adina’s refusal of other foods was stable with low rates and no trend, and this was the same in the follow-up stage. Table 19 provides an overview of the changes in level (mean) across conditions for Max and Adina.

Figure 12

Frequency of Acceptance and Refusal of Other Food.

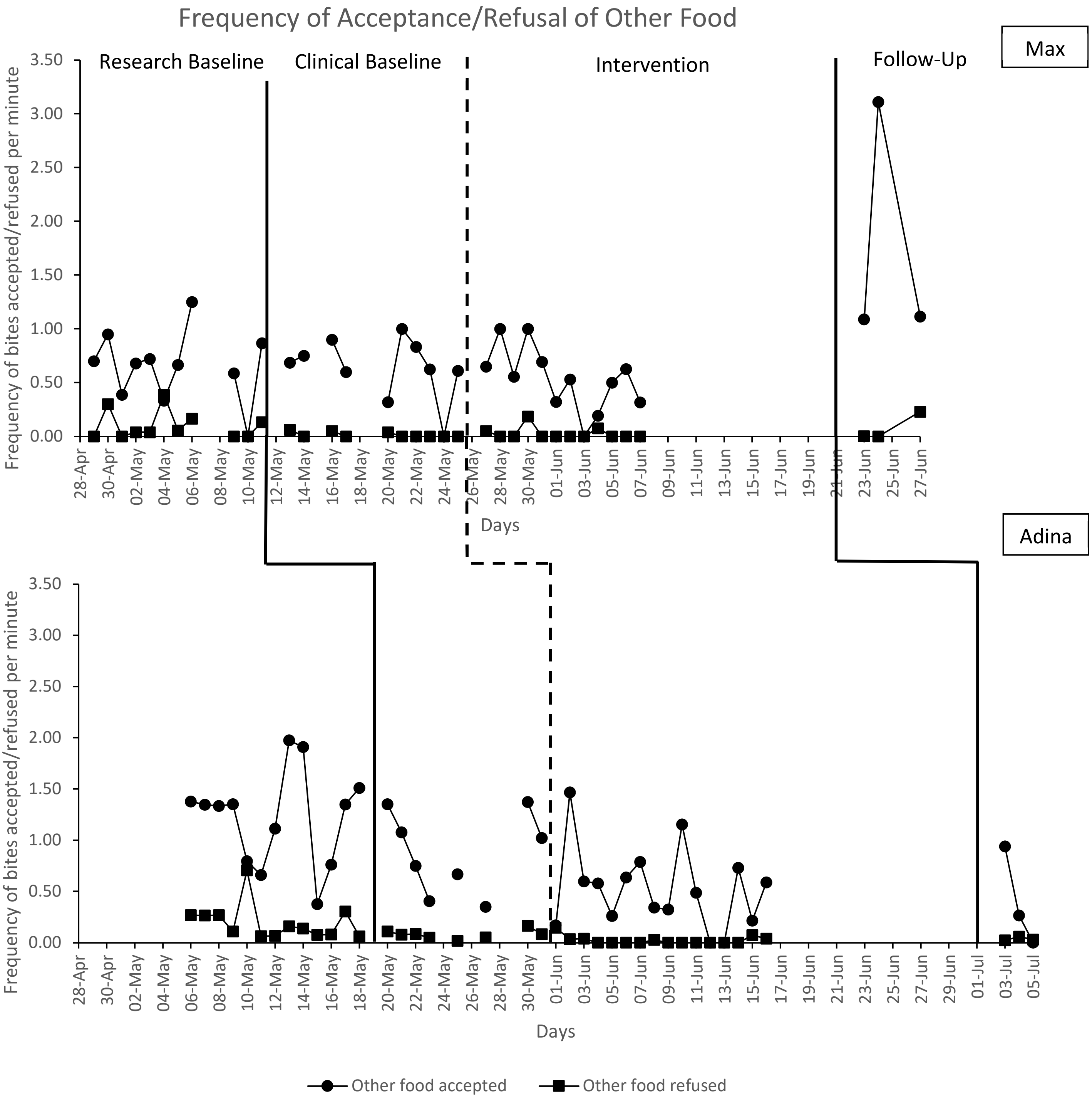


Table 19

Level of Acceptance and Refusal per Minute of Other Foods for Max and Adina Across Conditions.

		Research Baseline	Clinical Baseline	Intervention	Follow-up
			Mean (Range)		
Acceptance					
	Max	0.65 (0-1.25)	0.63 (0-1)	0.53 (0-1)	1.77 (1.09-3.11)
	Adina	1.22 (0.38-1.97)	0.87 (0.35-1.37)	0.52 (0-1.47)	0.4 (0-0.94)
Refusal					
	Max	0.1 (0-0.39)	0.02 (0-0.06)	0.03 (0-0.19)	0.08 (0-0.23)
	Adina	0.2 (0.06-0.71)	0.08 (0.02-0.16)	0.02 (0-0.14)	0.04 (0.02-0.06)

Other Challenging Mealtime Behaviour

Figure 13 illustrates the way in which Max's and Adina's other challenging mealtime behaviours (kicking and tantrum, respectively) progressed throughout the study. These behaviours were identified at the baseline session; thus, they were tracked throughout the baseline, intervention, and follow-up stages of this research. There is a phase change line that can be seen between the baseline and follow-up stages, indicating where the clinical baseline period ended, and the implementation of strategies began (i.e., the families were implementing the strategies outlined in their action plans).

Max's kicking remained at zero rates throughout the entire study. Adina's tantrums were variable during the research baseline stage, with no trend and low rates throughout except for three days. In the clinical baseline stage, her tantrums remained variable, with low rates and no trend.

During the intervention period, Adina’s tantrums were stable with no trend and at zero rates except for one day, and in the follow-up, this was at zero rates. Table 20 provides an overview of the changes in level (mean) across conditions for Max and Adina.

Figure 13

Frequency of Other Challenging Mealtime Behaviours.

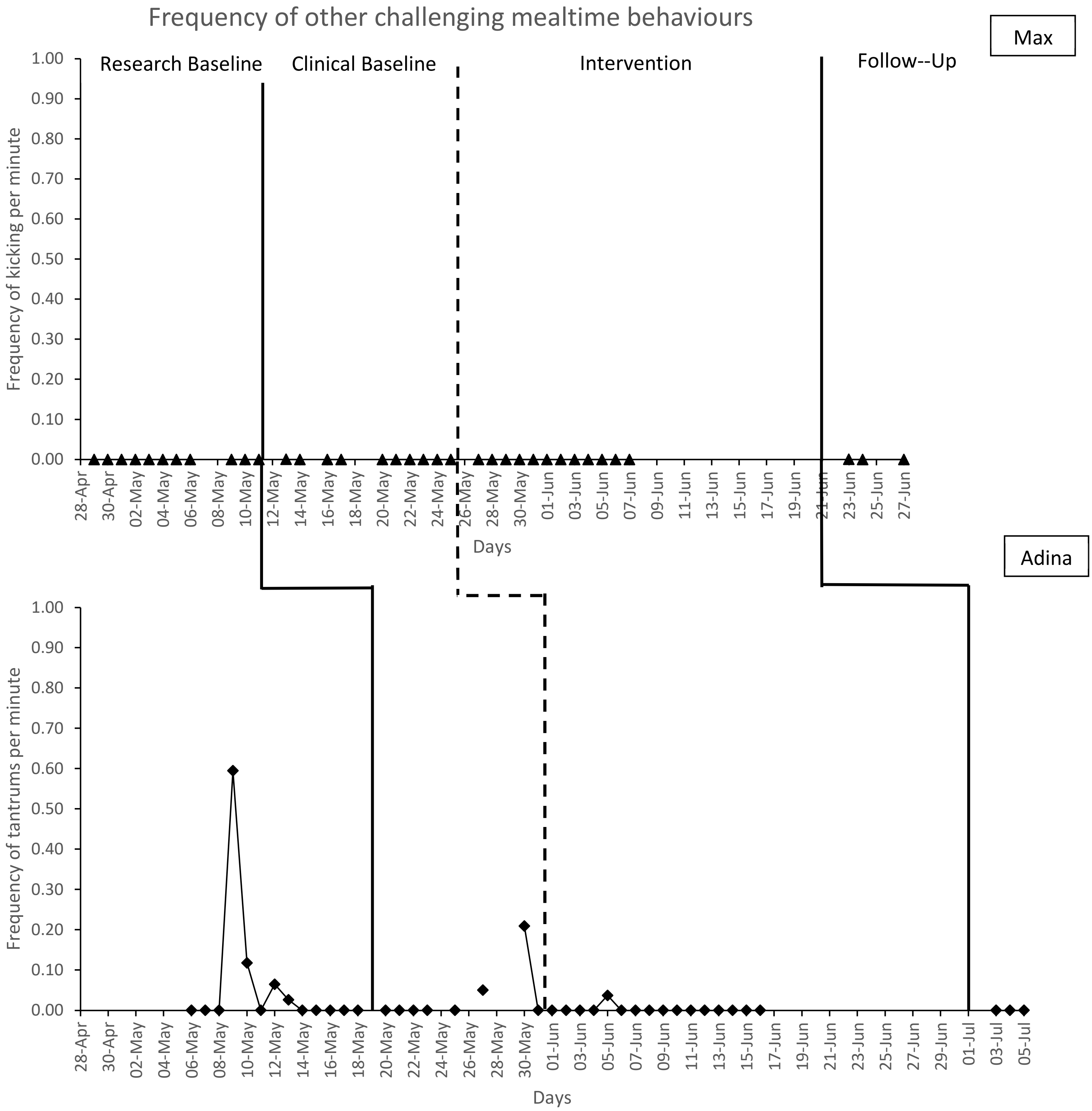


Table 20

Level of Other Challenging Mealtime Behaviours per Minute for Max and Adina Across Conditions.

		Research Baseline	Clinical Baseline	Intervention	Follow-up
			Mean (Range)		
Kicking					
	Max	0	0	0	0
Tantrum					
	Adina	0.06 (0-0.59)	0.03 (0-0.21)	0.00 (0-0.04)	0

BPFAS

Table 21 below displays the BPFAS scores for all family carer participants pre- and post-intervention. Given that there are only three participants, it would not have been meaningful to calculate statistical significance in the change in the scores from pre- to post-intervention. As a result, any changes in participants' pre- and post-intervention scores will be presented descriptively.

Table 21

Pre- and Post- BPFAS Results, Broken Down by Scores for Both Families.

	Total frequency score		**Total problem score**		**Child frequency score**		**Parent frequency score**		**Child problem score**		**Parent problem score**	
	Pre	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**
Family One												
Molly	88*	79	15*	0	69*[a]	60	19	19	13*[a]	0	2[a]	0
Family Two												
Jiang	106*	69	21*	2	73*[a]	51	33*[a]	18	15*[a]	2	6*[a]	0
Viviana	103*	92*	19*	10*	70*[a]	68*[a]	33*[a]	24 *[a]	13*[a]	7*[a]	6*[a]	3*[a]

* Significantly higher than normative mean

[a] Clinically significant (following guidelines outlined by Dovey et al., 2013)

Molly's responses on the BPFAS obtained during the baseline session (i.e., pre-intervention) indicated that there were 16 possible areas of concern, and this reduced to six possible areas of concern post-intervention (see Appendix UU). Before the intervention, Molly's responses indicated that four scores out of six (i.e., 66.7%) were significantly higher than the normative mean, and three scores out of four (i.e., 75%) were clinically significant (as per guidelines outlined by Dovey et al., 2013). Molly's responses after the intervention had reduced such that none of the scores were significantly higher than the normative mean, nor were any clinically significant. In fact, post-intervention responses indicated that three scores had reduced to zero.

Jiang's responses on the BPFAS obtained during the baseline session (i.e., pre-intervention) indicated that there were 20 possible areas of concern, and this reduced to six possible areas of concern post-intervention (see Appendix UU). Before the intervention, Jiang's responses indicated that six scores out of six (i.e., 100%) were significantly higher than the normative mean, and four scores out of four (i.e., 100%) were clinically significant (as per guidelines outlined by Dovey et al., 2013. Jiang's responses after the intervention had reduced such that none of the scores were significantly higher than the normative mean, nor were any clinically significant. In fact, post-intervention scores indicated that one score had reduced to zero.

Viviana's responses on the BPFAS obtained during the baseline session (i.e., pre-intervention) indicated that there were 19 possible areas of concern, and this reduced to 11 possible areas of concern post-intervention (see Appendix UU). Before the intervention, Viviana's responses indicated that six scores out of six (i.e., 100%) were significantly higher than the normative mean, and four scores out of four (i.e., 100%) were clinically significant (as per guidelines outlined by Dovey et al., 2013). Viviana's responses after the intervention had reduced such that all scores were lower than the responses before the intervention, however all six scores out of six (i.e., 100%) continued to be significantly higher than the normative mean, and all four scores out of four (i.e., 100%) continued to be clinically significant.

Qualitative Results

Social Validity

Participants were asked about the social validity of the goals, the intervention, and the outcomes of the intervention (see Appendix VV for an overview). They mostly reported that the goals were appropriate and important. However, there was a sense from Jiang and Viviana that the research goal of increasing consumption of target foods could have been enhanced by making it clearer from the start that one of the goals would be to create a positive mealtime experience for the family. This was not an explicit goal from the beginning of the intervention but was a major component of the conversations around supporting Adina as discussions progressed about making the mealtime environment less aversive and more supportive to her.

When asked about whether they felt the goals outlined at the beginning were important and acceptable, participants responded:

> "Yeah because we did loads about Max's eating and helping him be comfy and less anxious for mealtimes, so that's brilliant." (Molly)

> "I think the way of thinking and the paradigms are a bit different, initially, the goals should be a positive eating experience, not getting her to eat broccoli, cucumber and vegetables so…it's just changing the way you think about what is realistic and what the goal should be." (Jiang)

> "It's great that…we learned about Adina…I think was maybe misunderstanding from our side what the goals were. But then, because we thought as I said to make her eat these three, because *I* want her to eat that." (Viviana)

Creating a positive mealtime experience was an important outcome that all participants reported, and which will be explored later. Additionally, participants described how the intervention itself was perceived to be appropriate for participants, and that they felt it was an important way to address their children's feeding difficulties. Participants described feeling comfortable with the strategies identified and comfortable with the intervention process.

> "[The strategies] were good…there's nothing dodgy there, nothing dodgy." (Molly)

> "I think it's appropriate to do that way because if you don't work together, then we're not gonna realize what the target is, and we're not gonna work together to achieve our goals…also making sure that [the goal is] achievable and that it's…specific for Max as well…if I'd been left to my own devices…I would have been like, right, knife and fork by two days time, you know. But you helped guide that." (Molly)

> "All these things we implemented are acceptable to us…and creates the environment for her, where she's happier and she behaves" (Viviana)

There was a sense of a feeling of empowerment in Viviana, as she discussed that when there was joint working between the researcher and the family to identify strategies to try out at home, she noticed that they had known what they needed to change all along, and that they had just needed some support to put these strategies in place.

> “Even some of the strategies came up with you and *we* suggested them…*We knew*…we knew it all along…we are grateful for this experience…because we realize that we knew so much and we could have tried to change things, but we've never done it because there's nobody to say, to guide us.” (Viviana)

Participants reported important and acceptable outcomes from participating in this intervention. All participants described that their children experienced significant and important outcomes from the changes in the mealtime environment.

> “He's more relaxed…at mealtime, he's happier and he's more interested in what we're eating…he's asking for a larger variety of food. He's not just going straight for the junk food. He's asking for things like fruit. That's really good.” (Molly)

> “She's less afraid and less anxious.” (Jiang)

> “I think her meal experience is more pleasant for her because she's not getting the tantrums if she doesn't want, she doesn't want, and we respect that, so we learn to respect that. We still offer her things, but we don't push her.” (Viviana)

Additional to the outcomes reported by participants that they noticed in their children, all participants also reported important and acceptable outcomes that they experienced themselves.

> “I'm more patient with her. I'm more tolerating. I'm understanding her better, I respect her choices more. I don't feel the need to force, and neither the guilt that, oh she's not eating and I'm an awful parent.” (Viviana)

> "I changed because I'm not anxious…so I think it changed the fact I'm confident, comfortable." (Viviana)

> "I think [mealtime has] actually now become more of a bonding experience with Adina, whereas before it wasn't, it was more like a task I had to do." (Jiang)

> "When there's a hiccup and…the meal isn't successful, you can look back and be like, 'Oh yeah, that's why that happened, I understand that'. And if I understand it…I don't get upset with myself. Because I'm like 'OK, well, I'll try and avoid that next time'…So that helps me emotionally as well cause when you don't understand what's going on your child's just refusing to eat anything that you think they need, it's, it's very hard." (Molly)

Importantly, Molly's description about being able to understand what is going on with Max's eating was also described by Jiang and Viviana.

> "I think it's good because we had a combination of different strategies and we can choose the ones that we would use and then there were also different degrees of how easy or difficult it is to implement something and you can sort of test some and see the response, test other than see the response." (Jiang)

> "This intervention for me it's a lifestyle changing event because it's something that we learned about her and we can adopt even to some extent when we travel, it's completely different, but we know how to adapt." (Viviana)

Similarly to Viviana, Molly reported that the strategies they were implementing had become a part of her routine, and something that she naturally does.

> "I've done it enough times to see that it helps…I'm doing them and not realizing that they are strategies…I'm just doing them." (Molly)

Participant Experiences

Participants mostly reported a wide range of things that they enjoyed about participating in this intervention, some things that they did not enjoy, and some suggestions for improvement. An overview of these is provided in Appendix WW. General comments about the things they liked about the process centred around comments about the intervention process and changes they noticed in their children.

> "It's good because it's individualised and tailored towards the family environment and situation, whereas most of the information that is provided to you is generic based on the most common scenario that's encountered…I know it's resource intensive, but you feel it's better because it's tailored towards the situation. So then you're more likely to be concordant with the intervention because it is tailored towards the situation and you wouldn't suggest something that's outside of feasibility." (Jiang)

Importantly, participants also provided comments about the importance of learning to understand why trying new foods was so difficult for their children. The sense from these interviews was that the key factor from participating in this intervention was learning to understand why their children struggled with new or non-preferred foods. This was reported as being helpful to participants and there was a sense that this helped participants experience more positive mealtimes with their children and shift their perceptions of mealtime challenges.

> "It was really helpful to really get down as to all the different factors that influence Max's behaviour when he's eating, and it really helped to understand what he's going through when he's trying to eat a meal. And the layers of complexity surprised me…And I, I forget that the other adults around me haven't done as much learning about this, so sometimes my husband says something like 'ohh he's not eating that because of this'. And I'm thinking 'ohh no, no, no, it's this, this and this.'…I've got strategies that I would like to use and suggest,

> and my husband disagrees with but because he's not done the stuff, so…I wanna tell him a bit more about it and get him on board.” (Molly)
>
> “I think it's changed the experience of feeding Adina…you really can see how there's benefit associated with making changes to the way the feeding experience is for the child…I realised that there's a lot of benefit in…spending time with Adina feeding her…She would rather I be with her during her eating journey than for me to have everything ready in case she melts down… It's a learning process and the observations you made are helpful to persuade me of the benefits of creating a positive environment for the feeding and it translates to a better outcome for all of us.” (Jiang)
>
> “As I said, we discover more about us, about Adina, how to make it better experience…we learn more about our daughter…I was maybe at the beginning, I was hoping that Adina would eat more vegetables…out of this intervention…And then I realized…going slowly with you…each meeting explaining…realise that actually you're not gonna tell me any strategy how to make Adina eat vegetables because you can't, and making me realize *why* you can't, you know I can't make her eat tomatoes and cucumbers and peppers just right now…But it's understanding how, this was the help. Understanding what actually the intervention was about, was analysing her, creating the environment, making it better, see what is disturbing and then being up to her and I think this this was for me the best part.” (Viviana)

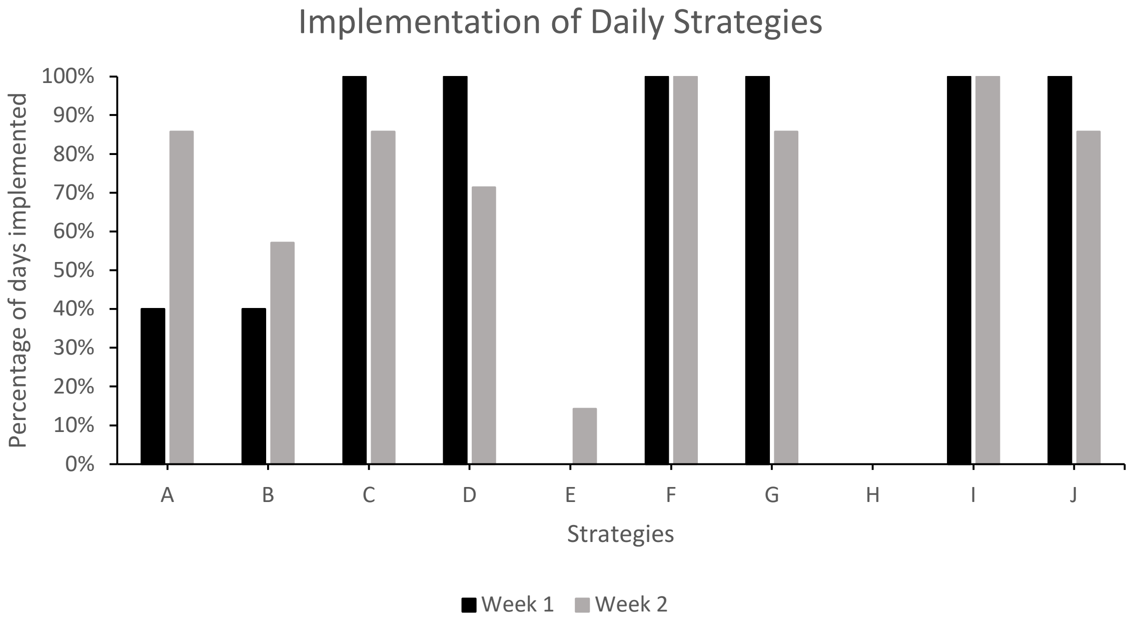
Intervention Implementation

This study and intervention was carried out as it was intended; 100% of sessions were run for both families, and families attended 100% of baseline, intervention, and follow-up sessions. Both families engaged in all the data collection required to a high level, though there were some exceptions which will be discussed later. Family One collected data throughout 81.5% of the intervention stage and 100% of the follow-up stage. Family Two collected data throughout 85.7% of the intervention stage, and 100% of the follow-up stage.

The families also collected data (described previously in Strategy Implementation) on the action plan strategies which they were trying out during the coaching part of the intervention stage. This data showed that both families were implementing the agreed strategies on their respective action plans consistently. Figures 14 and 15 show the percentage of days that Molly implemented daily and occasional strategies on Max’s food refusal action plan. Figures 16 and 17 show the percentage of days that Jiang and Viviana implemented daily and occasional strategies on Adina’s food refusal action plan.

Figure 14

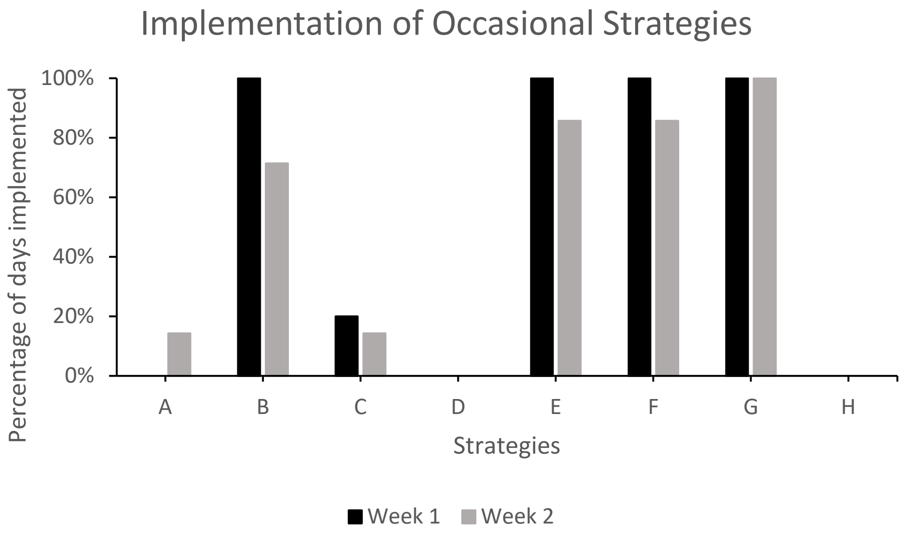
Molly's Implementation of Max's Food Refusal Action Plan Daily Strategies.



Note. **A:** Reduce number of bites presented if ill, tired, full on snacks, daily routine has been interrupted (or let self-feed @ own pace); **B:** Prepare him for interruption in the daily routine; **C:** Sign on door outside TV room; **D:** Scattered attention provided when adult needs to do other things/pay attention elsewhere; **E:** If sister is distressed, wait until calm before presenting food or let self-feed at own pace; **F:** Leave non-preferred food in sight after refusal; **G:** Continue to provide attention but change tone based on what he tries (non-preferred or preferred); **H:** Encourage other adults to praise him when he tries non-p food from them; **I:** Consistent embedded opportunities to self-feed, mixed in spoon-feeding**; J:** Model eating the non-preferred food with positive facial expressions and verbal statements.

Figure 15

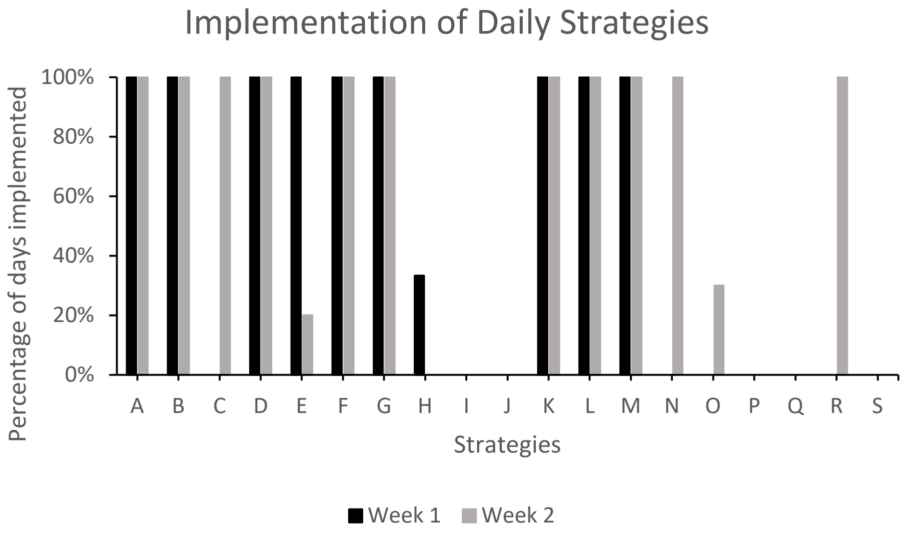
Molly's Implementation of Max's Food Refusal Action Plan Occasional Strategies.



Note. **A:** Try eating in a different setting; **B:** Feed others the same meal; **C:** Someone else offers the food; **D:** Helps prepare the meal; **E:** Turn TV on before comes down for lunch; **F:** Select long video/DVDs to play during lunch; **G:** Opportunity to ask for next bite after refuses food; **H:** Provide special reinforcers when tries non-preferred food (e.g., YouTube sounds cheering, peppa pig cheering, etc.).

Figure 16

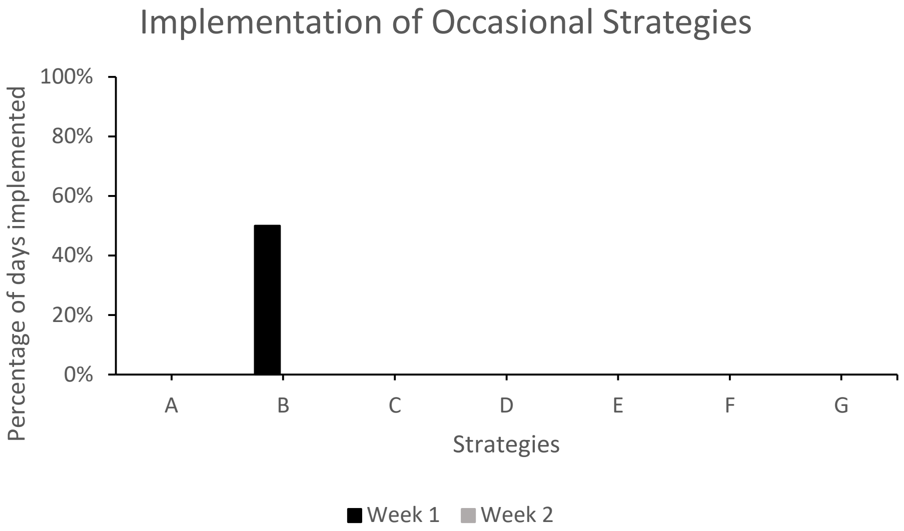
Jiang and Viviana's Implementation of Adina's Food Refusal Action Plan Daily Strategies.



Note. **A:** Following her lead to start eating; **B:** Following her lead to transition out of preferred activity into dinner; **C:** Following her lead to go up in the highchair; **D:** Prepare food in advance; **E:** Sanitising the environment before dinner; **F:** Sporadic attention; **G:** Physically present, **H:** Increase distance between siblings; **I:** Eat the same food as her; **J:** My turn, your turn game; **K:** Ensure preferred foods are available during dinner; **L:** Reminder to eat/take a bite when focused on her videos and not eating; **M:** Avoid creamy foods; **N:** Follow through with 'routines' where possible; **O:** Provide special reinforcers when tries non-preferred food; **P:** De-escalation; **Q:** Continue to provide attention but change tone based on what she tries (non-preferred or preferred); **R:** Encourage placing food on table; **S:** Model eating the non-preferred food with positive facial expressions and verbal statements.

Figure 17

Jiang and Viviana's Implementation of Adina's Food Refusal Action Plan Occasional Strategies.



Note. **A:** Food cut in different shapes; **B:** Round food adjustments; **C:** Helps prepare the meal; **D:** If sister is loud/disruptive, wait until calm before presenting food or let self-feed @ own pace; **E:** Play downloaded favourite video rotation; **F:** Reduce number of bites presented if difficult transition prior to dinner, day less structured, has had poorer sleep than usual; **G:** If food was refused, wait before re-presenting it.

Researcher Fidelity

Additionally, as noted previous, after each session with a family was completed, the researcher completed a self-checklist to ensure that all the necessary components of that session were carried out to ensure consistency in the implementation of the session components across families. For all sessions across stages (i.e., baseline, intervention, and follow-up) for both families, all the session components were implemented 100% of the time by the researcher.

Discussion

The aim of this study was to work with family carers to develop bespoke strategies and coach them through the implementation of these, as part of a behavioural intervention approach for feeding difficulties amongst their child with IDD. The intervention was designed to match the amount of service delivery that might be feasible within the NHS context. The objectives of this study were to: improve the child's behavioural feeding difficulty (e.g. increasing acceptance of target foods); assist families in supporting their child with their feeding difficulty; explore the practicalities of delivering this intervention in a family context; explore families' experiences of participating in this intervention approach; and explore whether this is a socially valid way of providing intervention for behavioural feeding difficulties amongst children with IDD.

The results from this study showed that it was possible to deliver this intervention approach and work with family carers to develop bespoke strategies and coach them through the implementation of these. The observational results showed that there was no improvement in the children's feeding behaviours in relation to increasing consumption of target foods. The self-report measure results suggested some shift in child and parent behaviours, as perceived by parents. The qualitative data suggested some shift for families in their understandings of why their children exhibited feeding difficulties. The results also suggested that parents perceived there to be mixed social validity, highlighting how they found the intervention and outcomes appropriate and acceptable, yet the goal could have been enhanced by focusing more on achieving a positive mealtime experience, rather than solely focusing on increasing their child's consumption of target foods. As such, there was also an interesting finding in relation to reappraising goals and priorities for families that have implications in relation to intervention approaches used within family context for children with IDD exhibiting behavioural feeding difficulties. Each of these findings will be explored independently, followed by a synthesis of results describing the results in relation to each other.

Behavioural Data

The results from this study showed that there was no improvement in the amount of target food consumed by Max and Adina, as represented by the graphical data, thus indicating that the intervention did not produce a change in Max and Adina's feeding behaviours. Most behavioural interventions do demonstrate a significant reduction in behavioural feeding difficulties and increase in target food acceptance (e.g., Cosbey & Muldoon, 2016; Najdowski et al., 2012; Sharp et al., 2011), illustrating a stark difference between the findings of this study and findings from other behavioural intervention feeding literature. It is important to highlight that this study was an initial pilot of this approach, and the current data will provide rich information about how to proceed with this intervention approach, despite having findings that illustrate that no change was observed in the children's feeding behaviours.

Importantly, the graphical data from this study show that undergoing this intervention with a researcher did not decrease any challenging mealtime behaviours for Max and Adina, but crucially, it did not increase their challenging mealtime behaviours. These dependent variables were monitored throughout the study as they represented indicators of distress that were linked to food refusal. For both families, it was determined that when the food refusal escalated (i.e., the children were pushed too much to try a non-preferred food), they would engage in these challenging mealtime behaviours. Thus, these were tracked to monitor that the levels of distress related to trying non-preferred foods stayed low to non-existent throughout the study. These results show that while Max or Adina did not try any of their target foods, their families participating in this intervention did not make anything worse for them by putting them under any distress related to trying non-preferred foods. It was considered that this was likely an important factor in the perceived social validity of the intervention for parents. Continuing to push children to try a food they have refused can be considered to be an EE procedure, and as described previously, implementing EE warrants careful ethical consideration (Tereshko et al., 2021b). A side effect of EE can sometimes be an extinction burst, where there is an increase in the frequency, duration or intensity of the behaviour that is trying to be extinguished (Cooper et al., 2020). Woods and Borrero (2019) explored the frequency of extinction bursts in 10 children who were receiving EE intervention for their food refusal. They found that 30% of the children exhibited extinction bursts but noted these were often short lived. While this is promising, it is important to note that the study was carried out in an intensive six- to eight-week in-patient programme in the US, with the EE intervention being delivered by trained feeding therapist. It is likely that experiencing an extinction burst would be more tolerable and acceptable for trained clinicians than it would be for parents implementing strategies on their own in their homes. As such, it was considered important and significant that the children in this study did not demonstrate an extinction burst, and parents were not subjected to the emotional distress of witnessing a temporary ‘worsening’ in their child’s food refusal.

It is important to highlight as well that the results in this study were variable in relation to acceptance or refusal of the different foods, and that this is likely to be demonstrative of the heterogeneity of feeding difficulties generally. For example, Max ate more other foods at follow up, while Adina reduced her acceptance of other foods throughout the study. Max refused other foods at a similar frequency throughout the study, and Adina’s decreased, though this was not deemed significant because it was already low to begin with. These findings highlight the idiosyncrasies in the presentation of feeding difficulties in each child and are highly representative of the need for an individualised approach for all children exhibiting feeding difficulties. Clearly, Max and Adina’s patterns of acceptance and refusal were different to each other's throughout the study period. This is also commonly seen in the behavioural feeding intervention literature. For example, participants may respond differently to the intervention, and this could result in not seeing a change in the measured behavioural dependent variables (or the same change) or making changes to the intervention that account for the reasons why change might not be occurring for a participant (e.g., Riordan et al., 1984; Stubbs et al., 2018; Wilkins et al., 2014).

BPFAS

Interestingly, although there was no change in Max and Adina's feeding behaviour observed in the collection of observational data, Molly, Jiang, and Viviana's scores on the self-report BPFAS showed a decrease in their perceptions of the occurrence of child and parent behaviours, and whether they perceived these to be a problem. For Molly and Jiang, this change in BPFAS scores reduced so they were no longer clinically significant or significantly higher than the normative mean. For Viviana, her scores on all the BPFAS scores reduced from pre- to post-intervention, however all those that were identified as being clinically significant or significantly higher than the normative mean at pre-intervention, continued to remain so at post-intervention, despite the observed decrease.

These findings indicate some promising shifts in parent's perceptions of child and parent behaviours. They are particularly interesting in light of the lack of observed change in Max and Adina's behaviour throughout the course of the study. While these shifts are promising, it is important to note that self-report measures are open to bias, and it is possible that changes to parents' perceptions of their own and their child's behaviours occurred because they were feeling more positively about their situation, rather than because there were any changes to their own or their child's behaviours. Piazza-Waggoner et al. (2008) compared BPFAS scores with direct observations of mealtime behaviours in young children with cystic fibrosis. They found that some items on the BPFAS appeared to be good proxies for the actual observed behaviour (e.g., length of the meal, child leaving the table, child negotiating, parent coaxing, etc.), while other parent-report items were not supported by the observational data (e.g., crying, tantrums, child refusing food at mealtimes but requesting food at other times, etc.). These findings meant that parent's responses on several, but not all, items could be considered reliable reports of their family mealtimes. This is important to consider as there is some data to support that the BPFAS is a mostly reliable measure (when compared to direct observation data). However, this further highlights a discrepancy between the reported shifts in parents' perceptions of their own and their child's behaviours and the lack of observed behaviour change in the children. It is possible that the shifts identified in this study were not also observed through the behavioural data because the items on the BPFAS did not directly map onto the behavioural targets that were selected in this intervention. For example, there are no specific question on the BPFAS about acceptance or refusal of preferred and non-preferred foods, rather there are 35 scenarios of feeding situations which may or may not indicate a challenging feeding scenario.

It is also important to highlight the variance observed in BPFAS scores from pre- to post-intervention for Jiang and Viviana. Jiang's scores demonstrated a significant shift from pre- to post-intervention, and while Viviana's shifts were very promising, they did not indicate a reduction in scores that indicated these were no longer clinically significant or significantly higher than the normative mean. Although Jiang and Viviana participated in the intervention to the same degree (i.e., they were both present at all sessions together, and neither of them missed a session), they reported different perceived changes from pre- to post-intervention on the BPFAS. This is likely to be indicative of the fact that Jiang and Viviana as individuals may have perceived different aspects of Adina's feeding difficulties to be challenging from each other. This was observed when reviewing their respective answers on the BPFAS and identifying that they were not always in agreement about how often something did or did not occur, and whether it was or was not a problem to them, individually. This variance does not invalidate their scores, rather it highlights the individual nature of perception of behavioural change, and further illustrates the importance of involving all family caregivers in interventions for behavioural feeding difficulties. Clearly, there may be differences in perceptions, and these are a part of the family system, which need to be considered if providing family support for behavioural feeding difficulties.

Qualitative Data

There were some interesting qualitative findings in this study that provided insight to the shifts described for parents. There was also an interesting reappraisal of goals reported by participants, which warrants further consideration and will be discussed in this section.

Firstly, the qualitative data gathered post-intervention provided some insight to the shifts observed on BPFAS results for parents. In the qualitative data, participants described the importance of learning to understand why trying new foods was something their children struggled with. The sense from the interviews was that the key factor for them was learning to understand the range of factors that made their children less likely to eat new or non-preferred foods. Importantly, it appeared that this understanding supported families in experiencing more positive mealtimes with their children and shifting their perceptions of mealtime challenges. Parents reported no longer viewing things as challenges, and rather understanding their children and the complexities of their feeding difficulties. This supports findings from the Parent Study (Chapter Two) that found that understanding why their children's' feeding difficulty was occurring, allowed parents to change their behaviours and attributions, and in turn reduced the impact of the behavioural feeding difficulty.

Additionally, an interesting finding was the reappraisal of goals that participants described. Originally, the goal that was agreed with both families was to increase the amount of food that Max and Adina ate, and this was specific to vegetables, and one protein source (i.e., spaghetti Bolognese) for Max. This was what families described was important to them and what they selected, in combination with the researcher, to target as the goal for this intervention. This is a common goal or target behaviour in the behavioural intervention literature (e.g., Barnhill et al., 2016; Seiverling et al., 2017). Throughout the intervention, as further discussions centred around creating an optimal mealtime environment for Max and Adina, and as families were supported through identifying factors in the environment that made it more likely for Max and Adina to refuse food, it appeared as though a reappraising of goals occurred. While the initial goals of supporting Max and Adina to eat a predetermined set of target foods was not met, it appears that parents in this study reappraised what was important, and they became more focused on creating a more positive mealtime environment for their children. This was an unexpected finding from this study, however it is possible that creating a positive mealtime environment may be more important for families, and is a goal of feeding interventions that may benefit from being clearly defined, measured, and explored going forwards. It is important to interpret these results cautiously, however, as there was a very small sample of participants, such that a formal thematic analysis was not possible. Furthermore, the researcher carrying out the qualitative interviews was the same person as the interventionist throughout the intervention, and a professional working relationship was established with families throughout the course of this study. This means that there may have been issues with participants feeling confident to report negative findings or experiences, or reporting their experiences as being more significant and important than they may have been, due to wanting to show intervention effects.

Recently, Taylor and Taylor (2022) explored eight caregivers' treatment acceptability ratings for a full range of treatment procedures at pre- and post-intervention for behavioural feeding difficulties. They found that all caregivers gave strong ratings to the importance of goals, showing that caregivers unanimously considered that their child's behavioural feeding difficulty was an important area that warranted intervention. Taylor and Taylor's findings supports findings from the Parent Study (Chapter Two) that found that parents reported wanting to feel validated in their feeding concerns, and to have professional recognition that this was an area that they needed support with. Importantly, however, is the fact that Taylor and Taylor (2022) did not explore the social validity of the specific intervention goal itself in their study. As such, the current study contributes to the limited social validity literature for behavioural feeding interventions by highlighting that parents may see achieving a positive mealtime environment as a more important goal than increasing the number of bites or percentage of bite accepted of a target food. Notably, this is not a common goal evident in behavioural feeding interventions. Seiverling et al. (2017) asked parents to identify feeding goals pre-intervention. They asked parents to report whether they had each of 13 possible feeding goals for their children by answering either 'yes' or 'no'. None of the 13 possible feeding goals related to having a positive mealtime experience, rather they mostly focused on increasing food consumption in some form or decreasing challenging mealtime behaviours or medical issues that affected feeding (e.g., increase food variety, increase food texture, increase food volume, resolving reflux related to eating, decreasing vomiting related to eating, etc.). This further highlights the contribution of the identification of the importance of a positive mealtime experience as a potentially important goal for parents in behavioural feeding interventions.

Implementation of the Intervention

While parent involvement in behavioural approaches to feeding difficulties is not common and parent training in behavioural interventions has not been well described in the literature (Aponte et al., 2019), this study showed that it was possible to work with family carers to implement an intervention for feeding difficulties that was rooted in behavioural approaches. This was demonstrated in multiple ways. Firstly, the data showed that it was possible to implement an intervention designed in this way because of the continual engagement of families in this study. Families attended 100% of session in this study and engaged in data collection at home at high levels (>80% of meals during the intervention phase and 100% of meals during the follow-up phase). Additionally, families implemented the food refusal action plan strategies as was planned (see Figures 14-17). This continual engagement indicated that it was possible to work with families in this way. This data is not commonly reported in the behavioural feeding intervention literature but is important to illustrate that parents were able to engage with the intervention. While behavioural feeding intervention studies that do involve parents often report on the procedural fidelity of parents in implementing the intervention outlined (e.g., McCartney et al., 2005; Penrod et al., 2010;

Seiverling et al., 2012), in this study, parents were provided with options of strategies to implement flexibly as and when they were able to, and this did not allow for monitoring procedural fidelity. Despite this, tracking the percentage of days that strategies were tried provided valuable information about where parents were allocating their efforts and allowed for reflective conversations of this, and also provided information of how often parents were engaging with the intervention strategies outlined.

Secondly, the amount of service delivery appeared to be appropriate to deliver all intervention components, as the researcher was able to deliver 100% of all session components for every session. However, Molly and Viviana reported in the qualitative data that having more sessions spread out over more time would have helped. This suggestion from participants would fit in with what most NHS settings would be able to provide, if the clinical sessions were increased from 5 to 6-8 and were delivered over a longer period of time, rather than in weekly sessions over a short period of time. For clinical applications, the only difficulties this would pose would be in NHS settings that were able to offer less than 5 sessions of support. Despite this, all the intended intervention components (i.e., assessment, formulation, parent training, collaborative working, coaching) were delivered to both families. This means that all the data collected from this study can be interpreted as a true result of the test of the intervention model itself, as the intervention was fully carried out as intended.

Synthesis

Overall, this study was an initial pilot of a family intervention for behavioural feeding difficulties amongst children with IDD, that measured behavioural outcomes for children and found that there was no change in the behaviours of the children in this study. Interestingly, the parent self-report and qualitative data suggested some shifts in parent perceptions of the mealtime difficulties experienced, as well as provided information about the importance of parents understanding the complexities involved with their children’s feeding difficulties, and learning to support them in a way that makes their mealtimes a more positive experience for the family. While the behavioural data in this study suggest that the intervention was not effective, there was no measure implemented to capture data directly related to positive mealtime experiences, as this was something reappraised and highlighted throughout the study, rather than an explicit goal of the study and intervention from the outset. Additionally, the behavioural changes in the children and the parents reported by parents on the BPFAS were not behaviours that directly mapped onto the behavioural data that was being collected throughout the study. This means that while families reported changes on the BFPAS, the behavioural data itself was measuring a different aspect of the feeding situation (e.g., frequency of bites accepted or refused). This means that there were methodological limitations related to how the target behaviours were identified, defined, and measured. It was not possible to capture objective behavioural data on target behaviours that captured the changes reported by parents on the BPFAS and in the qualitative interviews, as these target behaviours were not selected on the basis of creating a more positive mealtime environment from the start of the intervention process. Though this is a limitation of this research, the selection of the target behaviours focusing on increasing bites and decreasing refusal in the child's behaviour was selected as the target dependent variable for this study as these are common dependent variables found in the behavioural feeding intervention literature (e.g., Alaimo et al., 2018; Bachmeyer et al., 2009; Didden et al., 1999). Going forth, studies should seek to explore behavioural dimensions of positive mealtime experiences to capture these changes objectively and observationally, as this may be important for families and is a dependent variable that should be explored further in research. Additionally, future research should explore goal setting centred around creating a positive mealtime environment with families.

Strengths

There were a number of strengths of this research. Firstly, there was a rigorous approach taken to the implementation of all sessions with each family by the researcher to ensure that the sessions were implemented consistently across families. For all the sessions, 100% of the necessary components were implemented for both families. This gives confidence that both families received the same intervention approach throughout their participation in this study. Similarly, though there were some difficulties that will be described later, the IOA for the data collected for the different dependent variables was generally high (see IOA section described in Methods above). This gives confidence that the data collected from parents and the researcher were representative of the true value of bites taken or refused that occurred. Thirdly, a fundamental underpinning to this study was the joint or collaborative working approach that the researcher undertook in each session with Molly, and Jiang and Viviana. There were significant efforts made throughout this study to ensure that families were listened to, and all their thoughts and experiences incorporated to the shared understanding of why their children were having difficulties accepting non-preferred foods. As the intervention stage progressed, where necessary, the researcher guided participants gently to reframe their interpretations to the context that the shared understanding was rooted in (i.e., what makes mealtime more unpleasant for Max/Adina, and how can we reduce this?). Fourthly, the qualitative data of participants' experiences shows that all participants described enjoying participating in this intervention research and learning from it. Finally, participants reported that they found the intervention and the outcomes to be important and acceptable to them, illustrating that this work had robust social validity for the participants, despite the improvements in goal selection that were noted (i.e., focusing on creating a positive mealtime experience rather than increasing the number of bites of target food consumed). It is important to note that both Viviana and Jiang reported that they would have preferred the goal at the start to be to create a positive mealtime environment for the family, rather than establishing some bites of a target food with Adina. They did not interpret this as a criticism of the approach, rather it was evident from their descriptions of their experience and the outcomes they viewed that the understanding they gained about creating a positive mealtime for Adina to eat in was the most significant thing for them, and they felt this should be a clearer goal for families from the start.

Limitations

While there are many strengths of this study, there are also some significant limitations to address. Firstly, was the difficulty experienced by Jiang in quantifying the number of bites that Adina took. Adina took bites of food that were inconsistent; one bite could be roughly a 1-inch cube size of chicken nugget, or half of a ham slice (where this was stuffed into her mouth or similar). The bites taken for Max were more consistently sized, whereas Adina's accepted foods were varied, like chips that she would break into small pieces and eat or the large strips of ham in one bite, etc. This demonstrates a significant limitation to the quantification of the number of bites that Adina consumed. Secondly, Adina had long dinnertimes, which meant that it was difficult to obtain high rates of behaviour for any of the dependent variables because meals were so long as she would occasionally watch videos or drink milk for an extended period of time and not take bites. This was not an issue with Max's data. Similarly, there were issues with the IOA data collected by Jiang in two situations (the average IOA of acceptance of target food during the follow-up stage, and the average IOA of refusal of preferred food during the intervention stage). In these two situations, the average IOA for the data in that condition was lower than the acceptable standard outlined in this study. This means that there is less confidence that the data collected from Family Two, that was not checked and amended by the researcher, was representative of the true value of bites taken or refused that occurred in those conditions, for those dependent variables. There was a similar issue with the baseline data for average IOA of refusal of preferred food for Family One. In this situation the average IOA of refusal of preferred food during the baseline stage was lower than the acceptable standard outlined in this study. This means that there is less confidence that the data collected for this variable in this stage was representative of the true value of bites of preferred food refused by Max. Importantly, for data related to bites refused, irrespective of the category (i.e., preferred, other, target), it was significantly easier to obtain lower IOA because there were less opportunities for refusal than there were for acceptance. For example, if there were two refusals of preferred food in one mealtime, and one was missed by an observer, the IOA was reduced down to 50%, without any opportunities to raise the agreement percentage. Therefore, IOA for all variables related to food refusal needs to be interpreted in this context as well.

Fourthly, while it was positive that participants engaged with all the sessions, completed all the necessary data collection, and completed all the activities throughout, this means that the engagement demonstrated by participants in this study shows the best possible scenario of research, and changes in the children's behavioural feeding difficulties were still not observed, indicating that this intervention did not work and warrants changes to the intervention and research design if it were to be investigated further in the future. Additionally, full engagement is not likely to be the experience of clinicians working clinically with families (see Chapter Four), . It is important that this research is replicated going forth with participants from demographics that may be harder to reach or engage with (i.e., families without access to internet, with less flexibility around availability, etc.), and obtain qualitative data about what helps and what does not help families from these backgrounds that may be less likely to engage with clinical work. Alongside this, the participants in this study were clearly highly educated. In both families, one participant was a doctor, and in the case of one family, one of these doctors was also a researcher. These results must be interpreted in this context, as it is highly likely that the intervention would have different results and engagement if working with a different population (i.e., families with less education, less understanding about research, etc.).

Next, it was clear that the period of implementing strategies and doing the follow-up was too short to see any real difference in the children's feeding. The strategies developed between the researcher and the family were only applied for five weeks, and this is not enough time to see change with the type of intervention approach taken (i.e., antecedent- and reinforcement-based). The behavioural interventions in the literature for feeding difficulties which use consequence-based procedures like EE, have been reported to run over the course of a range of time periods, from as little as four to five days of intensive treatment (Pizzo et al., 2009) to as long as four to eight months (de Moor et al., 2007), though many report number of sessions rather than intervention duration (e.g., LaRue et al., 2011; Wilkins et al., 2014). Some demonstrations of behavioural intervention for feeding difficulties that focus on antecedent approaches rather than consequence-based approaches have been reported to last between three to six and a half months (Cosbey & Muldoon, 2017; Gentry & Luiselli, 2008), suggesting that longer may be needed to implement antecedent-based approaches for feeding difficulties. Similar difficulties in intervention duration exist for behavioural interventions focused on antecedent approaches, where many only report number of sessions (e.g., Hagopian et al., 1996; Hodges et al., 2017).

It is also not possible to discern whether the changes reported or seen in this study are reflective of the intervention itself or due to having contact with a researcher who sought to interact with parents in a kind, understanding, encouraging, and non-judgmental demeanour throughout. It is possible that the families reported experiencing a positive change in their mealtime environment simply by virtue of having had objective, professional input on what was observed during their mealtimes, and by knowing that there was somebody that they could speak to about the mealtime challenges they faced, and who was validating these struggles through observing their mealtimes and engaging in conversations about their mealtime challenges. Finally, the improvements reported in Adina and Max's behaviour could be due to maturation effects, and not due to the intervention, thus it is important to be cautious when interpreting the results of this study, as it was run over the course of two to three months, and as such could have captured natural changes in the children's behaviours due to maturation.

Finally, the study design was primarily a single-case design in the form of a delayed multiple-baseline design. There were limitations based on the design related to the number of families in the study. Two families, or two tiers in a multiple-baseline design is not considered sufficient to demonstrate a functional relation. While the results from this study have not been interpreted as demonstrating a functional relation between changes in the dependent variables and the implementation of the independent variable, this study was originally designed to demonstrate this effect, and having only two participants in a multiple-baseline design is not sufficiently rigorous of a design to illustrate the presence of a functional relation. There were significant time and resource limitations (described previously) which meant that another family could not be recruited to participate, as the intervention was intensive and the researcher was unable to work with three families at the same time, in a staggered fashion, as would have been necessary for a delayed multiple-baseline design with three families.

Implications for Research

This study provides many implications to consider for research going forwards. It was clear that in this study which was carried out in home settings, it was difficult to quantify bite sizes for Adina as her bite sizes were inconsistent. Future research should seek to explore ways to quantify bite sizes better when delivering interventions in home settings, with parents as primary data collectors. Some previous behavioural feeding intervention literature carried out in home settings with parents as implementers of the intervention have provided very extensive operational definitions to quantify the number of bites taken by the children (e.g., Werle et al., 1993), however the data collectors were researchers and a graduate assistant, indicating that this level of data collection was likely to be more complex for parents, especially in a mealtime setting when families are also focused on feeding their children. Additionally, for Adina the topography of her food refusal changed throughout the course of the intervention to a topography that was deemed socially acceptable for her parents (i.e., moving the food off her tray and onto the table rather than throwing the food). Future research should seek to define food refusal in ways that allows for changes in topography of food refusal to be monitored, if meaningful and important for the family. This was a big, missed change in this study that could have been quantified and captured in the behavioural data if throwing food had been conceptualised as part of the response class of food refusal, but data collected separately for this.

Future research should seek to embed more training checks as part of the intervention itself if parents are the primary data collectors to ensure that fidelity is high for all dependent variables across all conditions for all families, as this study found that this was mostly highly, but on occasion there were some variables that were inconsistent and there were no opportunities for on-going training as this was not part of the research design. These inconsistencies were noted and discussed with parents, however ongoing training on data collection for variables where the IOA is lower than the accepted standard would be important moving forwards. This is significant as data could be compromised otherwise, and confidence in the findings may be low. In a recent systematic review of parent training in behavioural interventions for feeding difficulties, Aponte et al. (2019) found that only 25% of included studies reported parent procedural fidelity in the implementation of the intervention, and there was no data extracted in relation to parental fidelity in studies where parents were the primary data collectors, indicating that this is an area warrants further exploration. Some studies have reported IOA between parents and researchers, finding that IOA was very high (i.e., on average >97%; Gentry & Luiselli, 2008; Najdowski et al., 2010), indicating that it is possible for parents to achieve high levels of agreement with researchers when they are collecting data.

From this study, it was evident that the amount of work to carry out a family feeding intervention is significant and the researcher experienced difficulties carrying out this work independently. It is important for research going forwards to be run by a team or multiple researchers, as it is important for work to be checked, supervised, or reviewed by an additional researcher to ensure that nothing is missed and the standard of the clinical work is high. This was something that was implemented to a degree in the form of a supervisor (NG) reviewing clinical work and providing feedback and input, however this intervention was designed such that it progressed very quickly, and it was not always possible to ensure all work was reviewed with a supervisor. Ideally, two or more researchers are needed to work together to carry out these interventions for research purposes. It would also be important going forth to ensure that this work is carried out as part of a multidisciplinary team, as this is recognised as best practice for behavioural feeding difficulties (Lukens & Silverman, 2014; Sharp et al., 2010; Sharp et al., 2017).

Additionally, it is important to explore going forwards if the changes reported by parents (gathered from the BFPAS and the qualitative data) are due to the intervention itself or due to having contact with *someone*. It was considered that when families are so desperate for support and change, having any kind of involvement is better than nothing, so things may naturally feel like they are improving, when there may not be any real behavioural change. Future research should seek to explore this, potentially through a comparison study, comparing a group with contact with a non-judgmental, kind, empathetic professional and another group that has gone through a family feeding intervention to determine whether the changes reported are due to the intervention, or contact with a helpful and supportive individual. Finally, future research should seek to carry out intervention research that focuses on shared goal selection and explores the effectiveness of intervention support that focuses on creating positive mealtime environments. It would also be important for future research to operationally define and measure changes in the mealtime environment to quantify a change in increased positive mealtime environments or experiences, as families described in this study, but the relevant data was not collected to capture this change.

Implications for Clinical Practice

This study also provides many implications for clinical practice going forwards. Primarily, as found in this study, it is clearly important for families to establish a positive mealtime experience. Therefore, intervention goals could potentially consider being not just centred around increasing or establishing consumption of a new food as in common in the behavioural feeding literature (e.g., Barnhill et al., 2016; Seiverling et al., 2017), but also explicitly to work on creating a positive mealtime environment. This is important to ensure that the clinical work that is carried out has high social validity for families. Very little research has been carried out specifically to explore social validity in behavioural feeding interventions, and while it is clear that parents strongly rate the importance of focusing on their child’s behavioural feeding difficulty (Taylor & Taylor, 2022), it is not clear what specifically this means for families. As mentioned, Seiverling et al. (2017) asked parents to identify feeding goals pre-intervention, and provided 13 options, none of which related to having a positive mealtime experience. It would appear that this goal may not be currently prioritised, and clinicians should be aware of this to support families in exploring this socially valid goal and tailoring their interventions in this way.

A key implication for clinical practice is that working with families is key to getting buy in from families (Bradshaw et al., 2017). The premise for having buy in from families is to ensure that families adhere to the intervention strategies when they are implementing them on their own (Kasari et al., 2010). Importantly, this should be considered as being a continual and dynamic process that centres around ensuring that all parties are on the same page (see findings from Chapter Four). This is part of the role of the clinician delivering an intervention, and clinicians need to be aware of this and prepare for this when supporting families. This may mean that clinicians working to support families in this situation may need specific training provided for this, or this should be a part of inductions for new staff members working in this capacity to ensure they are aware of this and prepared for this. Previous research has also involved parents in the formulation and intervention process and demonstrated that there were significantly larger reductions in the behaviours targeted when a parent-enhanced approach to intervention (i.e., involvement in formulation, intervention development, and participation in intervention sessions) was taken (Reynolds et al., 2013). Additionally, formulations have been used to guide intervention development in other research areas (i.e., sleep research), and parents have been reported to be involved in the assessment and formulation process, with researchers additionally reviewing the formulation and intervention plans with families to ensure their understanding and commitment to the implementation of the intervention plan (McLay et al., 2018). Clearly, involving parents on a continual basis in the assessment, formulation and intervention process is important, and this process is continual and dynamic, meaning that it may be important to review with parents to ensure they understand and are still ‘on the same page’ as the researchers (e.g., McLay et al., 2018).

Additionally, it is likely that the pace at which this intervention was delivered was too fast. In clinical practice, it may be important to work at a slightly slower pace during the assessment to creating an action plan meetings to ensure that families have the opportunity to develop and maintain this shared understanding with the interventionist. Following this, it may be important for meetings to be spaced out further during the implementation for the coaching portion of the intervention to be carried out over a longer period. This might also allow for a skills-building component to be brought in for the children exhibiting behavioural feeding difficulties, as this might have furthered the constructional nature of the intervention approach (Goldiamond, 1974; Gore et al., 2013). Unfortunately, it was not possible to add in for this study as there was not enough time, but if this was delivered over a longer period of time, then this would be possible and important to add into families’ action plans.

Carrying out this study also took a lot of clinical hours. The researcher calculated the amount of time spent on delivering the intervention and came to a conservative conclusion that the amount of work amounted to about 130 hours. This is very important to note as it highlights the amount of clinician time that may be needed to carry out feeding interventions in family contexts using this approach. Clinicians delivering support for children with IDD exhibiting behavioural feeding difficulties and their families should be aware of the amount of work that these interventions take, and it would be important to raise awareness to clinical commissioners of the need for more clinician time allocated to supporting children with IDD exhibiting behavioural feeding difficulties and their families, as this is likely to need more time than what is most likely provided to clinicians currently. This is also important to highlight given that one of the main reasons why allied health professionals leave the NHS is due to excessive workload, pressure, or stress (Loan-Clarke et al., 2010). Clinicians have previously described the pressures of their clinical caseloads (see Chapter

Four), indicating that it is possible they do not have sufficient time to provide support or intervention for behavioural feeding difficulties as these likely require.

Finally, an important implication for clinical practice arising from this study is that helping families understand why their child's feeding difficulties are happening may enable them to continue to support their child better, and this could be a helpful focus in clinical work. When parents can identify why their child's behaviour is occurring, they gain important insights in relation to how they may be able to change these behaviours (Park et al., 2011). Families in this study learned how to do this, identify environmental events that made eating and mealtimes more aversive for their children, and how to break down those patterns such that their children had a more supportive mealtime environment. It is anticipated that this may enable parents to continue to support their child in the long-term with their eating as they have learned the skills to identify patterns that make it less likely for their children to eat, and how to set up the environment to prevent these triggering events from occurring. This is something that families may be able to take with them going forward and apply to new situations. Some research has also shown that when parents are supported in developing functional assessment skills (i.e., identifying why their child's behaviour is occurring), they can be very independent in implementing strategies to address their child's challenging behaviour (Frea & Hepburn, 1999), further highlighting the importance of supporting families to understand why their child is refusing food, so they may be able to address their child's behavioural feeding difficulty at home, on their own. Clinical practice might consider supporting families with this understanding and the practical skills of learning how to identify patterns and break them down is a focus of the clinical work as this may empower parents and may give them the skills to be able to move forward with their child's eating independently. Finally, further research is warranted to determine if a collaborative, non-aversive, community-based intervention approach can effectively improve behavioural feeding difficulties amongst children with IDD.

Conclusion

In conclusion, the findings from this study showed that this intervention did not produce a change in the behavioural targets. While there was some data to suggest promising shifts in parental perceptions of their child's behaviours and their own behaviours from the BPFAS and qualitative data, this was not observed as changes in the behavioural data. As discussed, it is likely that these changes were not observed in the behavioural data due to limitations of the target behaviours that data was collected on, and the fact that these did not map onto the BPFAS items directly, as they were measuring different things. Importantly, it was decided to collect behavioural data designed to capture changes in the acceptance and refusal of food, as this is commonly what is measured in the behavioural interventions for behavioural feeding difficulties. It was determined that going forwards, targeting, and measuring a positive mealtime environment should be researched further. It may also be important to explore goal selection around creating a positive mealtime environment for families. When supporting families, it is clearly important to support them with understanding why their child's feeding difficulty is occurring, and crucially, teaching families how to identify environmental events that are likely to make food and the mealtime environment less pleasant for their children and reduce how likely they will be to try new or different foods. This may support family empowerment and provide them with the skills to support their child with their feeding in the long-term.

Finally, this intervention approach varied significantly to how the usual behavioural interventions for feeding difficulties are reported in the literature. These are usually delivered in clinic settings, by researchers or experienced behaviour analysts, and do not often report including parents (e.g., Milnes et al., 2019; Vaz et al., 2011; Vaz et al., 2012). Additionally, the current interventions for behavioural feeding difficulties primarily focus on consequence-based procedures like EE, though there is some more recent literature that is focused on solely antecedent and non-aversive, reinforcement-based procedures. The current intervention varied to this as it took a primarily antecedent-based approach, aiming to reduce the aversiveness of the environment and mealtime situation for the children, with the premise that this would provide them with the most supportive environment in which they could eat. This approach is significantly different to the current approaches used in the literature that primarily focus on consequence-based procedures (i.e., reinforcement, extinction).

Another difference was the conceptualisation of the assessment process as part of the intervention process. In the behavioural feeding literature, the intervention process is the period of time in which behavioural strategies are applied to a child’s behaviour (e.g., Ahearn, 2003; Dawson et al., 2003; Dempsey et al., 2011). The assessment process may be reported on, but it is not usually considered part of the intervention. This study took the approach of considering the assessment process to be part of the intervention process, as it was rooted in the process of developing a shared understanding and the assessment process was a collaborative one, in which a shared understanding was developed. Additionally, the focus on parent empowerment and coaching also varied from the current interventions in the feeding literature. While this may be a component of the interventions that is not reported in the research, it was a central focus of this study and something that was directly built into and reported on as part of the intervention process. Finally, the current intervention literature for behavioural feeding difficulty does not often collect data related to social validity, despite the prominence of procedures like EE being used and parents not often being involved. This is significant as there is not much data related to how families of children with IDD exhibiting behavioural feeding difficulties may find the interventions their children receive. This is surprising for behavioural interventions given that social validity of the work carried out should be part of the process of evaluating interventions. Clearly, the intervention in this study has varied starkly from the interventions in the behavioural feeding literature. This study has provided insights into different approaches for behavioural feeding difficulties amongst children with IDD and their families that may be more appropriate or suited for family contexts, and the findings provide interesting areas for future research to continue to develop contextual and supportive interventions for children with IDD exhibiting behavioural feeding difficulties and their families.

Chapter Seven General Discussion and Concluding Comments

Chapter Overview

This chapter will recap and synthesise the findings from the thesis in relation to the overall aim which was to investigate parent and practitioners' experiences of behavioural feeding difficulties and related supports and explore interventions for behavioural feeding difficulties amongst children with intellectual and developmental disabilities (IDD). A summary of the data in this thesis that addressed the thesis aims and research questions will be presented, along with a discussion of the contribution of these findings to the field. Following this, the overall strengths and limitations of this thesis in relation to the thesis aims will also be discussed and concluding with a discussion about implications for clinical practice and research and future directions.

Summary of Main Findings in Relation to the Thesis Aim

The aim of this thesis was to investigate parent and practitioners' experiences of behavioural feeding difficulties and related supports, and explore interventions for behavioural feeding difficulties amongst children with IDD. There were three research questions that guided this thesis, and multiple studies were carried out and described, which contributed to the overall aim of the thesis and the specific research questions. As such, the following discussion will summarise findings from each chapter in relation their contribution to the specific thesis research questions.

Stakeholders' Experiences and Understandings of Behavioural Feeding Difficulties Amongst Children with IDD

This thesis found that parent experiences of behavioural feeding difficulties were largely congruent, with some individual differences related to specific situations, and there appeared to be an important role of understanding behavioural feeding difficulties for stakeholders. These thesis findings will be discussed in this section, along with a discussion of the contributions of these findings to the field.

Congruent Parent Experiences

The impacts of behavioural feeding difficulties experienced by parent and families of children with IDD were explored across several chapters. Firstly, this was introduced briefly in Chapter One, where it was highlighted that the current literature shows that parents of children with behavioural feeding difficulties experience higher stress and more caregiver-related stress (Fishbein et al., 2014; Martin et al., 2013; Silverman et al., 2021). Some qualitative literature describing the impact of behavioural feeding difficulties on parents of children with IDD was also introduced in this chapter (e.g., Estrem et al., 2016; Estrem et al., 2018; Suarez et al., 2014). The first empirical study in this PhD explored in depth the experiences of parents of children with IDD in England exhibiting behavioural feeding difficulties (Chapter Two) and this was followed by a Systematic Review and Meta-Synthesis (Chapter Three) of the wider (i.e., not UK-specific) qualitative literature related to family experiences of or reactions to behavioural feeding difficulties in their children with IDD. It was clear from these three chapters that parents experience a variety of significant impacts as a result of their children's behavioural feeding difficulties. These impacts varied, but generally related to impacts to the child themselves, impacts to parents, impacts to the wider family, concerns for the future, the impact of support received for behavioural feeding difficulties and lack thereof, difficulties to daily life, and families letting go of their ideas of what family mealtimes would look like (Chapters Two and Three). The wider literature also highlighted the impact of behavioural feeding difficulties on family stress, showing that parents of children with behavioural feeding difficulties exhibit higher stress than parents of children without behavioural feeding difficulties (Fishbein et al., 2014; Martin et al., 2013; Silverman et al., 2021).

Interestingly, the findings from the Systematic Review and Meta-Synthesis (Chapter Three) illustrated that the experiences described by parents were largely congruent, meaning that while there were some individual differences of specific experiences, generally, parents were reporting similar experiences and impacts of behavioural feeding difficulties. It was clear that all parents struggle with behavioural feeding difficulties, they all have to find ways to cope, and it appeared that the overwhelming majority of parents struggled with support in one way or another. The synthesis also showed that the parents that appeared to overcome the impacts of behavioural feeding difficulties discussed learning to understand and accept their child's feeding situation (this will be explored in depth in the following section; The Role of Understanding).

The findings described contribute to the overall literature of parental experiences of behavioural feeding difficulties amongst parents of children with IDD by providing the first in-depth exploration of the parental experience in the UK context, and providing a synthesis of qualitative literature on this topic, which has illustrated the largely similar experience of impacts and difficulties obtaining support (with some variation in specific support experience, which will be explored further below) that families of children with IDD experience.

The Role of Understanding

Throughout the empirical work in this thesis, it became evident that understanding why their child's behavioural feeding difficulty was occurring or continuing to occur was important for families and possibly had a role in mitigating impacts and in the intervention process. Findings from interviews with parents (Chapter Two) demonstrated that parents of children exhibiting behavioural feeding difficulties had varied understandings of why their child was struggling with food. Usually, parents reported understanding that a range of factors contributed to this struggle, and while some parents were acutely aware that there needed to be very clear conditions for their children to eat, they were unlikely to be able to identify *all* of the contributing factors. This may be important and parents may require support to develop a complete picture of their child's feeding struggle.

Additionally, it appeared that understanding may mitigate the impact of behavioural feeding difficulties when this changed parents' attributions or mealtime behaviours (Chapter Two), and there were descriptions in the literature of understanding supporting acceptance of their child's feeding situations which was described as helping parents better support their children's eating needs (Chapter Three). The latter finding also aligned with previous findings (Chapter Two) that families need and look for ways to understand their child's behavioural feeding difficulty and this changes the way that they support their children. Understanding appeared to play a significant role in helping parents be more supportive of their children with their feeding. The data from this thesis would suggest that understanding and accepting their children is likely to be important for parents' well-being as this appeared to provide parents with a sense of relief or peace about their child's feeding situation and let go of guilt related to this (Chapter Two).

From the interviews with NHS Clinicians (Chapter Four), it was clear that they were aware of the importance of understanding why behavioural feeding difficulties were occurring, however they highlighted that this understanding needs to be shared by parents and clinicians. From these interviews, it appeared that one of the key factors in supporting these children and their families was through developing a shared understanding of the child's presenting behavioural feeding difficulty with the family. This is important, as it was clear from the interviews with parents (Chapter Two) that they were not likely to identify the full range of factors that influenced why their children exhibited these difficulties. Clinicians play a key role in the intervention process by supporting families through the development of this comprehensive and contextual understanding and ensuring that this understanding is shared, in order to facilitate family work (Chapter Four).

Supporting parents with the development of this comprehensive understanding was implicitly built into the intervention delivered in Chapter Six with the focus on collaborative working through the assessment and formulation processes. This was not something that was explicitly measured as part of the research because supporting parents with this understanding is considered to be good practice and should be done in all behavioural work. Behavioural work should be guided by a functional assessment (O'Neill et al., 2015) and this often involves some form of formulation process that synthesises the information gathered and uses that to inform an intervention (Hastings et al., 2013). While this is known, the assessment and formulation process in the behavioural feeding intervention literature is not often reported on in detail (e.g., Gentry & Luiselli, 2008, etc.; see Gale et al., 2011 for a detailed example of a functional assessment in behavioural feeding interventions). In the case of the Family Feeding Interventions in this thesis, the role of understanding was an implicit component of the intervention but was referenced to some extent in relation to collaborative working (Chapter Five).

Interestingly, despite parents' understanding of their child's behavioural feeding difficulty not being directly measured pre- and post-intervention, qualitative data gathered after families underwent the entire intervention process with the researcher suggested that there was some shift in the understanding parents had about their child's behavioural feeding difficulties. Parents described how important and meaningful it was for them to understand why it was hard for their children to try new foods. They described how they no longer viewed their child's behaviours as inordinately challenging, but rather accepted that this was how their child ate. This understanding seemed to support them in having more positive mealtimes. Despite this, it is important to note that there were many limitations to this study (see Limitations Section, Chapter Six) which must be considered, and ultimately render these preliminary findings.

Additionally, as the findings from this thesis indicate that parents' understandings of their child's behavioural feeding difficulty was important, approaches like cognitive behavioural therapy (CBT) or acceptance and commitment therapy (ACT) may also be relevant when supporting parents of children with IDDs exhibiting behavioural feeding difficulties. A previous review of the literature has indicated that cognitive behaviour interventions have been effective in reducing stress for parents of children with IDDs (Hastings & Beck, 2004). Additionally, mindfulness-based interventions have been shown to produce medium to large effect sizes in relation to reducing parental depression, anxiety, and distress and improving life satisfaction, parental well-being and self-compassion (Neece & Lima, 2016). Recently, Byrne et al. (2021) carried out a systematic review of the use of ACT in supporting parents, and many of the included studies focused on parents of children with IDDs. The review suggests that parenting interventions informed by ACT are effective in treating a range of difficulties exhibited by the children, and the results indicated that ACT supported parents in adjusting to raising an autistic child. This indicates the value of cognition- or mindfulness-based interventions for parents of children with IDD, which may be relevant for behavioural feeding difficulties given the clear reported importance of parental understanding and acceptance.

The findings described contribute to the overall literature of stakeholders' understandings of behavioural feeding difficulties amongst parents of children with IDD by detailing out in a grounded theory model of the impact of feeding difficulties on families and the role of understanding. This study's contribution was related to the reported power of understanding and the potential importance of this for families, which may be important to consider for interventions for feeding difficulties. Additionally, this thesis provided insight to the role of clinicians in supporting families with developing this understanding, and the importance of this understanding being shared. The focus on developing a shared understanding was present in Chapter Six in the form of stakeholder participation and collaborative working (Chapter Five) and produced some interesting results in relation to the suggested change in attributions, which is an area that warrants further exploration in research.

Stakeholders' Experiences of Support or Intervention for Behavioural Feeding Difficulties Amongst Children with IDD

This thesis provided interesting insight to stakeholder experiences of support or intervention for behavioural feeding difficulties amongst children with IDD. Families largely experienced difficulties receiving support for behavioural feeding difficulties, while their individual experiences of support varied. The clinician perspective on the challenges of delivering interventions was explored and yielded a consideration of the complexity of support required for behavioural feeding difficulties. Additionally, the goals of feeding interventions may be important to consider. These thesis findings will be discussed in this section, along with a discussion of the contributions of these findings to the field.

Difficulties Receiving and Delivering Support

From this thesis it was clear that lots of parents and families report struggling with support for their child's behavioural feeding difficulties. This has also been reported in the wider challenging behaviour literature (e.g., Griffith & Hastings, 2014). It is clear that difficulties with support are not isolated experiences, as families of children with IDD exhibiting behavioural feeding difficulties were largely reporting struggles with access to support, or receiving the right kind of support (e.g., Estrem et al., 2016; Parr et al., 2021; Rogers et al., 2012). There were individual differences in the specific situations reported, but the overall experience was largely congruent across parent and family reports explored in this thesis. This highlights the need to provide adequate support for children with IDD exhibiting behavioural feeding difficulties and their families. While this is clearly an area of priority, in the context of the UK, there appear to be systemic barriers to supporting children with behavioural feeding difficulties (Chapter Four), which relate to a gap in the service provided by the NHS, not having clarity in terms of service provision, and not having specific commissioning and funding to provide this support (Chapter Four). Findings from qualitative interviews of NHS clinicians delivering this support found that participants reported a notable gap in the service provided by the NHS, where children with these feeding difficulties did not have a specific service or provider that clearly provided support to them and their families. Participants in this study also reported not knowing who was supposed to provide this support (i.e., speech and language therapists, OTs, dietitians, etc.) and needing clarity in this area for these children to receive the appropriate support. They also reported issues with commissioning and funding, and the need for the commissioning to reflect the range of feeding difficulties they encountered in practice (i.e., dysphagia, behavioural feeding difficulties) rather than restrict them to only dysphagia, and increased funding to be able to provide specialised supports for behavioural feeding difficulties (e.g., parent group workshops, sequential-oral-sensory approach interventions, etc.). These systemic barriers mean it may be difficult for families in the UK to access support for behavioural feeding difficulties through the NHS. Families having difficulties accessing support or intervention through the NHS was also reported by parents in the qualitative study of parent experiences (Chapter Two). This thesis contributes to the understanding of the difficulties experienced by families in England of receiving support through the NHS for behavioural feeding difficulties, and the difficulties experienced by the clinicians that deliver this support in the NHS, like systemic barriers. These experiences are important to understand as they may highlight areas that need to be addressed or developed further in relation to supporting children with IDD exhibiting behavioural feeding difficulties and their families.

Duality of "Us" and "Them"

Data from this thesis described how while the parental experience is largely congruent, there are some individual differences in some situations, one of which is the area of support received (Chapters Two and Three). Some parents experience good supports, and others do not, but the general experience of having difficulties *obtaining* support is shared (Chapters Two and Three). Data from this thesis suggests that the supports received by parents are often not a positive experience that parents find to be helpful to them and their families' needs (Chapters Two and Three). Interestingly, findings from interviews with clinicians supporting this population in the NHS suggested that the nature of family work is sometimes perceived as challenging, or a barrier to their intervention work (Chapter Four). There was an interesting juxtaposition reported from NHS clinicians in relation to the support or intervention they provide for children with IDD exhibiting behavioural feeding difficulties. They reported recognising the importance of parents as intervention agents, collaborative working, person-centred approaches, and individualisation of interventions as key factors needed for optimal interventions for behavioural feeding difficulties yet noted that families could be difficult to work with. There appeared to be a risky circular phenomenon here which may be important to address to avoid a breakdown in the working relationship. It was considered that this juxtaposition could risk feelings of duality of "us" versus "them" rather than fostering a sense of "us" when working with families and trying to establish collaborative working (noted by NHS clinicians as being a key part of delivering support for behavioural feeding difficulties; Chapter Four). This could also pose issues with parent ‘buy in’, which centres around ensuring that families adhere to intervention strategies when they are implementing them on their own (Kasari et al., 2010). It is possible that without ‘buy in’ it might be less likely that parents would implement interventions suggested by a clinician, and ultimately result in the child not receiving appropriate support. This was considered a main finding to highlight in this thesis because of the potential risk of working relationship breakdown that this may pose. There are also additional considerations which limit the support that clinicians are able to provide, namely systemic barriers (Chapter Four). These may further compound the difficulties clinicians experience when delivering feeding support and may also compound difficulties faced in relation to family work. Clearly, supporting this population is complex, and clinicians face many challenges, including managing sensitive balances (e.g., supporting families, facing difficulties with family work, and systemic barriers to delivering support). This thesis contributed to the literature by detailing these nuanced interactions and challenges experienced by clinicians that support children with IDD exhibiting behavioural feeding difficulties in the UK – an area which has not been well-explored.

Feeding Intervention Goals

One main finding from the research carried out in this thesis was unexpected and related to the goals selected in behavioural interventions for behavioural feeding difficulties. As discussed previously (Chapter Five, Chapter Six), most of the current behavioural feeding intervention literature is about making changes in the child’s behaviour (e.g., reducing the number of food refusals, increasing the amount of food consumed; e.g., Cosbey & Muldoon, 2016; Nadjowski et al., 2012; Sharp et al., 2011). As such, it was considered that this would be an appropriate dependent variable to target for change in the Family Feeding Intervention Study (Chapter Six). Increasing the amount of non-preferred foods consumed and decreasing the number of food refusals was the explicit goal of these interventions, and this is what was measured in this study. However, the findings suggested that these goals may not be perceived to be the most important to families after going through the intervention process, this will be explored in this section.

At the start of this study, families described that it was important for them that their child consume different kinds of food, which included specifically vegetables and in the case of Max, a protein source. However, as the intervention went on and discussions with families in the intervention sessions centred around creating a positive mealtime environment for the child to increase their likelihood of accepting non-preferred foods (or food in general in the case of Adina as she was inconsistent even with her preferred foods), it appeared that families reappraised their goals. Clearly, this shift in goals for parents in this way was unexpected. It is possible that creating a positive mealtime environment may be more important for families than increasing the amount of food consumed or the number of bites taken.

Some of the only research into goal selection for behavioural feeding interventions was Seiverling et al. (2017) that asked parents to identify their intervention goals pre- and post-intervention. Of the 13 options parents were provided, none centred specifically around creating a positive mealtime environment for the child. It is not clear how behavioural researchers have arrived at targeting an increase in food consumed and decrease in food refusal as the dependent variables of focus, whether these have been arrived at as a result of a collaborative process with parents, and why this has persisted in the behaviour analytic literature with little expansion into exploring the family mealtime environment. This is surprising given the recognised importance in behaviour analysis of the role of the environment on behaviour (Skinner, 1965; Cooper et al., 2020). It is known that behavioural research has a publication bias (e.g., Sham & Smith, 2014; Tincani & Travers, 2019), so it is possible that other researchers have attempted to focus on this goal but have seen no change in the behaviour (as in this study, Chapter Six) and the work has remained unpublished. Additionally, it is not known what the outcome of behavioural feeding interventions may be if creating a positive mealtime environment was the goal that was measured and identified as the dependent variable. It is likely that the interventions themselves may need to look different to accomplish this goal. It is also likely that the current interventions for behavioural feeding difficulties, with the focus on aversive procedures, the contrived settings and interventionists (i.e., clinics, researchers) may be missing some contextual fit for families, especially if the goal were to be to create a positive mealtime environment. These are important considerations for behavioural feeding interventions moving forwards, especially as it would appear that creating a positive mealtime environment is not a goal that has been considered in this literature (e.g., Seiverling et al., 2017). It would appear the field may be focusing on one dimension of mealtime that may not be the most important for families (Chapter Six). There is also further research warranted to explore whether establishing positive mealtime environments has effects on eating over the long term, and this may be particularly important given the negative impacts of feeding difficulties. It would be important to ensure that having a positive mealtime environment has an effect on the feeding issue, as otherwise there may still be a significant impact on the child and the family.

While the current behavioural feeding intervention literature is impressive and large changes are seen, showing functional relations and experimental control between the reduction in food refusal or increase in food consumption and the implementation of the intervention, it is important to consider the cost at which this may be achieved. As described previously in this thesis (Chapter Five, Chapter Six) there are ethical implications with the use of extinction and punishment based procedures, which are mostly used in the behavioural feeding intervention literature (Tereshko et al., 2021b) and which are clearly very effective, but have important side effects which may be detrimental to those who experience them (i.e., increase in intensity, duration or frequency of the behaviour and extinction-induced aggression; Lerman et al., 1999). Given some criticism of behaviour analysis in the UK (e.g., Milton & Moon, 2012; Milton, 2014; Milton, 2018), this is important to consider as these procedures and interventions are likely to not be acceptable or have social validity to some in the UK. It is important additionally to consider that most of these interventions are carried out by researchers in clinic settings in the US (e.g., Borrero et al., 2013;

Johnson & Babbitt, 1993), and as there are limited long-term follow-ups in naturalistic settings, it is not known how these children’s behavioural feeding difficulties progress in the months or years after they are discharged. While the interventions described in this thesis (Chapter Six) were not successful in changing the children’s behavioural feeding difficulties, it is clear from the data and from parent reports that the children did not experience any distress as a result of receiving this intervention. It is clear that there was no harm caused to these children because the data do not show any indicators of increased distress (e.g., kicking for Max and tantrum for Adina). Additionally, there were limitations that may have contributed to why no changes were seen in the behaviour, such as the short length of the intervention and data collection period. A longer intervention, over the course of six-months to one-year may yield different results and be more similar to what could be delivered in the NHS as well.

Interestingly, the focus on creating a positive mealtime environment as a goal that needs to be emphasised with families was explicit in the logic model (Chapter Five) and implicit in the interventions developed and carried out with families in the content and focus of the intervention sessions. In the intervention sessions the discussions centred around reducing the aversiveness of mealtimes to increase the likelihood that the children would accept food and increase their eating. While this was implicit, the feedback from parents was that the focus on creating a positive mealtime environment as a goal may benefit from being explicit in interventions with families. It appeared that parents found this valuable about participating in the intervention and they described this as being a very important goal (Chapter Six). As such data should also be collected in relation to this going forth. While this is an interesting consideration and area to explore in further research, it is important to be tentative with these findings and for further research to be conducted in this area as these were derived from a limited sample of qualitative data and may not be representative.

The findings from the Intervention Study (Chapter Six) also highlighted that the social validity of feeding interventions may be enhanced by ensuring that creating a positive mealtime environment is a goal to focus on from the start of the intervention. Qualitative data from this study showed how parents discussed that the intervention strategies on their child's food refusal action plan were important, acceptable, and doable for them, as well as the outcomes of the intervention, but the goals could have been enhanced as described previously. Clearly, ensuring that the goals are meaningful for families and represent important changes to their entire mealtime environment would be important to explore moving forward to ensure that behavioural feeding interventions have strong social validity. Again, as this finding is derived from a limited sample of qualitative data, it is important to be tentative, but nevertheless it remains an area to consider in future research.

Using a Biopsychosocial Approach to Behavioural Feeding Difficulties to Inform Interventions for These Amongst Children with IDD

This thesis explored a biopsychosocial approach to behavioural feeding difficulties and considered the way in which this understanding informs interventions amongst children with IDD. As such, a contextual, values-based approach to family feeding interventions was developed (Chapters Five and Six) and tested (Chapter Six). This will be explored in depth in this section, along with some conditions that are necessary given the outlined underpinnings of this approach to feeding interventions (Chapter Five) but which may not affect behavioural change. These thesis findings will be discussed in this section, along with a discussion of the contributions of these findings to the field.

Contextual, Values-Based Approach to Family Feeding Interventions

This thesis also explored approaches to family feeding interventions for behavioural feeding difficulties exhibited by children with IDD. As it was explored early in this thesis (Chapter One), there are many theories which attempt to describe how behavioural feeding difficulties develop and why they continue to occur. It was determined that the most comprehensive theory to conceptualise the development and continued occurrence of behavioural feeding difficulties was the biopsychosocial theory (Berlin et al., 2009), as biopsychosocial approaches allow for multicomponent interventions

(Martin et al., 2008) which are likely to target the range of factors that influence behavioural feeding difficulties in individual situations. It is also clear that behavioural feeding difficulties are heterogenous (Beaudry-Bellefeuille et al., 2021; Gosa et al., 2020) and as such, they require a flexible theory that will consider a range of factors that influence why it is occurring, and the biopsychosocial approach allows for this. Therefore, the biopsychosocial theory allows for a contextual approach to understanding the development and continued occurrence of behavioural feeding difficulties and naturally allows for individualisation of intervention approaches for these. This approach was a guiding principle in the interventions described in this thesis (Chapters Five and Six), however there was a key deviation from the biopsychosocial approach in that the biological components influencing the children's behavioural feeding difficulties could not be addressed in the interventions in this thesis, and these were screened for in the exclusion criteria. This decision was made as it would not have been possible to provide any kind of intervention for biological influences on behavioural feeding difficulties (e.g., dysphagia, gastroesophageal reflux disease, etc.) due to the researchers' clinical boundaries of competence and the limited resources in this study.

The findings from this thesis showed that the lived experiences of families had only recently been explored related to the intervention literature for behavioural feeding difficulties (Chapter Three), indicating that research on interventions developed before research explored and understood the family experience. It is possible that current interventions (i.e., behavioural feeding interventions) may need to be adapted given new information about family experiences to ensure that they are appropriate for family contexts. The research in this thesis showed a clear impact on families (Chapters Two and Three), therefore it may be important for interventions for behavioural feeding difficulties to consider this in their assessment process and in the development of interventions and provision of support for families. For example, most of the behavioural feeding intervention literature focuses on direct interventions on the child (e.g., Ahearn et al., 1996; Brown et al., 2002; Cooper et al., 1995; Stubbs et al., 2018), but given the intense parent experience, interventions may need to ensure that parents are also well supported as part of a broader and contextual intervention. This is also highly important given that parents may need to be supported to be able to provide a supportive mealtime environment for their children. This shows that interventions for children with IDD exhibiting behavioural feeding difficulties may benefit from occurring in a family-context rather than focusing solely on the child. Additionally, it appeared that clinicians working in NHS settings delivering support for this population recognised the need for a contextual approach to interventions for behavioural feeding difficulties, that is individualised and with high levels of stakeholder participation (Chapter Four).

In this thesis, an intervention approach to behavioural feeding difficulties was piloted (Chapter Six). The results from this study showed that it was possible to deliver an intervention that was values-based and informed by contextual approaches and that parents did fully participate. It was possible to work with family carers to develop bespoke strategies and coach them through the implementation of these. The number of intervention sessions in this study was also guided by the capacity that might be able to be delivered in NHS settings, and the results from this study showed that the components were able to be delivered within these sessions. Qualitative feedback from parents showed that they would have valued some additional sessions, which as highlighted in the previous chapter, would be aligned with the number of sessions able to be delivered in NHS services (i.e., seven to eight intervention sessions, rather than only five intervention sessions).

Importantly, the interventions carried out in this research were guided by components with a strong logic behind them: a biopsychosocial approach, behaviour analysis, a PBS informed values-base, collaborative working, and an iterative coaching and bespoke approach (Chapter Five). The development of this logic model was built upon interviews with key stakeholders (e.g., parents and clinicians; Chapters Two and Four), and a synthesis of the literature (Chapter Three). This is a significant contribution in its own right, as a logic model for an intervention approach for behavioural feeding difficulties amongst children with IDD has not been initiated previously, and it is clear that current interventions for behavioural feeding difficulties do not often consider stakeholder perspectives. This initial logic model can be built upon to guide future collaborative working in this area.

In the context of this thesis, the logic model guided the development of an intervention for behavioural feeding difficulties amongst children with IDD, and this was implemented and tested in Chapter Six. The intervention sessions described in Chapter Six focused on working closely with parents to understand why their child was refusing food and creating a supportive environment that would reduce identifiable factors that made eating worse for them. The underpinning guiding values-base ensured that the intervention strategies developed alongside families were proactive in nature and avoided the use of restrictive and aversive practices that are commonly found in behavioural feeding interventions (e.g., Anderson & McMillian, 2001; Bui et al., 2013; Smith et al., 2019). As mentioned previously, taking part in this intervention did not make anything worse for Max and Adina (as evidenced by the lack of increase in kicking or tantrums throughout the intervention period). It is important to reiterate that the current behavioural interventions use aversive procedures like escape extinction and punishment which were eschewed in this study (Chapter Six). While there were no changes to the children's behavioural feeding difficulties demonstrated in this study, this study has provided an important first step for the use of these approaches in the UK context and it would be important to continue to refine the use of antecedent-based and contextual approaches in interventions for behavioural feeding difficulties to increase the effectiveness and social validity of interventions for behavioural feeding difficulties, especially in the UK context where behavioural approaches are not as widely accepted as other countries (i.e., the US; e.g., Milton & Moon, 2012; Milton, 2014; Milton, 2018).

Necessary But Not Sufficient Conditions

One of the findings from this thesis in relation to the delivered feeding interventions was that there were some factors that were clearly necessary for the interventions but that were not likely to be sufficient conditions to result in a change in the child's behavioural feeding difficulty.

These were parents understanding why the child's behavioural feeding difficulty was occurring, and interactions with an interventionist where there was relationship building and rapport and a good working relationship.

As described previously, findings from this thesis showed that understanding why their child's behavioural feeding difficulty was occurring was clearly powerful for parents (Chapters Two and Three), so this was considered to be a necessary condition in an intervention for the reasons described in the previous section. As mentioned, understanding a child's behavioural feeding difficulties describes the ability of a parent to identify the relevant factors that may be influencing why the child is refusing food and which make them more likely to refuse food. Supporting parents through this process means supporting them in being able to identify the factors that are making it more likely for their children to refuse food (Chapter Six). The Family Feeding Intervention Study (Chapter Six) incorporated elements of supporting families in developing this understanding (through collaborative working in the assessment and formulation process). The findings from this study suggested that supporting parents with understanding was likely not a sufficient condition to see a change in the child's behavioural feeding difficulty, because there was no change evident in Max or Adina's food refusal. This study showed that after going through the whole process, parents seemed to be reporting changed perceptions (i.e., large changes in BFPAS scores from clinical significance and significantly higher than the normative mean at pre-intervention and no longer clinically significant or significantly higher than the normative mean at post-intervention for two of the three participants, along with reductions across all scores from pre- to post-intervention for the remaining participant, and supporting qualitative data). However, there was no observed change in the child's behaviour that was measured (i.e., no change in the behavioural data for the various dependent variables), suggesting that supporting parents with developing this understanding was likely not enough to see an observed change in the children's feeding behaviours. This was interesting because it appeared that although it might feel to parents like the impact is reduced when they understand why their children's behavioural feeding difficulties are occurring, it was evident from the Family Feeding Intervention Study that the directly observed behaviours did not change within the time period, and the children were still exhibiting behavioural feeding difficulties by the end of the study. This was also seen in parent reports early on in this thesis (Chapter Two); while parents reported that understanding seemed to help with impact, their children were still currently exhibiting behavioural feeding difficulties, further highlighting that supporting with understanding as part of an intervention for behavioural feeding difficulties is likely not sufficient to result in actual change in the child's behavioural feeding difficulty, though a component analysis would be required to confirm this Alternatively, this did appear to be necessary in the sense of fostering a collaborative approach with families. It is important to note that it is possible that the dependent variables that were focused on may have missed an important shift, as it was evident from the intervention sessions that there was a big, missed opportunity by not tracking food throwing as separate behaviour of the same response class for Adina. Had food throwing been tracked independently of food refusals (while still part of the food refusal response class), there would be data to demonstrate a reduction in one topography of Adina's food refusal that was reported to be significant for her parents. Unfortunately, data was not collected on this separately, so there are only qualitative reports of this change or anecdotal comments from the sessions. It was also possible that behavioural changes were not observed because the intervention itself was not in place for very long and data collection ceased after only two weeks of implementing strategies, and then occurred for a brief period of time for a follow-up. If data had been collected over a much longer period of time (i.e., six months to one year; see Appendix XX), it is possible that there may have been changes observed in the children's behavioural feeding difficulties. However, these data were not collected so it is not possible to know what may have happened over a longer period of data collection. What is clear from the data in this thesis is that parents may report feeling better when they understood why their child's behavioural feeding difficulty was occurring, and that the impact was reducing (Chapters Two and Six), however this on its own did not produce a change in the children's behavioural feeding difficulties (Chapter Six).

Additionally, another necessary condition for family feeding interventions are the interactions with an interventionist that centre around relationship building, rapport, and a good working relationship. These are components of therapeutic work are sometimes referred to as ‘soft skills’ and they are essential when working with families in a behavioural capacity (LeBlanc et al., 2020; Taylor et al., 2018). While the intervention carried out in this thesis (Chapter Six) had strong behavioural underpinnings (Chapter Five), it is clear that there is more to interventions than just the use of behavioural technology (LeBlanc et al., 2020; Taylor et al., 2018); the way in which these are carried out is also important. The feedback received from parents also highlighted that the interactions with the interventionist themselves were important and mattered to them (Chapter Six). Behaviour analysts and psychologists of all backgrounds have increasingly acknowledged the important of the therapeutic relationship (Farber et al., 2018). Research has shown that an interventionist providing acceptance, valuing the person they are supporting and showing warmth (amongst others) is a significant part of the therapeutic relationship which has been shown to lead to improved clinical outcomes (Farber et al., 2018). This shows that simply providing individuals with a safe space to discuss their difficulties where they feel accepted and valued may make them feel as though progress has been made. While this is not a new finding, it is an important finding to reiterate in the context of behavioural research, where this is often not recognised as an important factor given that almost no behavioural intervention literature discusses the importance of these “soft skills”, and this is not often a priority in behaviour analytic clinical work (Taylor et al., 2018). The focus on rapport, relationship building (e.g., active listening, gentle reframing, etc.; Chapter Six), and establishing a good working relationship was implicit in the intervention approach taken in this thesis in the form of collaborative working and coaching (Chapters Five and Six). However, it would appear that while these “soft skills” are essential and conducive to working with families, they are arguably not sufficient conditions because, as mentioned, there was no observed change in Max or Adina’s behavioural feeding difficulties. As mentioned previously, there are a variety of limitations to this study, like the short intervention period, and the focus on certain dependent variables that mean that important changes may not have been captured. As such, this thesis has outlined some components that may be helpful in interventions for behavioural feeding difficulties based on findings from several studies in this thesis, however it is not clear whether these are likely to be sufficient to affect behavioural change as these have not been tested robustly in this thesis. This would be an important area to continue to explore in further research.

Overall Strengths and Limitations

The strengths and limitations of each individual study in this thesis are considered within each study's discussion section. As such, this discussion will focus on strengths and limitations that relate to this thesis as a whole and the arising implications for research and clinical practice. Whilst this research provides a contribution to the field in several ways, as outlined previously, and there were some strengths to the work, there were also some limitations which are highly important to consider when reviewing the findings of this thesis. The limitations of this thesis will be reviewed first, followed by the strengths, with implications and suggestions for clinical practice and research discussed throughout as relevant.

Overall Limitations

There were a range of limitations that are important to discuss in relation to the work carried out in this thesis and the thesis aims. One of these limitations was the recruitment method used in this thesis for all the empirical projects. All participants in this PhD research were recruited via social media or mailing lists and dissemination by others (i.e., someone sharing the research on social media after encountering it on a mailing list, NHS Research and Development Officers disseminating within their Trust). While this was convenient and easy to implement and appropriate given the exploratory nature of this thesis, it also meant that the research only reached families and clinicians that had internet access, etc. This was compounded by the need for access to technology (i.e., phone, tablet, laptop, etc.) to participate in the research. This meant that this research would not have been accessed by anyone who was not on social media or subscribed to mailing lists and had access to technology to participate. This is a limitation of the thesis as it means that participation by people that perhaps were in more complicated home situations (i.e., financial difficulties keeping them from being able to have technology devices, etc.) and arguably may need more complex support was not facilitated. As such, this research has not considered the additional needs of individuals that may be in these situations, and future research should seek to be more inclusive.

Secondly, there was a lack of collaboration with other clinicians in the implementation of the Family Feeding Intervention Study (Chapter Six). This is an important limitation of this thesis as it is recognised that a multi-disciplinary approach is best practice when supporting behavioural feeding difficulties Lukens & Silverman, 2014; Sharp et al., 2010; Sharp et al., 2017). Funding and resource limitations due to the nature of this research as being part of a PhD meant that additional clinicians (i.e., speech and language therapists, dietitians, etc.) were not able to be collaborated with or consulted with during the intervention study, and which limits the interventions delivered. The researcher also encountered difficulties carrying out all the clinical work herself and noted that working in a team would have likely been more appropriate. While this is a limitation, it is also likely to be a similar difficulty encountered by clinicians in practice (Chapter Four). Nevertheless, future research on feeding interventions should ensure that a team are involved and that the team encompasses a range of relevant healthcare professionals that would usually be present in a multidisciplinary team for behavioural feeding difficulties.

There were also issues related to the contexts in which this research was carried out. Primarily, this was all PhD research, meaning that there was limited time and resources, but this had particular implications for the Family Feeding Intervention Study (Chapter Six) where the researcher found the pace and intensity of the intervention extremely high and difficult to manage. Had there been more resources to have additional support or extra time beyond the scope of what is expected in a PhD, it would have likely made a big difference in terms of the time and resources available to dedicate to these interventions. On the other hand, it was considered that this experience was likely to be similar for clinicians working in the field (Chapter Four) and highlighted the complexity and intensity of family feeding interventions. This is highly important to consider in clinical settings as it is clear that clinicians already experience difficulties having enough time and resources to deliver support or intervention for children with IDD exhibiting behavioural feeding difficulties (Chapter Four). NHS services and clinical commissioning groups should consider the complexity and intensity of this work when allocating clinical hours and hiring staff to ensure that burnout is kept low amongst these professionals that have already been reported to leave the NHS mainly due to excessive workload, pressure, or stress (Loan-Clarke et al., 2010). Additionally, this research was carried out in the context of the ongoing COVID-19 pandemic that started six months into the researcher's PhD registration period. As such, the decision was to move all research online for the duration of the PhD, and while all the research was still able to be carried out, there was not input from parents and clinicians on the telehealth nature of the approach specifically. That the interventions were delivered via telehealth was not a key factor for evaluation, rather a response to the ongoing pandemic, however this may have influenced findings as the interactions with parents may have been different if the researcher had met parents in person and observed the mealtimes in person.

Finally, the researcher was not exempt from having biases in this research. All the empirical studies in this thesis involved in-depth conversations with participants, either in the form of in-depth qualitative interviews (Chapters Two and Four) or in the form of working closely in intervention sessions (Chapter Six). As such, the researcher grew to know participants very well. This meant that at times, it was difficult to gain perspective about the data collected as the researcher felt very close to the data and participant experiences. This limitation was amplified in the Intervention Study where the researcher developed an ongoing working relationship with families. It was an ongoing process for the researcher to maintain objectivity in data analysis while there was an established, collaborative, and positive working relationship with the families that participated (Chapter Six). It was helpful that there were clear procedures which guided each session (see study manual, Appendix HH) which supported the researcher in following the intervention protocols, while still allowing for unexpected situations and questions to arise, as is common when working with families (e.g., questions about autism diagnoses, needing to end sessions early for appointments, etc.). For the qualitative studies, methodical data analysis methods (Straussian grounded theory) helped the researcher maintain objectivity despite feeling close to the data and participant experiences. Maintaining objectivity and trying to reduce researcher bias was an ongoing process throughout this PhD which occurred through conversations with supervisors, clear data analysis procedures, clear study procedures and lots of reflexivity throughout, but it is still important to note as a limitation. It is likely that another researcher with a different positionality or approach may have teased out different findings from the data collected based on their perceptions of what was important to highlight.

Overall Strengths

One of the strengths of this thesis was the inductive approach taken throughout. This thesis began with a review of the literature leading to an in-depth exploration of the parent experiences of behavioural feeding difficulties in the UK to develop an understanding of this experience which was notably missing in the literature (Chapters One and Two). This led to a review of the literature of parent experiences to ensure that the parent experience was fully and comprehensively understood (Chapter Three). Following this, it was clear that the findings from both these studies highlighted difficulties with accessing support for behavioural feeding difficulties (Chapters Two and Three). This led to the conclusion that it would be important to understand the experience of clinicians that deliver support or intervention to children with IDD exhibiting behavioural feeding difficulties, in part to understand the challenges faced by clinicians (Chapter Four). All this data was then considered along with the literature to develop a logic model for an intervention approach for behavioural feeding difficulties amongst children with IDD (Chapter Five), which was used to guide the development of the intervention approach used in the final study of this PhD (Chapter Six). The studies in this PhD followed on from each other and were influenced and informed by the findings from previous studies, highlighting the inductive nature of this thesis, which was ultimately a strength as the entire work followed the data. This was considered a particular strength as the intervention approach taken in this thesis (Chapter Six) was informed by stakeholder perspectives (Chapters Two, Three and Four).

Additionally, the data collected in the Parent and NHS Clinician Studies (Chapter Two, Chapter Four) were instrumental in providing the researcher with an appreciation of the lived experience of those who support children with behavioural feeding difficulties, both at home and in professional settings. These studies both ensured that the researcher had unique, first-hand and in-depth exposure to the experiences of parents and NHS clinicians, which was critical for the later stages of this thesis (i.e., the Family Feeding Intervention Study, Chapter Six). This was a strength in this thesis as it allowed the researcher to approach the intervention study with this rich background and apply this knowledge to the development and delivery of this study (Chapters Five and Six). It also ensured that the research was more in tune with approaches that were likely to have contextual fit and social validity in the UK context and ensured that this information was directly considered in the development and delivery of the Family Feeding Intervention Study. Both these strengths ensured that the implications of parent and NHS clinician experiences of behavioural feeding difficulties and providing support were linked into the development of interventions for behavioural feeding difficulties.

Implications for Clinical Practice and Research and Future Directions

This thesis concludes with a summary of implications for research and clinical practice and future directions of these. While implications have been discussed in the relevant chapters, this discussion will focus on implications and future direction related to the aim of the thesis. The implications for clinical practice will be discussed first, followed by implications for research and future directions together.

Implications for Clinical Practice

This thesis has yielded many implications for clinical practice, and some of these will be discussed in depth in this section. Firstly, it was clear from this thesis that parents have their own understandings about why their child's behavioural feeding difficulty is occurring (Chapter Two). This understanding was clearly very powerful for parents, in some cases mitigating some of the impact they felt from the behavioural feeding difficulty and in other cases resulting in acceptance of their child and the ways in which their child needs to be supported (Chapters Two and Three). Importantly, while understanding was important, it was clear that parents are not often able to identify all relevant factors that influence their child's behavioural feeding difficulty (Chapter Two), so it is important for parents to be supported through that process when they are receiving support. This is important for clinicians to be aware of and be supported themselves in supporting parents in this way, because when parents can identify the range of factors that influence their child's food refusal, they can try to address those factors themselves at home, if they are supported through that process (as they were in Chapter Six). It is also considered that this may help with parental empowerment and allow parents to take interventions or strategies forth on their own – and this model of parents as intervention agents appears to be common in NHS settings (Chapter Four). As such, it is imperative that clinical work focuses on supporting parents to identify environmental events that make it more likely for their children to exhibit behavioural feeding difficulties and address these (see Chapter Six). It is also important for clinicians to be aware that supporting parents in developing this understanding may be an ongoing and cyclical process, and this is simply the nature of the clinical work (Chapter Four). While clinicians appeared to be aware of the importance of understanding for parents and shared understandings, they described being limited in their support by systemic issues. As such, it would be important for clinicians themselves to be better supported in delivering support or intervention for children with IDD exhibiting behavioural feeding difficulties.

Additionally, clinicians need to be aware that families often feel like they are battling with services, so it is important to validate families in their feeding concern (Chapters Two and Three). To support families with accessing support it may also be helpful to provide a guide of which professionals are able to support with behavioural feeding difficulties so families know who they can turn to, and wider healthcare professionals to also know who they might refer families to (Chapter Three). It may also be beneficial to give parents information about the nature of support for behavioural feeding difficulties in the NHS (i.e., they are likely to be the primary interventionist, implementing strategies at home; Chapter Four). This may support parents with knowing what to expect before they enter a service, so it does not feel like a battle with the service once they have been admitted (Chapter Four). More transparency in this process may alleviate the difficulties of medical model expectations of support and prepare parents to better engage in the intervention process and clinical work (Chapter Four).

Clearly, families experience significant impacts when a child exhibits behavioural feeding difficulties, and it is paramount that the whole family is supported in interventions for behavioural feeding difficulties (Chapter Three). Related to this, there is a risk of a feeling of duality rising between families and clinicians, which may be exacerbated when clinicians also view the nature of family work as a challenge. Feelings of duality can affect family and clinicians' ability to work together and ultimately the child exhibiting the behavioural feeding difficulty may suffer as they would not be properly supported. As such, it is important in clinical practice to continue to seek families' perspectives on their healthcare provision related to the behavioural feeding difficulty, and work with families in a collaborative way. It is important that family work itself is not viewed as a barrier to delivering support for behavioural feeding difficulties, rather as a part of the work itself and an ongoing process (Chapter Four). Additionally, the influence of systemic barriers (Chapter Four) would benefit from being explored further as there was a sense that clinicians were aware of what good support entailed (as evidenced by the three key areas needed for support; Chapter Four), but systemic barriers were clearly described as limiting clinicians in the support or intervention that they were able to provide.

As mentioned, clinicians face systemic barriers when working with this population in NHS settings (Chapter Four) and these systemic barriers warrant careful consideration as some research shows clinicians leave the NHS settings due to excessive workload (Loan-Clarke et al., 2010). The Family Feeding Intervention Study in this thesis provided a preliminary approximation to the number of hours needed when supporting this population in this way and it was evident that these interventions take a lot of time to carry out (Chapter Six). As such, the systems around clinicians need to support them to be able to deliver these interventions fully. This may mean increasing the number of clinical hours that are allocated to cases where there are behavioural feeding difficulties present. It is also imperative that clinical commissioners who make decisions about commissioning and clinical hours are aware of the workload intensity that these cases bring with them.

Additionally, clinicians supporting families should be aware of the potential importance of goal setting with families and consider the possibility of establishing a positive mealtime environment as an important goal to consider when supporting families (Chapter Six). This would help ensure that the clinical work carried out has social validity for families (Chapter Six), which may mean clinicians would find it easier to get ‘buy in’ from families, and that the families may be more likely to continue to implement strategies on their own after the intervention has ended.

Finally, the initial logic model presented in this thesis (Chapter Five) may be useful to guide the practice of clinicians. This initial logic model is a starting point for the field to continue to develop further, however its development can support clinical practice by outlining what is needed for behavioural feeding interventions using this approach. It also explains the rationale and mechanisms underlying the intervention approach, which could help with training clinicians that are new to supporting families of children with IDD with behavioural feeding difficulties. While this initial logic model may help to guide clinical work, though as mentioned previously, this is an initial step that the field would need to develop and refine further.

Implications for Research and Future Directions

This thesis has yielded many implications for research and future research directions, and some of these will be discussed in depth in this section. Future intervention research in the area of behavioural feeding difficulties should seek input from families and clinicians on the areas outlined as guiding the intervention and the intervention components themselves (Chapters Five and Six). While the perspectives of stakeholders informed the development of both the logic model and the intervention components, their input, and thoughts about the finished products (i.e., logic model and intervention approach) were not sought. This would present an interesting opportunity for a Delphi consultation with stakeholders about the logic model and intervention approach themselves, but unfortunately this was not possible in this thesis. This presents an interesting area of future research in behavioural feeding interventions and should be considered an important next step in the refinement of intervention approaches for behavioural feeding difficulties. A Delphi consultation would be a good next direction in terms of obtaining stakeholder input to the intervention approach and intervention itself and make adjustments based on stakeholder perspectives. This would allow for the input of parents and clinicians to guide any refinements on this intervention approach and would hopefully mean that the intervention approach and subsequent interventions would have further contextual fit for families and clinicians working in the NHS in the UK. Further to this, a larger scale study would be an important next step to evaluate the effectiveness of an approach based on the logic model in improving behavioural feeding difficulties. It may also be interesting to compare between this logic model based approach, and an approach similar to that which is common in the behavioural feeding intervention literature. Additionally, it would be important for further research to explore the systemic barriers in the current service provision in the NHS and explore ways to break those down to increase access to relevant professionals and address commissioning difficulties (Chapter Four).

Further research in this area should also focus on exploring goal selection with families of children with IDD exhibiting behavioural feeding difficulties. Findings suggest that this may be important to parents and may be more important than what current behavioural feeding interventions focus on (Chapter Six). This might involve exploring behavioural dimensions of what creating a positive mealtime environment means to families (i.e., what it looks like, how this can be measured and defined), and design future research to capture any changes to this dimension of mealtime objectively and observationally. This would mean that future research would also focus on exploring the effectiveness of interventions that focus on shared goal selection and creating positive mealtime environments. This is particularly important as it is clear that research on interventions progressed before research understood the family experience (Chapter Three) so the current interventions for behavioural feeding difficulties may need to be adapted to ensure they are appropriate for family contexts (i.e., carried out by parents, in home settings). Findings from this thesis showed that focusing on creating a positive mealtime environment as the intervention goal may have enhanced the intervention (Chapter Six), and as such, research on feeding interventions should consider this going forth and consider this in interventions going forwards. This is also an important future area of research as addressing the mealtime environment is aligned with a contextual approach to behavioural feeding difficulties (Chapters One and Five) whereby the focus is on changing the environment to make it more supportive, not changing the child.

Linked to this, future research should ensure that values-based and contextual approaches to interventions for behavioural feeding difficulties continue to be explored. It would also be important to explore how social validity ties in with this approach and whether this approach creates meaningful changes for families. Going forth, it would also be important to continue to explore antecedent- and reinforcement-based approaches, as it is clear that behavioural technology is needed and these approaches can be successful (Gosa et al., 2017; Tereshko et al., 2021a). It is important to continue to explore how the technology of behavioural approaches can be used to obtain behaviour change without sacrificing the ethics and values-based presented in this thesis, and while incorporating stakeholder perspective and experiences. This thesis has provided some research that can be built upon to achieve this, and it would be valuable for this to be continued within the behavioural feeding intervention research.

Concluding Comments

It is clear that behavioural feeding difficulties are common and bring with them a range of different impacts on the children with IDD that exhibit them and their families. Behavioural feeding difficulties amongst children with IDD are complex and warrant contextual approaches to understand the range of factors that may be influencing why these occur, and this should be considered in an intervention approach. The perspectives of parents and the clinicians that support these children and their families also provide valuable information to consider in the development of interventions for behavioural feeding difficulties. Whilst behavioural interventions for behavioural feeding difficulties are common and reported to be effective, there are significant ethical considerations warranted with the use of escape extinction (EE)and punishment for behavioural feeding difficulties and these are not appropriate approaches in the context of the UK. The development of an initial logic model in this thesis is a first step towards developing a collaborative approach to supporting children with IDD exhibiting behavioural feeding difficulties – an area that has been largely overlooked within the behavioural literature in this area. The effectiveness of an intervention guided by an initial logic model has yet to be determined and requires further refinement (e.g., through a Delphi consultation with parents and clinicians) and evaluation (e.g., with a more methodologically robust intervention study, like a multiple-baseline design with three families that illustrates a functional relation and has experimental control). However, the input of a literature review and perspectives of both parents and clinicians have come together to provide a research-informed initial model to guide this future work.

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Appendix A

Parent Study Interview Schedule

Research question 1**:** What is the child's behavioural feeding difficulty and what supports have parents received to date for these?

1. Can you tell me about your child?
    a. Prompt: age, diagnoses, feeding difficulty, medical conditions
2. What does mealtime with your child look like?
    a. Prompt: What does their feeding difficulty look like? What age did the issue emerge? Has it occurred continuously? Has there been any formal identification of a feeding issue? How often does the feeding issue occur? Has the feeding issue changed since it first emerged?
3. Have you received any supports for your child's feeding difficulty?
    a. Prompt: What did that support look like? How did you access this support?
4. Have you implemented any strategies to try to improve your child's feeding?
    a. Prompt: Are there any changes to the way you present food to your child? In what ways have you changed your mealtime routine to adapt to your child's feeding difficulty? In what ways have you adapted your lifestyle to cope with your child's feeding issue? In what ways have you implemented the strategies suggested by the supports/intervention you received?
5. Have you implemented any strategies for gaining support or learning more about your child's feeding difficulty?
    a. Prompt: read a book, join a support group, visit the GP, self-refer to a professional, etc.

Research question 2: What are parents' ideal supports for their children's feeding difficulties and themselves in managing these feeding difficulties?

6. Describe to me your ideal support/intervention for your child's feeding difficulty.
    a. Prompt: Is there anything you would have liked that you did not receive? Focused on more? See a specific professional?
7. Is there anything that you think would improve your child's feeding?
8. Is there anything that would help support you to manage your child's feeding difficulty?

<u>Research question 3</u>: What implicit theories do parents of children with an IDD have about their child's behavioural feeding difficulty and what are their perceptions of what influences this feeding difficulty?

9. Can you describe how the feeding issue first started?
10. Have you got any ideas on why it happens or keeps happening?
    a. Prompt: Anything in particular that might have started this? Any thoughts about why the feeding issue may have started/has continued? When you say x how does that fit with the feeding difficulty?
11. Is there anything or anyone that helped form your opinion on how the feeding difficulty started or continues?
    a. Prompt: A certain intervention? A professional? A support group? Your education/professional background? Online research?
12. Is there anything else about feeding difficulties that you would like to add?

Appendix B

Parent Study Resources for Families

Feeding Matters Family Support

https://www.feedingmatters.org/resources-support/family-support/

- Provides information about an international system of support for families

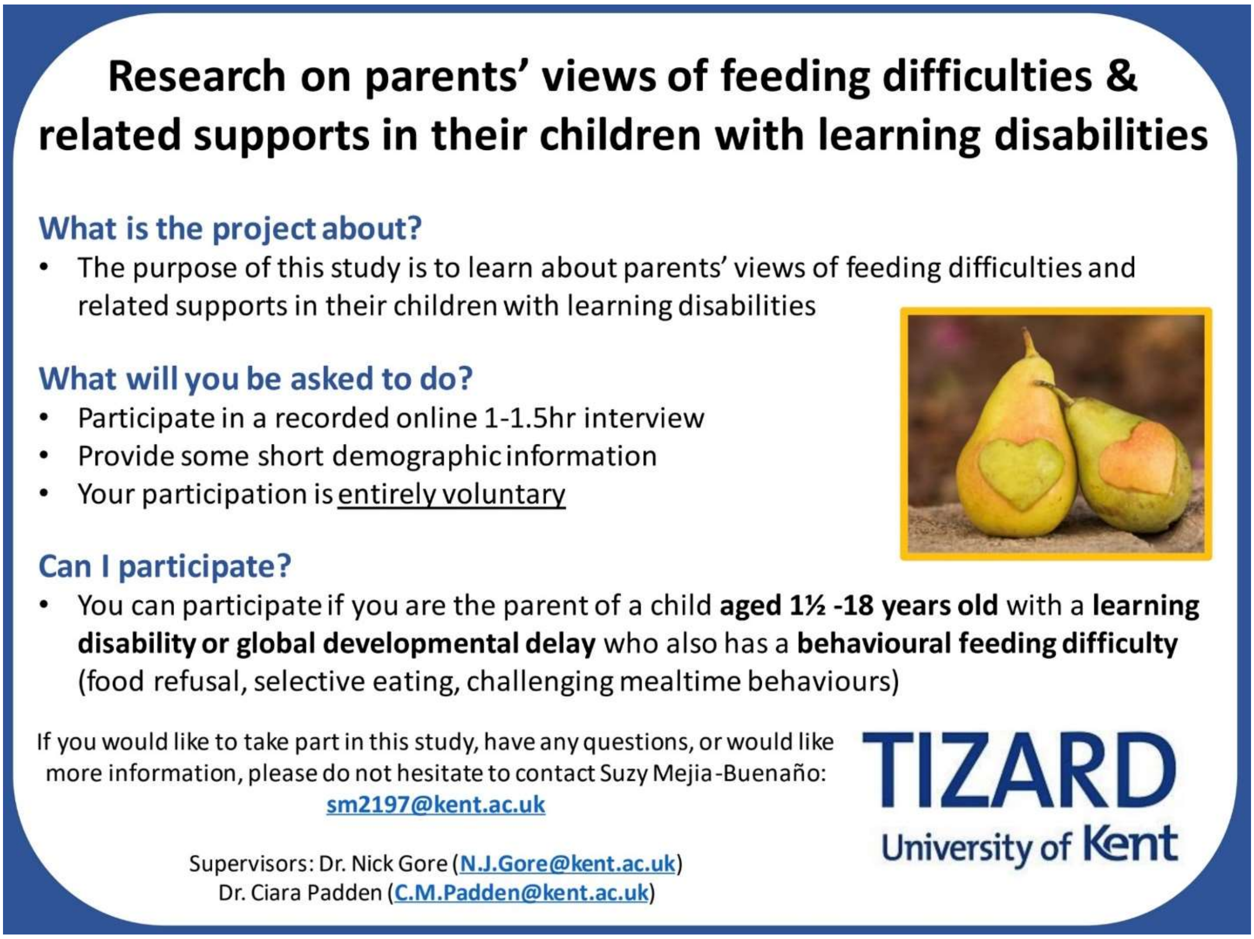
Challenging Behaviour Foundation

https://www.challengingbehaviour.org.uk/supporting-you/for-families/for-families.html

- Provides information about accessing family support services via telephone or online chat, and joining a family carer email network

Appendix C

Parent Study Research Poster



Research on parents' views of feeding difficulties & related supports in their children with learning disabilities

What is the project about?

- The purpose of this study is to learn about parents' views of feeding difficulties and related supports in their children with learning disabilities

What will you be asked to do?

- Participate in a recorded online 1-1.5hr interview
- Provide some short demographic information
- Your participation is entirely voluntary

Can I participate?

- You can participate if you are the parent of a child **aged 1½ -18 years old** with a **learning disability or global developmental delay** who also has a **behavioural feeding difficulty** (food refusal, selective eating, challenging mealtime behaviours)

If you would like to take part in this study, have any questions, or would like more information, please do not hesitate to contact Suzy Mejia-Buenaño:
sm2197@kent.ac.uk

Supervisors: Dr. Nick Gore (N.J.Gore@kent.ac.uk)
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TIZARD
University of Kent

Appendix D

Parent Study Participant Information Sheet

Tizard Centre, University of Kent
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Parents' information sheet

Title: **Parents' views of feeding difficulties and related supports for their children with learning disabilities**

Dear Parent,

You are being invited to participate in a research study conducted by Suzy Mejia-Buenaño, a PhD student in Applied Psychology at the Tizard Centre, University of Kent. Her supervisors are Dr. Nick Gore and Dr. Ciara Padden. You are receiving this information sheet as you have expressed interest in learning more about this study. This study has been reviewed and approved by Tizard Centre Ethics Committee at the University of Kent. Before you decide if you want to participate, it is important for you to understand why the research is being conducted and what it will involve, therefore some background information has been provided below.

Purpose of the study

This study will examine parents' views of behavioural feeding difficulties in their children with a learning disability. We are also interested in hearing about related supports for your child's feeding difficulty. This information will help us develop a parent-informed intervention for feeding difficulties in children with learning disabilities.

Why you are being asked to participate?

You are being asked to participate because you are the parent of a child aged 1½ to 18 with a learning disability and a behavioural feeding difficulty, and you have expressed interest in this research. Your participation is entirely voluntary. If you decide to volunteer your time, you can:

- Complete the consent form, digitally sign it, and return it
- Return the completed consent form along with an email statement that you consent to participate in the study
- Provide recorded verbal consent at the start of your interview

You are free to withdraw your participation at any time without giving a reason.

What you will be asked to do

If you agree to take part, you will need a computer, or laptop, tablet, or mobile phone with internet connection. You will be asked to participate in a 1-1.5 hour online, video-recorded interview with Suzy through Microsoft Teams. You will be asked questions about your child's feeding difficulty and related supports. You do not need to download any software or applications for this interview; a link will be provided. You will be asked to provide some demographic information. The interview can be arranged around your schedule, including outside of normal working hours.

What are advantages or disadvantages of participating

Your experiences will help us develop a parent-informed intervention approach to feeding difficulties in children with learning disabilities which will be beneficial to many people. The topic might be upsetting for you to discuss, if this happens Suzy will ask you if you want to withdraw or continue at a later date.

What will happen to your information

After the interview, you will be given the opportunity to review your interview transcript, if you wish. Once the study is finished, Suzy will contact you with information about our findings.

Your information will be kept confidential, stored securely, and all your responses will be anonymised as quickly as possible after data collection. This means that any information that could either directly or indirectly indicate who you are will be removed and replaced with a pseudonym. You or your child's name will not be used in transcription or in later reporting of research results in academic publications or conference presentations. Only Suzy and her research supervisors at Tizard Centre will have access to completed material (i.e. transcripts, demographic information). For additional information about the University's Privacy Notice for Research (GDPR), please click here.

Limits to confidentiality

There are limits to the degree of confidentiality possible since Suzy and her research supervisors will have access to your recorded interview, they will know your identity and may be able to recognise you. Nobody beyond them will be able to identify you. Another limit to confidentiality is that we have the obligation to report anything that indicates that you or your child is at risk of harm. If this occurred, you would be informed that we would be contacting the relevant child protection services.

What happens if you wish to make a make a complaint?

You will be given a form at the end of your involvement, so that you can give feedback or make a complaint. In addition, at any time, you can contact my supervisors, Nick Gore or Ciara Padden by email: N.J.Gore@kent.ac.uk or C.M.Padden@kent.ac.uk. Alternatively, you can contact the Secretary of the Tizard Centre Ethics Committee, Liz Lukehurst by email: E.Lukehurst@kent.ac.uk.

Thank you for taking the time to read this information sheet.

Suzy is available via email or phone to answer any questions you might have.

Yours sincerely,

Suzy Mejia-Buenaño

Appendix E

Parent Study Demographic Information

PARTICIPANT DEMOGRAPHIC INFORMATION

Title: ***Parents' views of feeding difficulties and related supports for their children with learning disabilities***
Researcher: Suzy Mejia-Buenano
Email: sm2197@kent.ac.uk
Supervisors: Dr Nick Gore and Dr Ciara Padden
E-mail: n.j.gore@kent.ac.uk and c.m.padden@kent.ac.uk

You can choose to answer the following questions verbally on the telephone before your interview, or verbally at the start of your interview.

Age: ___________________________

Gender: ___________________________

Ethnicity: ___________________________

Number of children: ___________________________

Number of children with a learning disability: ___________________________

Ages of all children: ___________________________

Ages of children with a learning disability: ___________________________

Name of Participant:___________________________

Date:_________________

Appendix E

Parent Study Consent Form

CONSENT FORM

Title: ***Parents' views of feeding difficulties and related supports for their children with learning disabilities***

Researcher: Suzy Mejia-Buenano
Email: sm2197@kent.ac.uk
Supervisors: Dr Nick Gore and Dr Ciara Padden
E-mail: n.j.gore@kent.ac.uk and c.m.padden@kent.ac.uk

	Please tick
I confirm that I have read and understood the information sheet attached for the above project.	☐
I have had the opportunity to ask any questions and these have been answered to my satisfaction.	☐
I understand that I will participate in an online, videorecorded interview about my child's feeding difficulty and related supports.	☐
I understand that my participation is voluntary and that I do not have to take part.	☐
I understand that I can choose to withdraw before, during or after the interview (it will not be possible to withdraw after data analysis has taken place), without giving a reason.	☐
I understand that all of my responses will be made confidential (anonymised) and neither myself nor my child will be identifiable from data that may be presented in academic publications, or conference presentations.	☐
I understand the limits to confidentiality, specifically that the interviewer and the research team will know my identity and personal details.	☐

I understand that confidentiality cannot be maintained if I mention something that indicates that I or my child is at risk of harm. I understand that I would be informed that the relevant child protection service was being notified. ☐

I understand that a video and audio recording will be made of the interview and this will be stored securely. ☐

I understand that information I give will be shared with research supervisors. ☐

I would like to participate in this research. ☐

Name of Participant:__________________________

Signature:_____________________________

Date:_________________

If taking verbal consent at the start of the interview only:

Witness name: _____________________________

Signature: _____________________________

Date: __________________

Appendix G

Parent Study Comments Form & Participant Feedback

University of Kent | Tizard Centre

Feedback / Comments Form

Thank you for agreeing to talk to Suzy Mejia-Buenaño to help with her research about *parents' views of feeding difficulties and related supports for their children with learning disabilities.*

We hope that everything was alright when you talked to Suzy. We would be interested in any comments you would like to make, positive or negative.

When things go well, we like to encourage researchers by giving them good feedback. But if things don't go well, it will help us to know this.

Please send any comments you have to:

Suzy Mejia-Buenaño *(first option)*
PhD Researcher
Sm2197@kent.ac.uk

Nick Gore or Ciara Padden *(second option)*
Supervisors
N.J.Gore@kent.ac.uk or C.M.Padden@kent.ac.uk

Liz Lukehurst *(if still not satisfied)*
Secretary to the Tizard Centre Research Ethics Committee
E.Lukehurst@kent.ac.uk

Thank you once again for helping the Tizard Centre with our research.
Tizard Centre Research Ethics Committee

Participant feedback:

“Thank you for presenting me with the opportunity to talk about xxx and his eating habits.....you made me feel very comfortable and at ease immediately, and throughout showed care and empathy towards me, especially when I became emotional. 😀

I hadn’t expected that I would still become so upset about it, but that was a lesson for me as well; I thought I was ok about his eating, but really it still upsets me deep down.

As time has gone on, I haven’t had the chance to speak to anyone in depth about it, so it was helpful from that point of view too.”

Appendix H

Straussian Grounded Theory Task Analysis

Data analysis steps	Justification
1. Read each transcript through, making general notes/memos about themes, ideas, topics that are present. This occurred throughout the data collection/transcription process, but I will review this once more before undertaking the bulk of analysis.	To reduce reductionistic stage of putting data into initial codes without first being immersed in the data as a whole properly.
2. Compile notes and develop initial, open codes based on larger themes/topics (i.e. descriptions of feeding difficulty, impact, interpretation of the feeding difficulty, supports received, intervention recommendations, supports wanted, etc.). This will emulate what I presented at the continuation presentation, but will go into further depth.	First stage in the coding process. Keeps the process grounded in the data.
3. Read each transcript through and open code. Constant comparative method ongoing.	First stage in the analysis process. The use of the constant comparative method is acknowledged as being a way to increase validity of qualitative research.

Data analysis steps	Justification
	Constant comparison method = data broken down into manageable pieces and each piece compared for similarities and differences. Data that are similar in nature (conceptually) will be grouped together under the same conceptual heading.
4. Review with 1 or both supervisors.	Helpful to ensure interpretations are clear, grounded in the data, reduce any subjective interpretations of the data and reach agreements about the data.
5. Look at open codes and start making connections across categories. Look at conditions, context, action/intervention strategies, consequences, and interpretations. Code based on making these connections (i.e. axial coding). Constant comparative method ongoing. *How do the categories relate to each other?*	Second stage in the analysis process. Put the data back together in different ways after open coding. This will relate the data back to itself/see how the data interact in a dynamic way.

Data analysis steps	Justification
6. Review with 1 or both supervisors. Generally discuss stage 3.	Helpful to ensure the axial codes are clear, grounded in the data, comparisons are not too subjective and reach agreements about the data. Generally discussing stage 3 (selective coding) will ensure supervisors are in agreement about the direction of the final stage of analysis.
7. Select the core category and systematically relate it to the other categories. This will involve identifying the core category and relate this to the other categories. Ex. interpretations of parent's implicit theories of feeding difficulties—related to the description of the feeding difficulty, supports received, supports wanted, etc. Validate the relationships (based on the data) and fill in categories that need further refinement/development. This core category is supposed to be the central phenomenon around which all the other categories are integrated.	Final stage in the analysis process. This stage of data analysis will provide the structure for the theory generated from this research (and which will contribute to my emerging working theory.
8. Review with 1 or both supervisors.	Helpful to ensure the study's findings are grounded in the data, clear and representative of the data.

Appendix I

Parent Study Preliminary Set of Open Codes

Open code name	Open code description
Additional LD/IDD needs other than FD	The presence of LD/IDD can affect the family's situation in other ways more than just food/make the food situation more difficult to cope with
Child impact	The ways in which the feeding difficulty has or could impact on the child themselves
Concentration difficulties	Feeding difficulty being compounded by a difficulty with concentration
Concerns for the future	Concerns for the child's future given the feeding difficulty
Diagnostic overshadowing	Support not provided for feeding difficulty as it is seen as part of a broader diagnosis
Early feeding issues	Feeding issues described from very early on (including but not limited to medical or physiological issues)
Early intervention	Early intervention seen as important to support/improve feeding difficulties before they develop further
Factors that would reduce/support with the feeding difficulty	Elements that parents thought would help improve the child's feeding difficulty
Food as a battle	Sense/explicit statements that battles/fights experienced around food/mealtimes
Ideal supports	Supports parents would have liked to receive or think would be an ideal intervention/support for their child's feeding difficulty

Open code name	Open code description
Impact of communication on feeding difficulty	Feeding difficulty almost compounded/ exacerbated by child’s difficulty communicating (food preferences, rationalizing, explaining)
Implicit theory feeding difficulty development	Parents’ implicit theories about the development of their child’s feeding difficulty
Implicit theory feeding difficulty maintenance	Parents’ implicit theories about why their child’s feeding difficulty has maintained/continued to occur
Information about feeding difficulties is key	More information about feeding difficulties is necessary (for parents, professionals, learning about it, dealing with it)
Judgement	Feeling of being judged as a parent because of child’s feeding difficulty
Lifestyle adaptations/impact	Ways in which families have had to adapt their lifestyle due to child’s feeding difficulty & thoughts/perspectives around this
Mothering theme	Unique perspective of feeding difficulty and impact as a mother
Nutrition/health concern	Concerns about child’s nutritional intake and health due to the feeding difficulty
Parent impact (emotional and psychological?)	Direct/indirect impact on parent (s) due to child’s feeding difficulty
Parent implemented efforts or strategies	Efforts or strategies employed by parents to address the feeding difficulty (directly/indirectly)
Poor elements of support received	Elements of support received that parents were unhappy / dissatisfied with

Open code name	Open code description
Positive elements of support received	Elements of support received that parents enjoyed / appreciated
Sensory influence on FD	Impact/influence of sensory on the feeding difficulty
Staff with LD/IDD & FD knowledge	Difficulties of/frustration with being referred to or encountering staff that had no knowledge about these kinds of feeding difficulties or LD/IDD/ASD
Support for parents	Kinds of supports that parents might need in order to handle/continue to handle the feeding difficulty in a way that is sustainable for their families
Support groups	Feelings about usefulness/helpfulness of support groups
Survival	Struggle for survival – descriptions of the life and death severity of the situation
Willingness to starve	Acknowledgement that for this population the children would rather starve than eat foods that are not safe

Appendix J

Parent Study Final Open Coding Framework

Main open code	Subcategory codes
Interplay/context of other aspects of IDD	• Concentration difficulties • Diagnostic overshadowing • Impact of communication difficulty on feeding difficulty • Sensory influence on the feeding difficulty
Impacts	• Child impact • Parent impact (emotional, psychological & caregiver functioning) • Lifestyle adaptations/impact o Parent implemented efforts/strategies • Nutrition/health concern • Concerns for the future
Early feeding issues	
What would help?	• Information about feeding difficulties • Staff with LD/IDD & FD knowledge • Support groups • Early intervention • Support for parents
Food as a battle vs survival	• Judgement & mothering theme • Willingness to starve
Things about the development & maintenance of feeding difficulties	• Implicit theory feeding difficulty development • Implicit theory feeding difficulty maintenance

Main open code	Subcategory codes
Experiences with services	• Poor elements of supports received • Positive elements of supports received

Appendix K

Parent Study Hypothesised Interactions Between Code Categories & Outcomes of Matrix Queries

Initial thoughts about potential interactions	Outcome of matrix query
Early feeding issues leading to food as a battle vs survival	No interaction present
Food as a battle vs survival leading to impacts	Powerful interaction
Impacts being compounded by interplay/context of other aspects of IDD	No interaction present
Food as a battle vs survival being compounded by IDD factors	No interaction present
Impacts leading to experiences with services	Powerful interaction
Experiences with services leading to what would help?	Powerful interaction

Appendix L

Outcomes of Matrix Queries Showing Relationships Between Code Categories to Explore

	Food as a battle vs survival	**Impacts**	**Interplay/ context of other aspects of IDD**	**Experiences with services**	**What would help?**	**Things about development, maintenance or cause of the FD (including Early feeding issues)**
Food as a battle vs survival	-	Many interactions	No results returned	Few powerful interactions	Few results, not powerful	Few powerful interactions
Impacts	-	-	Few powerful interactions	Many interactions	Many interactions	Many interactions
Interplay/context of other aspects of IDD	-	-	-	Few results, not powerful	No results returned	Few results, not powerful
Experiences with services	-	-	-	-	Few powerful interactions	Few results, not powerful
What would help?	-	-	-	-	-	No results returned
Things about development, maintenance or cause of the FD (including Early feeding issues)	-	-	-	-	-	-

Appendix M

Parent Study Axial Coding Framework Developed from Matrix Query Results Exploration

Axial Coding Framework

- Feeding/mealtimes experienced as a battle caused parents to adapt their strategies or lifestyles in efforts to get their children to eat
- Feeding difficulty caused impact to both parent and child
- Families described the feeding difficulty as causing them to have a concern for their child’s health, nutrition & future
- Parents’ descriptions of experiences with services causing them to feel blamed or judged
- Services not focusing on child’s feeding as a primary need was linked to multiple impacts
- Families’ experiences with services was linked to their ideas about what would help
- Families’ descriptions of receiving good support was linked to their situation improving, although not resolved (food still a battle, but a different battle)
- Families not getting the support from services for their feeding needs caused food to feel like a battle with services
- Child’s sensory sensitivities can have compounded impacts
- Child’s ability to communicate can mitigate the impact of the feeding difficulty
- Information about feeding difficulties can help and lack thereof can compound impact
- Impacts reduced with the appropriate supports
- Understanding of the feeding difficulty by the parents and others alleviated the impact of the feeding difficulty

Appendix N

Parent Study Initial Predictions of Data Interaction & Outcomes of Matrix Query

Initial thoughts about potential interactions	Outcome of the matrix query
• Parents are not usually receiving appropriate supports for their child with an IDD's behavioural feeding difficulty	Not outcome of matrix query but overall, the big picture of what parents described
• When parents have received appropriate supports, these have alleviated the impact of the behavioural feeding difficulty	Yes – verified from relationship interaction
• When parents have perceived the support received to be inappropriate (or unhelpful) it has compounded the impact of the feeding difficulty (i.e. it's no longer that food is a battle because of the feeding difficulty, but it's also a battle with services with food consumption at the center of it)	Yes – verified from relationship interaction
• When parents understood why the feeding difficulty was happening it alleviated the impact/changed their approach to support their child & important for service providers to understand why it was happening to provide appropriate support	Yes– verified from relationship interaction
• Parents ideas of ideal supports were likely influenced by both the appropriate supports they had received and the 'inappropriate' supports they received	Yes – verified from relationship interaction

Appendix O

Parent Study Checking Relationships Between Axial Codes for Identification of Selective Codes & Study Findings

	Food as a battle causes adapted	FD causes impact to parent & child	FD causes concern for child’s nutrition,	Experiences with services cause parents to feel blamed or	Poor experiences with services linked to multiple impacts	Experiences with services linked to	Good support linked to situation improving	Poor experiences w services causing food	Sensory sensitivities can compound impact	Communication linked to impact of FD	Information about FDs causes or	Appropriate supports caused reduced	Understanding D&M caused alleviated
Food as a battle causes adapted strategies/ lifestyles	-	Many interactions	-	-	-	-	Few powerful interactions	-	-	-	-	-	-
FD causes impact to parent & child	-	-	Many interactions	Few powerful interactions	Few powerful interactions	-	Few powerful interactions	Few powerful interactions	-	-	Few powerful interactions	Few powerful interactions	Few powerful interactions
FD causes concern for child’s nutrition, health & future	-	-	-	-	Few powerful interactions	Few powerful interactions	-	Few powerful interactions	-	-	-	-	-
Experiences with services cause parents to feel blamed or judged	-	-	-	-	Few powerful interactions	Few powerful interactions	-	Few powerful interactions	-	-	Few powerful interactions	-	-
Poor experiences with services linked to multiple impacts	-	-	-	-	-	Few powerful interactions	-	Many interactions	-	-	Few powerful interactions	Few powerful interactions	-

	Food as a battle causes adapted	FD causes impact to parent & child	FD causes concern for child’ s nutrition,	Experiences with services cause parents to feel blamed or	Poor experiences with services linked to multiple impacts	Experiences with services linked to	Good support linked to situation improving	Poor experiences w services causing food	Sensory sensitivities can compound impact	Communication linked to impact of FD	Information about FDs causes or	Appropriate supports caused reduced	Understanding D&M caused alleviated
Experiences with services linked to parents’ ideas of what would help	-	-	-	-	-	-	Few powerful interactions	Many interactions	-	-	Few powerful interactions	Few powerful interactions	Few powerful interactions
Good support linked to situation improving but not resolving	-	-	-	-	-	-	-	-	-	-	Few powerful interactions	Few powerful interactions	Few powerful interactions
Poor experiences with services causing food to feel like a battle with services	-	-	-	-	-	-	-	-	-	-	Few powerful interactions	Few powerful interactions	Few powerful interactions
Sensory sensitivities can compound impact both ways	-	-	-	-	-	-	-	-	-	Few powerful interactions	Few powerful interactions	-	-
Communication linked to impact of FD	-	-	-	-	-	-	-	-	-	-	-	-	Few powerful interactions
Information about FDs causes or alleviates impact	-	-	-	-	-	-	-	-	-	-	-	Few powerful interactions	Few powerful interactions
Appropriate supports caused reduced impact	-	-	-	-	-	-	-	-	-	-	-	-	Few powerful interactions

	Food as a battle causes adapted	FD causes impact to parent & child	FD causes concern for child’s nutrition,	Experiences with services cause parents to feel blamed or	Poor experiences with services linked to multiple impacts	Experiences with services linked to	Good support linked to situation improving	Poor experiences w services causing food	Sensory sensitivities can compound impact	Communication linked to impact of FD	Information about FDs causes or	Appropriate supports caused reduced	Understanding D&M caused alleviated
Understanding D&M caused alleviated impact for parents	-	-	-	-	-	-	-	-	-	-	-	-	-

Appendix P

Summary of Reviewed Studies (in Alphabetical Order)

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
1. Adams et al. (2020)	1) To describe common feeding difficulties exhibited by autistic children 2) To describe mealtime challenges for the caregiver 3) To describe mealtime strategies used by the carer	South Africa	***Caregiver characteristics*** *n* = 40 Age = 18-65 Gender = Female (*n* = 35), male (*n* = 3), unspecified (*n* = 1), unreported (*n* = 1) Race/ethnicity = Not reported ***Child characteristics*** *n* = 40 Age = 3-9.6 Gender = Male (*n* = 33), female (*n* = 7) Diagnosis = ASD (*n* = 40) Race/ethnicity = Not reported	Exploratory questionnaire	Mealtime experiences of caregivers w/a child w/ASD in South Africa	Thematic analysis (Braun & Clarke, 2013)

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
2. Adams et al. (2021)	1) To explore the experiences of mothers feeding their autistic child with feeding difficulties in South Africa to better facilitate effective interventions. 2) To focus on the impact of context and culture on feeding disorders in South Africa.	South Africa	***Caregiver characteristics*** *n* = 7 Age = 29-45 Gender = Female (*n* = 7) Race/ethnicity = Black (*n* = 6), Indian (*n* = 1) ***Child characteristics*** *n* = 8 Age = 4-9 Gender = not reported Diagnosis = ASD (*n* = 8) Race/ethnicity = Not reported	Semi-structured interviews	Exploration of mothers' experiences of feeding children w/ASD in South Africa	Thematic analysis (Braun & Clark, 2013)

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
3. Ausderau & Juarez (2013)	1) To explore the impact of feeding challenges on family mealtimes among families of autistic children 2) To examine mothers' narratives to provide further understanding and rich description of their family mealtimes	United States of America	***Caregiver characteristics*** *n* = 6 Age = Not reported Gender = Female (*n* = 6) Race/ethnicity = White (*n* = 5), Latinx (*n* = 1) ***Child characteristics*** *n* = 6 Age = 2-7 Gender = Not reported Diagnosis = ASD (*n* = 6) Race/ethnicity = Not reported	Semi-structured interviews	Impact of ASDs and eating challenges on family mealtimes	Narrative & thematic analysis

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
4. Burkett et al. (2022)	1) To elucidate mothers' perspectives on managing restricted eating in autistic pre-schoolers	United States of America	***Caregiver characteristics*** *n* = 11 Age = not reported Gender = Female (*n* = 11) Race/ethnicity = not reported ***Child characteristics*** *n* = 11 Age = 3-6 Gender = Male (*n* = 10), female (*n* = 1) Diagnosis = ASD (*n* = 11) Ethnicity = White (*n* = 9), Asian (*n* = 1), African American (*n* = 1)	Focus group & ethnonursing design	Mothers' stressors and solutions to restricted eating in pre-schoolers with Autism	Leininger's data analysis enabler

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
5. Curtiss et al. (2021)	1) To better understand the processes that facilitate family meals and elucidate challenges that families of autistic children face 2) To explore how families overcome challenges in order to promote wellbeing and family functioning	United States of America	***Caregiver characteristics*** *n* = 16 Age = 30-53 Gender = Female (*n* = 16) Race/ethnicity = Not reported ***Child characteristics*** *n* = 16 Age = 5-14 Gender = Not reported Diagnoses = ASD (*n* = 16), intellectual disability (*n* = 4) Race/ethnicity = White (*n* = 10), Black (*n* = 1), Latinx (*n* = 1), Asian (*n* = 1), Multi-ethnic (*n* = 3)	Mealtime observations & interviews	Dialectic of control and acceptance in mealtimes with autistic children	Grounded Theory (Corbin & Strauss, 2009)

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
6. Estrem et al. (2016)	1) To examine parents' perspectives of paediatric feeding problems to generate a more comprehensive definition of the problem	United States of America	***Caregiver characteristics*** *n* = 12 Age, Gender, Race/ethnicity = not reported ***Child characteristics*** *n* = 9 Age = mean: 2.3 (range 1.17-4.5) Gender = not reported Diagnoses = developmental delay (*n* = 9), ASD (*n* = 3), Fragile X syndrome (*n* = 1), Williams syndrome (*n* = 1) Race/ethnicity = White (*n* = 5), Black/White (*n* = 1), Latinx/White (*n* = 2), Native American/White (*n* = 1)	Semi-structured interview (secondary analysis)	Parents' perspective of the concept of paediatric feeding problems	Concept analysis framework (Rodgers & Knafl, 2000) & Qualitative content analysis (Miles & Huberman, 1994)

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
7. Estrem et al. (2018)	1) To describe parent perspectives of their child's eating and of feeding management 2) To identify themes of feeding management in the context of everyday family life	United States of America	***Caregiver characteristics*** *n* = 12 Age, Race/ethnicity = not reported Gender = female (*n* = 9), male (*n* = 3) ***Child characteristics*** *n* = 9 Age = 2.3 (range 1.17-4.5) Gender = not reported Race/ethnicity = White (*n* = 5), Black/White (*n* = 1), Hispanic/White (*n* = 2), Native American/White (*n* = 1) Diagnoses = ASD, Fragile X syndrome, Williams Syndrome, developmental delay (n of each not specified)	Semi-structured interviews	Family life descriptions when a child has a feeding disorder	Comparisons across families' thematic summaries

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
8. Floríndez et al. (2021)	1) To explore how the process of visual food journaling provided an opportunity for Latinx families who had autistic children and typically developing children in Los Angeles, California to better understand their diet and food choices in relation to their oral health	United States of America	***Caregiver characteristics*** *n* = 10 Age = not reported Gender = female (*n* = 9), male (*n* = 1) Race/ethnicity = Latinx (*n* = 10) ***Child characteristics*** *n* = 10 Age = 6-12 Gender = male (*n* = 9), female (*n* = 1) Diagnoses = ASD (*n* = 10) Race/ethnicity = Latinx (*n* = 10)	Semi-structured photo-elicitation interviews	Eating challenges and food selectivity in Latinx children with and without ASD & implications for oral health	Thematic analysis

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
9. Glasson et al. (2020)	1) To use qualitative methods to explore the impacts of gastrostomy on the lives of both children with intellectual disability and their families within a quality of life framework	Australia	***Caregiver characteristics*** *n* = 21 Age, Race/ethnicity = not reported Gender = female (*n* = 21) ***Child characteristics*** *n* = 21 Age = 2-18 Gender = male (*n* = 12), female (*n* = 9) Diagnoses = CP (*n* = 11), genetic diagnosis (*n* = 7), GDD/ID (*n* = 3) Race/ethnicity = not reported	Semi-structured interviews	Gastrostomy and quality of life in children with intellectual disability	Directed content analysis

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
10. Hillman et al. (2017)	1) To fill a gap in the literature regarding the unique experience of traditional (i.e. non-custodial) grandparents of children with ASD from the first-person perspective, including both positive and negative aspects of grandparenting	United States of America	***Caregiver characteristics*** *n* = 1870 Age = under 65 (*n* = 1047), 65+ (*n* = 823) Gender = female (*n*=1533), male (*n*=337) Race/ethnicity = White (*n* = 1795), Black (*n* = 37), American Indian or Native Alaskan (*n* = 1), Latinx (*n* = 75) ***Child characteristics*** *n* = 2053 Age = 1-18 (*n* = 1833) Gender = male (*n* = 1558), female (*n* = 312) , not reported (*n* = 183) Race/ethnicity = not reported Diagnoses = ASD (*n* = 2053)	Survey (open ended questions)	Grandparents' experience of ASD	Grounded theory (Strauss & Corbin, 2008)

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
11. Ismail et al. (2020)	1) To explore the nutritional knowledge among parents and special educators of autistic children and how it reflects on their food provision practice through a qualitative approach	Malaysia	***Caregiver characteristics*** *n* = 14 Age = female Mean age = 36.3, male Mean age = 33, range of all participants 28-43 Gender = female (*n* = 8), male (*n* = 6) Race/ethnicity = not reported ***Child characteristics*** N = not reported Age = range 4-7 Gender, Race/ethnicity = not reported Diagnoses = ASD all (no *n* provided)	Focus groups	Exploring eating and nutritional challenges for children w/ASD	Thematic analysis

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
12. Lazaro et al. (2016)	1) To investigate the eating behaviour of autistic individuals through their mothers' narratives 2) To collect information on the family's eating behaviour and how the family deals with the child's eating restrictions	Brazil	***Caregiver characteristics*** *n* = 18 Age = mean 42.2 Gender = female (*n* = 18) Race/ethnicity = not reported ***Child characteristics*** N = not reported Age = 5-28 Gender = all male (*n* not reported) Race/ethnicity = not reported Diagnoses = ASD (*n* not reported)	Semi-structured interviews	Maternal narratives of eating behaviour of their children with ASD	Narrative approach

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
13. Parr et al. (2021) – Chapter 9	1) Understand parents' and health professionals' views on interventions to test in research, important outcomes to measure and measurement tools to use 2) Explore their views on future research priorities for interventions and choosing appropriate outcome measures	United Kingdom	***Caregiver characteristics*** *n* = 19 Age, Gender, Race/ethnicity = Not reported ***Child characteristics*** *n* = Not reported Age, Gender, Race/ethnicity = Not reported Diagnoses = Neurodisability (*n* not reported)	Focus groups	Parents' views on intervention research, outcomes, measurement tools, views on future research priorities for interventions & choosing appropriate outcome measures for these	Not reported

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
14. Rogers et al. (2012)	1) To explore qualitatively the processes involved in addressing the feeding challenges of young autistic children from the mother's perspective 2) To investigate how feeding challenges develop and change, and what mothers do to ensure that their autistic children are fed adequately over time	Canada	***Caregiver characteristics*** *n* = 11 Age = 28-47 Gender = female (*n* = 11) Race/ethnicity = White Canadian (*n* = 10), African Canadian (*n* = 1) ***Child characteristics*** *n* = 12 Age = 4-10 Gender = male (*n* = 11), female (*n* = 1) Diagnoses = ASD (*n* = 12) Race/ethnicity = not reported	Semi-structured interviews	Mothers' challenges in feeding their children with ASD (more than just managing picky eating)	Grounded theory

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
15. Suarez et al. (2014)	1) To learn about the experience of mealtimes from the perspectives of parents of autistic children with food selectivity	United States of America	***Caregiver characteristics*** *n* = 4 Age = not reported Gender = female (*n* = 4) Race/ethnicity = White (*n* = 3), Latinx (*n* = 1) ***Child characteristics*** *n* = 4 Age = 6.8-8.5 Gender = male (*n* = 4) Race/ethnicity = not reported Diagnoses = ASD (*n* = 4)	Semi-structured interviews	Examining mealtime experiences of mothers of children with ASD and food selectivity	Phenomenological analysis (Moustakas, 1994)

Author & year	Study aims/ objectives	Country	Sample description (age in years)	Stated method	Topical focus	Theoretical approach to analysis
16. Tan et al. (2021)	1) To describe what mothers' report is supportive, what is unsupportive or may even hinder them in achieving successful feeding and swallowing for their child 2) To describe where mothers seek support from	Australia	***Caregiver characteristics*** *n* = 16 Age = not reported Gender = female (*n* = 16) Race/ethnicity = not reported ***Child characteristics*** *n* = 16 Age = M=5.6 (range 2-12) Gender = male (*n* = 10), female (*n* = 6) Race/ethnicity = not reported Diagnoses =ASD (*n* = 4), SPD (*n* = 3), GDD (*n* = 4), FTT (*n* = 2)	Semi-structured interviews	Mothers' perspectives of support for their children with feeding/ swallowing disorders	Thematic analysis (Braun & Clarke, 2006)

Appendix Q

JBI Quality Indicators

[REDACTED]

Appendix R

Detailed Synthesis of Themes or Summary of Main Findings for Included Studies

Author & year	Main themes or summary of findings	Points under each theme
1. Adams et al. (2020)	Common feeding challenges in children w/ASD • Picky eating • Eating times (too fast and too slow)	• Children ate only certain types of food related to texture, taste and/or colour, had to ensure this preferred food was available even if meant more effort (i.e., pre-preparing meals). • Picky eating is frustrating and may be easier to provide food that they accept even if different to what rest of the family eats • Extra planning and cost related to selective eating • Children eating too slow or too fast, annoyance at long mealtimes, concerns about eating too quickly (not chewing properly, may choke or vomit, making a mess)
	Caregiver mealtime challenges • Eating together • Financial implications • Unsupportive friends and families	• If children were selective eaters but were able to sit at mealtimes without making a mess, caregivers didn't consider their feeding habits to be a challenge • Successful mealtimes described to be when all family members sat at a table, ate together and shared stories, caregivers reported autistic child would refuse to sit at the table or disrupt rest of family during mealtimes • Even caregivers with incomes experienced financial concerns managing their child's diet, had to cook 2 meals which resulted in financial stress and burden for caregivers, some

Author & year	Main themes or summary of findings	Points under each theme
		caregivers unable to provide preferred foods and force fed children what the rest of the family was eating • Lack of support from families, limiting where they could go and who they could visit, families restricted to meals at home for their autistic children, choosing to avoid places due to lack of support (further exclusion and isolation), absence of a strong support system impacts caregivers well-being emotionally, socially, and psychologically
	Mealtime strategies • Negotiating • Positive reinforcement • Television • Ignoring the child's behaviour	• Mealtimes required adaptations to typical family mealtime to promote eating and mealtime participation, strategies aimed at encouraging mealtimes that were more 'typical' in caregivers' perspectives (sitting at the table with the rest of the family, eating what the rest of the family is eating, reducing mealtime distractions) • Strategies were also used to try to alleviate caregivers' stressors (negotiating, positive reinforcement, television, ignoring the behaviour)
2. Adams et al. (2021)	Description of feeding difficulties	• Mothers struggled with understanding what was wrong with their child's feeding; diagnosis helped them understand the issue and helped them accept the situation and ways they might be able to help their child (they had an explanation, and this helped them find more appropriate ways of managing the feeding difficulty)

Author & year	Main themes or summary of findings	Points under each theme
		• Child's restrictive diets meant unhealthier food options with sensory preferences, children would engage in challenging mealtime behaviours or food refusal when presented other food options, and mothers struggled to find healthier options so resorted to feeding them what they would eat (although aware of negative consequences of unhealthy foods)
	Financial burden of selective eating	• Financial stress and burden associated with caring for and feeding an autistic child (cost of food, food preparation for a selective eater, wasted food due to child refusing to eat, trying to meet child's specific dietary requirements, inconsistent diets, preparing separate meals for their autistic children than the rest of the family • Most money goes into buying food and harder to set money aside for other things, difficult to budget for whole family when feeding autistic children, financially draining to feed children specialised diets (as recommended by professionals like GPs or dietitians) • Financial burden already high to these mothers (unemployed or low-income jobs, financial aid for their child is the only source of income, single parents with no financial support from child's father)
	Adapted mealtime routines	• Mealtimes needed to be adapted to accommodate autistic child (child eating separate to rest of the family)

Author & year	Main themes or summary of findings	Points under each theme
		- Mothers taking on the primary role of feeding, mealtimes reported as meaning that families sit around a table together to eat but this was not their reality, and felt that they couldn't experience typical mealtimes - Family routine and mealtime behaviours were adapted to accommodate autistic child, dictating the structure of mealtime and families had to work around the child's needs
3. Ausderau & Juarez (2013)	Eating together	- Mothers emphasised the importance of eating together as a family but feeding difficulties posed challenges to eating together as a family - Giving up on family mealtimes, dissatisfied at not having family mealtimes
	Adapted mealtime routines	- Adaptations made to mealtimes to encourage participation and eating, forming mealtime routines to alleviate stress and make space for child's feeding difficulty - Strategies were provided by interventionists, stumbled on, gradual exposure, following child's rules for food presentation and preparation, and going to lengths to keep the child at the table - Families participated less in mealtimes but showed resilience to autism and feeding challenges by creating more supportive feeding environments

Author & year	Main themes or summary of findings	Points under each theme
		- These adapted practices often became integrated to their normal mealtime routines
	Constructing mealtimes alone	- Mothers felt a sense of responsibility for feeding the family and pressure to create family mealtimes - Excessive amounts of time creating family meals and difficult accommodating needs of their autistic child (2+ menus created) - Lack of understanding and support regarding mealtimes from relatives, friends and partners; mothers were constructing mealtime with limited support
	No longer just a sibling	- Siblings took on a different role, encouraging positive behaviours for their autistic siblings, modelling desired eating behaviour, initiating therapy strategies to encourage their sibling to try what they were eating - Siblings impacted by imitating autistic sibling's poor feeding behaviours and wanting to eat what their siblings were eating, added stress to family mealtimes - Conflicting feelings about giving siblings this responsibility
4. Burkett et al. (2022)	Coping with the struggle to achieve adequate nutrition while maintaining hope for change	- Worry exacerbated when child preferred unhealthy foods - Children were brand specific and mothers avoided deviating from these preferences, which added more stress to mealtimes

Author & year	Main themes or summary of findings	Points under each theme
	• Concern for adequate nourishment • Anxiousness versus hopefulness for change	• Mothers described anxiety due to their child's refusal to eat any food at all • Frustration at cycling between accepting a new food and then refusing to eat/touch that same food • Difficult to anticipate and prepare foods children would accept if it varied from week to week • Feeling hopeful when find a strategy that works and defeated when it is no longer effective
	Feeling stressed, guilty, dismissed, but reaffirmed when joining a community of mothers • Stress and guilt about their own failures • Feeling dismissed by others • Feeling a sense of community with other mothers	• Asking mothers to provide new foods for children during feeding interventions put a strain on the whole family • Mothers having to decide between having difficult mealtimes to implement strategies they were being recommended or having an easy mealtime with what the child will eat • Guilt that their child's food preferences are unhealthy, but which are provided so their children eat something and ensuring their children don't stave but having to go to lengths to ensure they ate (in a high chair, in front of the TV) • Dismissed/judged by healthcare professionals, family members, people in the community in social situations, which increased their guilt and stress at mealtimes • Desire to go out in public and have their child eat normal food without being stared at

Author & year	Main themes or summary of findings	Points under each theme
		• Mothers found it valuable to be part of a group where they were not judged and felt heard, refreshing being around people that understood but difficult to encounter these people • Sometimes talking to other parents was more helpful than talking to health care professionals because they understood the lived experience
	Using trial and error for feeding strategies learned from multiple sources • Strategies learned on their own • Strategies learned from other parents and healthcare practitioners	• Parents had to be innovative to find ways their children would eat • Learning from other parents was beneficial and decreased parents needing to do trial and error for strategies they found, helpful to take the pressure of the parent and learn from someone else
5. Curtiss et al. (2021)	Expressions of love through control: "I'm doing this because I love you"	• Parents used control during mealtimes as expressions of love • Parents had to exert control for a mealtime routine to be achieved • Parents controlled what families ate, what food was kept in the house, when and where eating occurred, and rules and exceptions of these during mealtimes • Parents wanted to prepare their children for the future and that meant setting boundaries/expectations

Author & year	Main themes or summary of findings	Points under each theme
	Expressions of love through acceptance: “he can be himself here”	• Parents expressed love through acceptance in the ways that they interacted with their children, set expectations and supported them • Providing a space where their children could be themselves and experience acceptance • When parents could see beyond their child’s challenging behaviour, they were able to find ways to support them, and it was challenging for parents to support their children when their expectations were not aligned with the child’s needs
	Balancing control and acceptance: “the talk and chatter. And the food.”	• Acceptance shaped parents’ expectations of what their child could and should to, and this changed the ways they supported their children, when the expectations aligned it strengthened the parent/child bond and parents had to provide control so their children could meet the expectations • Acceptance allowed parents to respect their children’s own thoughts, wants, opinions, agendas. Parents who allowed for their children’s agency in this way were more likely to have higher quality interactions with their children. Children felt safe to express their agency. • Acceptance of the child’s limits, preferences and strengths allowed mothers to align the control necessary for participation in mealtime activities

Author & year	Main themes or summary of findings	Points under each theme
	Struggling to balance control and acceptance: “please don’t let things blow up”	• When there was a struggle for balance there could be misaligned expectations between parent’s wishes and the child’s capabilities • What the child ate was a common area that parents struggled balancing acceptance and control in • As was general mealtime behaviour and routines
6. Estrem et al. (2016)	Attributes of the feeding difficulty (features or characteristics of the problem) • Problematic feeding behaviours • Selectivity or restriction by texture, type or presentation • Failure to thrive and growth issues • Feeding problem as a journey	• Challenging mealtime behaviours were a barrier to consuming enough food • Child’s food intake was restricted in some way due to texture avoidance, food allergy, limiting quantity, preferences for ways food is presented • Parents worked hard to ensure their children ate enough and being told their child was FTT or not growing adequately changed the feeding strategies they used. Child could resolve from FTT status but not reflective of feeding difficulty being resolved, but rather the efforts of parents to work hard to have successful feeding • Parents characterised their child’s feeding difficulty as a journey that unfolds over time, changes in feeding described as a ‘roller coaster’
	Consequences/effects of the child’s feeding difficulty	• Parents used multiple strategies to address their child’s feeding difficulties (not eating away from home or planning in

Author & year	Main themes or summary of findings	Points under each theme
	• Adaptations made by parents • Parent impact • Family impact • Feeding tubes	advance extensively, making purees, eating in high chairs), best chance for successful feeding if done at home • Parents had limited ability to work, be away from their child, sadness and frustration to the limits on their own lives due to child's feeding difficulty, mothers had daily/constant impact as often primary feeders, constantly on their minds • Child's feeding difficulty limited time for other family activities, difficult to do on outings, holidays and travel, child's feeding described as all-consuming, distress with extended family not understanding child's limitations • Feeding tubes were seen as a consequence of feeding difficulties, some positive views and some negative, expressions of relief upon knowing child would have nutrition when it was so difficult previously
7. Estrem et al. (2018)	Child's daily life and identity as an eater • Defined by the differences • Defined by the (un)predictability in feeding success • Intertwined with other conditions	• Parents saw their child's daily life as being normal despite their feeding difficulty & child's daily life was dictated by feeding needs and adjustments to facilitate feeding • What children ate described in context of what, how they ate and how it was different from what peers might eat • Successful feeding was unpredictable, and families anticipated more intensive feeding support needed

Author & year	Main themes or summary of findings	Points under each theme
		• Concurrent conditions seen as being highly related to the feeding difficulty (feeding difficulty occurring as a result of their concurrent condition)
	Feeding management ability • Knowing their child • Parents knowing their own strengths and partner's strengths • Finding the easy way and identifying the 'harder stuff'	• Feeling like they could recognise their child's hunger cues/fullness cues or impending refusal, this helped with knowing when they could push their children's eating/how much. It was disconcerting to parents when children refused a food that was previously accepted • Parents identifying their own strengths/weaknesses – being consistent, giving breaks, hard to push new foods/complex textures, following professionals' advice, confidence to modify that advice to suit family's needs. Acknowledging/ praising when partner had a strength they did not • Adapting routines to manage their child's feeding, felt less able to manage if routine couldn't be established/these were disrupted
	Feeding management effort • Mealtime efforts • Food preparation effort • Efforts to seek extraordinary care • Care coordination	• Time and work parents perceived themselves giving to their child's feeding management – extraordinary & extremely time consuming & always on their minds • Feeding took a long time (accepting first bite or continue eating until had enough) • Food preparation was time consuming (making pureed foods, battle to try different foods)

Author & year	Main themes or summary of findings	Points under each theme
		• Intensive feeding programmes attended or considered but inaccessible to some families (time off work) • Lots of effort from parents to coordinate child's care, appointments, referrals, etc. • Thinking about managing feeding their child all the time/all day long
	Family life difficulty • Feeding was not flexible • Not sleeping, not eating	• Extent to which parents viewed child's feeding difficulty as making family life a challenge • Child could not be fed successfully outside of the home, families adapted to/avoided daily activities outside of the home, families unable to travel with or without the child, outings planned around mealtimes because feeding outside the home was not an option, unable to eat out at restaurants or could go but with adaptations and adjusted expectations, child limited in who could feed them so parents unable to be away from child • Concurrent sleep and eating problems meant there was never a respite
	Feeding management impact	• Having a child with a feeding difficulty changed the way that families lived their daily lives, bringing unexpected and unwanted changes, some reported it bringing them closer together

Author & year	Main themes or summary of findings	Points under each theme
		• This struggle was not common with others and they felt isolated and anxious • Needing to create new ways to be a family • Families living with uncertainty, hopeful for the future but difficult to imagine what their family life could be like
	Parent mutuality	• Partnered parents mostly shared short- and long-term goals for their child’s feeding • Parents could have different approaches or philosophies of mealtime management than their partners
8. Floríndez et al. (2021)	“Maybe I don’t do as well as I thought I did”	• Wanting to encourage child to eat more nutritious food and wishing did not give into demands so frequently
	“He is actually pickier than what I thought”	• Noticing that their children were more selective than they thought when they saw with pictures from visual methodology what their children ate
	“Food became fun”	• The photo journaling process encouraged their children, who were normally more selective, to try new foods (pushing their sensory boundaries and food limits)
9. Glasson et al. (2020)	Negative emotions	• Challenging behaviours had been associated with feeding difficulties before a gastrostomy (reduced following gastrostomy)
10. Hillman et al. (2017)	Barriers to care • Instrumental concerns	• Diet (mealtime preparation and eating) was a barrier to activities of daily living eating due to limited foods accepted due to issues with food texture

Author & year	Main themes or summary of findings	Points under each theme
11. Ismail et al. (2020)	Lack of knowledge on Malaysia's dietary guidelines	• Superficial description of guidelines provided, difficult to follow guidelines with a child that is a selective eater
	Child's food preferences/ Challenge of child's age factor influencing adherence to Malaysian dietary guidelines	• In toddler stage, children seemed to make more decisions about the foods they preferred (mostly based on texture and appearance)
	Challenge in introducing new foods	• Issues accepting food due food appearance is based on colour and texture • Issues accepting food due to sensory issues
	Oral health related to sensory issues	• Oral health issues related to child's eating habits and preferring hard and crunchy foods
	Parents perception of child nutritional status	• Children looked malnourished (over/under weight) and thought to be caused by long-term food refusal and food selectivity
	The need to have a nutrition module or guidelines for children with ASD	• Worry about child's nutritional status (how picky eating would affect weight) • Wanted specific guidelines to provide based knowledge about healthy food and would consider sensory issues • Wanted suggestions on variety of foods and recipes
12. Lazaro et al. (2016)	Child's eating patterns • Breastfeeding • Changes in eating behaviour	• Breastfeeding was stopped early because infant refused to breastfeed, supplemented feeding with formula was recommended by a doctor because baby spat breastmilk out and refused to take it, extended breastfeeding described

Author & year	Main themes or summary of findings	Points under each theme
	• Food restrictions	• Sudden and unexpected changes in eating behaviour • Children rejected foods with certain seasonings, vegetables/legumes, fish, fruit (or consumes only specific fruit), food without juice/sauce. Varied restrictions on texture of food, complaints about smell of food
	Family's attitudes in relation to child's eating habits • Mother's attitudes regarding new foods • Where meals are taken	• Some mothers accepted child's refusal to eat before they tried a food, others did not and attempted to contrive their interest in the food • Some families put children outdoors for mealtimes or fed the child separately to other members of the family
	Food related behaviour • Behaviour altering foods • Food used as a bargaining chip • Strategy used to get food • Reaction to the foods that are rejected • Reaction to new kinds of foods	• Some foods altered the behaviour of the children (overt behaviours and organismic changes) – irritation, euphoria, agitation, stereotypic behaviour, sleep difficulties, increased crying, increased difficulty in social situations, bowel regularity, constipation, abdominal swelling. Mothers consulted professionals about GFLC diets but did not take this forward for financial reasons. • Incentive provided for children to finish their meal (snacks or preferred activity). This usually replaced lunch or dinner with high-calorie dessert or snack • Children had strategies to get their preferred food and family members gave the child what they wanted when they

Author & year	Main themes or summary of findings	Points under each theme
		insisted or screamed. This could escalate to self-injurious behaviour and tantrums • Children could show nausea or vomiting as a reaction to food texture and it could influence the family's attitudes • Children could outright refuse new foods and it could influence mother's future behaviour
13. Parr et al. (2021) – Chapter 9	Interventions for eating, drinking and swallowing for young children with neurodisability	• Usual practice to use multiple interventions at the same time or sequentially • Some interventions crucial to optimise safe eating and drinking • Psychological support for parents and children important first-line intervention because of high level of anxiety and stress related to eating, drinking and swallowing difficulties (but not often available from professionals) • Informal support from peers on social media/support groups can reduce isolation, help with sharing ideas and recognise progress
	Individual context of the child and family	• Importance of individual context to determine goals of interventions and influence the selection of interventions for families • Need to work with parents and professionals to determine priorities for an individual child

Author & year	Main themes or summary of findings	Points under each theme
		• Noted considerations related to: family's capacity to understand and implement interventions; family culture/attitudes around food, eating habits, and mealtime; child and family's motivation to change; child's developmental age (rather than chronological age) and developmental profile; child and family's psychological well-being and additional stressors on families/children; child's health
	Underlying medical issues	• Need to address medical concerns before/alongside eating, drinking, swallowing interventions because of significant effect on health, quality of life and well-being • Interventions may not work because medical concerns not addressed first
	Differences between professionals and between professionals and parents	• Health professionals do not always share parents' views of long term prognosis for a child's eating, drinking and swallowing difficulties and can lead to misinformed and unrealistic expectations around eating
	Differences in services offered across the UK and the multidisciplinary team • Multidisciplinary team working • Service delivery	• MDT working recommended because no one profession holds all the answers, MDT could involve: SaLT, dietitian, OTs, paediatrician, nurses, psychologists, school staff • Parents need consistent messages from health professionals to support them with feeding interventions and manage their intervention expectations

Author & year	Main themes or summary of findings	Points under each theme
		• Concerns about lack of recognition and availability of formal support or intervention for children with behavioural feeding difficulties • If child's needs not recognised by health professional's parents wouldn't seek help from them • Parents identified their own strategies (internet, charity groups) • Limited health professional resources meant finding alternative ways of working with children and families to meet their needs • Children with behavioural feeding difficulties receive limited support from local health/community services and a small number of them are seen in tertiary NHS services, children at risk of aspiration or choking received most attention • Parents found formal guidelines around service provision, role boundaries and care pathways unhelpful and frustrating • Some services only assess, advise and discharge, requiring referral to local teams to review children again – challenging for parents where it is difficult to re-refer (long waiting lists etc.). • Parents reported that health professionals did not assess the capacity of parents to implement the interventions they recommended

Author & year	Main themes or summary of findings	Points under each theme
	Health	- Important outcome - Focus on ensuring children have safe swallows as has significant implications – respiratory health issues, parental anxiety, etc. - Concerns about chronic nutritional deficiencies
	Growth	- Important outcome - Parents thought health professionals placed greater value on weight than they themselves did, and focusing on weight gain could increase parents' anxiety - Focusing on weight gain could affect parents' engagement with an intervention if they felt criticised or judged in relation to their ability to care for their child if their child didn't gain/maintain weight as expected
	Nutrition	- Important outcome - Linked to the amount of food and the variety of food, and an issue for children with feeding difficulties - Concern of impact of unhealthy diets on children's health in the future - Parents concerned about limited future choices when children were more independent from them - Could push for adequate intake but might not be tolerated by child, could cause stress for parents if vomiting, reflux, fluid/food loss occurred during meals

Author & year	Main themes or summary of findings	Points under each theme
		• Difficult to check for adequate nutrition through blood tests
	Quality of life and participation	• Key outline • Child's enjoyment of food and mealtimes was important and had an influence on their quality of life • Quality of life should be considered for parents and siblings also, as feeding difficulty had an impact on them also • Families experienced stress from not being able to participate in social situations that involved meals • Parents considered it important for children to experience different textures and tastes of food and manage eating in different environments • Acknowledgement that child's feeding difficulty could impact the parent-child relationship, high levels of stress experienced and affects their relationship with their children
	Psychological well-being	• Reductions in stress and anxiety of parents was an important outcome • Psychological well-being was often overlooked • Interlinked stress and anxiety of parent and child • Stress noted to arise from: limited professional support and resources; variability in feeding difficulty; fear of asking for help because not wanting to be judged; etc. • Parents wanted to feel more in control and select the aims and strategies of feeding interventions

Author & year	Main themes or summary of findings	Points under each theme
		• Parents felt motivated to work on interventions when they shared decision making with health professionals and worked with them using small goals • Pressures to eat could increase child’s anxiety or stress around food, children experienced frustration at their limitations as well • Thought that anxiety and stress could be reduced quickly with appropriate involvement and intervention by a health professional
14. Rogers et al. (2012)	Recognising the feeding challenges: “You wake up and realise he’s only eating five different foods” • Patterns of onset • Beyond picky eating • Restricted and narrowing repertoire	• Feeding challenges present from birth and persisting as child got older or typical feeding until 12-14 months when number of foods became restricted or combination of both • Confusing and hectic process trying to feed their children, trying to understand what was ‘normal’ picky eating or a genuine feeding issue & resorting to catering to child’s preferences in efforts to get any food into them • Analogies describing child’s feeding issues • Difficulties establishing enough food for adequate intake and nutrition (some ended up hospitalised), missing or limited repertories in at least 1 food group
	Defining the nature of the feeding challenges: “He gags at the smell of food cooking”	• Mothers trying to understand why their children were exhibiting these difficulties

Author & year	Main themes or summary of findings	Points under each theme
	• Sensory differences • Need for sameness • Food jags • Behavioural challenges • Co-morbidities	• Sensory aversions to properties of food, sometimes resulting in vomiting • Related to characteristics of ASD, needing consistency and being inflexible, becoming brand-specific, sensitive to changes in taste and the way food looked when it was presented, foods being dropped entirely if changed at all • Food accepted for some time then suddenly dropped, inconsistencies in accepted foods, difficult for mothers to ascertain what was normal and what was a genuine feeding issue • Challenging mealtime behaviours explained by mothers (severe aversions, communication difficulty, difficulties sitting) • Comorbidities (anxiety, food sensitivity, lactose intolerance, gut issues), oral-motor/chewing difficulties, hoarding/mouth stuffing, not feeling hunger or responding to hunger cues • Described difficulties meeting child’s eating needs in social situations, and feeing child while on a whole-family vacation
	Seeking support and validation of the feeding challenges: “When I say he doesn’t eat, he doesn’t eat”	• Health-care professionals dismissing mothers, being left on their own to manage • Inadequate or inappropriate advice received • Diagnostic overshadowing of medical problems due to ASD diagnosis

Author & year	Main themes or summary of findings	Points under each theme
		• Feeling like feeding issue not treated as important even though recognised it was serious • Referral to specialised feeding clinic was challenging or discouraging
	Staging their approach: "I basically try to follow my own instincts" • Initially ensuring adequate intake • Moving beyond intake • Increasing repertoire	• Mothers wanted to follow their child's lead and used a gradual approach to implementing individualised feeding strategies and approaches • First thing was figuring out what was going on with the child's feeding issue and ensuring they were consuming enough food. Mothers cooked what was quick and children would eat, at times they would only give them highly preferred foods – at this time the goal was to find what the children would eat without causing distress (i.e., prioritising food consumption, not pushing the boundaries or balanced diet) • Then mothers tried to increase food intake and adapted meals to increase nutrition and acceptability to child (stuffing accepted foods with nutrients)
15. Suarez et al. (2014)	Unfulfilled hopes for mealtime as quality family time	• Deep dissatisfaction with family mealtime experience (stressful, chaotic, draining – resulting in separate meals for family members) • Different to what they imagined family mealtimes before autistic child was born – feeling of missing out on normal family activities

Author & year	Main themes or summary of findings	Points under each theme
		• Family mealtimes described as unpleasant and having negative impact on family life • Feeling like were not able to create and enjoy quality family mealtimes – feelings of guilt and worry for their child's future as a result
	Reasons for mealtime not working for the family	• Autistic child had difficulties sitting at the table • Child unable to sit at table and limited variety of accepted food were described as reasons why family couldn't achieve the mealtimes they wanted and being dissatisfied with these • Noted that children were limited by insisting on sameness in regards to food and the sensory properties of food
	Strategies to make mealtime a success….or not	• Lots of strategies tried to try to improve their mealtime experience • None were successful with regards to meeting mothers' wishes and expectations for mealtimes • Many attempts to make mealtimes less chaotic even if it meant giving up their ideas of mealtimes (e.g., giving up on family meals) • Carefully picking mealtime environments, especially when families were eating outside of the house) • Cooking several different meals – exhausting for mothers

Author & year	Main themes or summary of findings	Points under each theme
		• Attempts to keep autistic child in their chair during meals (strapping, rewards, social stories) bu none resulted in sitting down for family meals consistently • Attempts to increase variety of food consumed, some help from professionals but no ongoing support for this issue, strategies not successful or resulting in meaningful change
	Searching for answers	• Compassion for autistic child and their mealtime difficulties • Feeling confused and frustrated over family's mealtime situation • Searching for answers and trying to understand to be able to help their families and experience more positive mealtimes
16. Tan et al. (2021)	Microsystem	• Important to get knowledge about child's disorder from health professionals to help mothers deal with their child's complex issues • Struggle with understanding (dis)ability • Feeding as the highest concern but didn't know who would provide feeding support • Difficult to access support even when MDT was involved • Negative outcomes for the family attributed to child's feeding difficulty (marriage breakdown, marital conflict, conflict with parents or in-laws, child relationships, sibling relationships)

Author & year	Main themes or summary of findings	Points under each theme
		• Mothers felt critiqued in their parenting (blamed for inaccessibility of support, causing their child's condition, source of conflict w/child's grandparents) • Support within immediate family who joined mothers in seeking support or answers • Mothers felt responsible for family's discomfort & disappointment with the child's challenges (family support led mothers to question their own mothering abilities)
	Mesosystem	• Support in social networks • Helpful approaches found online but on American/international sites, feeling like these approaches not well understood by health professionals implementing them in Australia • Social support helped validate mothers' concerns, but it would have been highly valuable to talk to others experiencing the same kind of difficulty but this wasn't available • Not easy to eat away from home – judged in the community • Mixed experiences of support from child's school/day care (supportive vs. not understood or accepted)

Author & year	Main themes or summary of findings	Points under each theme
	Exosystem	• Mothers actively seeking support • Negative experiences with health professionals when accessing support (disbelief, judgmental attitudes) • Complex undermining of the mothers' roles and their competence as mothers by health professionals (attribution of blame on mothers) & mothers asserting their roles and defending their decisions/efforts • Health professionals blaming them and assuming unwarranted and insensitive mental health or psychosocial issues • Not wanting to be viewed as demanding • GPs acting as gatekeepers to other services • Given shallow and unreasonable suggestions in unhelpful matter made mothers feel like GPs and paediatricians were not listening or believing • Speech pathologists criticsed for not having an interest in or knowing about feeding difficulties • Mixed experiences of nurses (valuable, helpful and knowledgeable vs. only interested in breast feeding) • Difficulties transitioning from hospital to community services – feeling like losing expertise, parents not aware of implications of this transition on their child's care, lack of

Author & year	Main themes or summary of findings	Points under each theme
		communication between health professionals, inconsistency with therapists
	Macrosystem	- Difficulties accessing services often systemic restrictions related to services (long waiting times, difficulties accessing feeding teams)
	Chronosystem	- Impact of many transitions of care related to the child's age and stage of development - Schools and daycares perceived as not supportive or inclusive when managing feeding difficulties

Appendix S

Master Themes and Subthemes with Supporting Quotes and Translational Analysis

Master theme	Translation	Subthemes	Example supporting quotes
Impacts to the family system	Reciprocal	Daily life difficulties	“The thing that has affected me the most is when it comes to money. At the school they just give us transport money. It is a challenge because I have to use his grant money to buy him things that he needs, his food and then that is not the right way to do it. I have to cater for other things, for clothes and other things that he needs. Then they have school trips that they need the grant money for. But now I am using it to buy this expensive food for him so that he can eat” (Adams et al., 2021; p. 169).
	Reciprocal	Caregiver impact	“Frankly... it’s hard being tied to your child when you are the only one that can feed them” (Estrem et al., 2016; p. 5). "He wants the dollar pack of hotdogs…I feel like I’m killing my child because I’m giving him crap. But I don’t know what else to

Master theme	Translation	Subthemes	Example supporting quotes
			do" (Burkett et al., 2022; p. 2592).
	Reciprocal	Constructions of mealtimes & letting go of these	“It is stressful. I would love him to have a nice hearty meal with his sister and myself and dad. He refuses to try “normal” food and his reaction really makes me sad. Mealtimes are divided because sometimes even the sight of our food will upset him. We would love to sit at the table and all eat together” (Adams et al., 2020; p. 5). “Watching other people eat is kind of a sore spot with him, he won’t eat with us at the table . . . so like we don’t even have it set up to eat as a family anymore which kind of stinks. . . . he and Jessie usually eat at that table (small table in the living room) because we still want him to eat with at least somebody.” (Ausderau & Juarez, 2013; p. 318).

Master theme	Translation	Subthemes	Example supporting quotes
			"We don't sit down [for meals] as a family anymore. It's too stressful. That's been a very huge impact on our life" (Suarez et al., 2014; p. 104). "I feel like as a family we are missing our connection. We're missing the opportunity to be connected with each other" (Suarez et al., 2014; p. 104). "Sitting together having a family meal is not our reality" (Tan et al., 2021; p. 5)
How families cope	Reciprocal	Capitulating to get food 'in'	"I have guilt feeding him what I feed him because it's awful food, but that's all he's going to eat… it's all he's going to eat and you can't let him starve" (Burkett et al., 2022, p. 2593). "If you ever saw those meltdowns you wouldn't want to offer [non-preferred] food either" (Rogers et al., 2012; p. 24).

Master theme	Translation	Subthemes	Example supporting quotes
			"Basically, [he can eat] vegetables, fruit, milk. I know those snacks are not good. However, that is what he always wants to eat" (Ismail et al., 2020; p. 9).
	Reciprocal	A new normal	"I make a deal with him that after he finished with eating I will go buy McDonalds for him or tells him that his father is coming so he will drive with him anywhere he wants to go" (Adams et al., 2020; p. 6). "We tried strapping him in with a belt so he couldn't get out of his chair. We tried rewards. We tried positive reinforcement. We tried everything" (Suarez et al., 2014; p. 105).
Things related to support		Lack of support	
	Reciprocal	From families	"Old-school attitude of 'if he's hungry he'll eat it' isn't helping" (Tan et al., 2021; p. 5).

Master theme	Translation	Subthemes	Example supporting quotes
			“Caleb is very dependent upon me, so like even though they are, there are bodies to help, it ends up just being me” (Estrem et al., 2016; p. 5).
	Refutational	From healthcare professionals	“I was basically told to deal with it. And then told his nutrition will be, like crap” (Rogers et al., 2012; p. 27) “[The doctor] put him on Pediasure. They said, “You have 2 weeks. Be back here in 2 weeks. Ifhe has not gained weight, we will admit him. They will put a tube in,” and they were really worried …‘cause his hair was brittle; he was malnourished, completely. They classified him as “failure to thrive.”… It was very scary” (Rogers et al., 2012; p. 27). “He’ll grow out of it…” (Tan et al., 2021; p. 7).

Master theme	Translation	Subthemes	Example supporting quotes
			“GP seeing him over one and a half years just saying reflux reflux” (Tan et al., 2021; p 7). “It was early that we knew feeding was going to be hard for her. … there was a lot of spitting up, there seemed to be a lot more vomiting. She was an awful sleeper. I think it got passed off for a few months as colic, other people around us started to think no, this is more serious, you should try to… find another resource. We were referred to a pediatric GI here…, and that’s where we got… Julie was seven months at this point, the official diagnosis of GERD, and started putting her on some medicine” (Estrem et al., 2016; p. 4). “Speechie described symptoms but no intervention” (Tan et al., 2021; p. 7). “We had a Speechie they did communication. If the speechies had told me. She might not be on a tube” (Tan et al., 2021; p. 7).

Master theme	Translation	Subthemes	Example supporting quotes
	Reciprocal	Interventions	“He also advised me to put him on a gluten free diet but it was not working for us and it was also very costly. So, we stopped after about a month.” (Adams et al., 2021; p. 169).
	Reciprocal	Systemic issues	“The feeding team, I don’t know why we sort of fell through, but we do see the cleft team at the hospital every six months, and they got us through our last swallow study, which was unsuccessful again” (Tan et al., 2021; p. 8).
	Reciprocal	Things that (might) help	“It’s nice when you kind of find your people because… you don’t come across a bunch of parents that can’t get their kid to eat stuff, so when you do I can talk for miles about it and it’s great” (Burkett et al., 2022; p. 2593). “It’s nice to hear what other people experience and you pick up on things and you’re like ‘oh yeah that’s a good idea, I should try that’” (Burkett et al., 2022; p. 2594).

Master theme	Translation	Subthemes	Example supporting quotes
Understanding and acceptance	Reciprocal		“Just me and my Mum trying to fight for answers” (Tan et al., 2021; p. 5). “Before his gastrostomy he would put his head down during mealtimes and look away and you could see it was something that he didn’t enjoy doing. It was something that was stressful, and he knew we were upset” (Glasson et al., 2020; p. 971). “There’s a huge range of normal and he’s getting closer to that. He does a good job of faking normal and that’s, sadly, the goal to pretend to be normal, so that you can be accepted. He can be himself here. We try to not make him fit into molds, like he has to at school and out in public. He can be himself here and all of his odd little glories. He can be himself here” (Curtiss & Ebata, 2021; p. 5).

Appendix T

NHS Clinician Interview Schedule

Research question 1: What are the supports or interventions provided to children with learning and/or developmental disabilities exhibiting feeding difficulties and their families?

1. How are children with learning and/or developmental disabilities with feeding difficulties referred to you?
    a. Prompt: Who refers them? How would these cases or service users be brought to your attention? How would these service users land in your case load?
2. What happens after a referral is made to your services?
    a. Prompt: How are the cases reviewed/evaluated? Would you typically do an assessment of the referred feeding difficulty? What assessments would you deliver for the feeding difficulty? What kind of information would you collect from the family?
3. Can you tell me about the kind of support or intervention that you provide for this population with feeding difficulties?
    a. Prompt: What does that support look like? What does that intervention look like? What would that support/intervention usually consist of? Parent training, short courses, group therapy, 1:1 therapy, how many sessions over how many weeks, etc.
4. What influences the support or intervention you or your service provide?
    a. Prompt: What factors would you consider when deciding what support or intervention to provide? How do you decide what kind of approach to take with the cases referred to you? What influences your decision about what approach to take?
5. When providing support or intervention, what involvement do you have with the child who has been referred and their family?
    a. Prompt: What are your interactions with parents or caregivers like?

6. What do you think parents or caregivers understand about their child’s feeding difficulty?
    a. Prompt: What do you think parents or caregivers view as influences to their child’s feeding difficulty?

<u>Research question 2</u>: What are professionals’ perspectives about what constitutes a good support or intervention for feeding difficulties and the barriers to providing this?

7. How do you make that support or intervention for feeding difficulties happen?
    a. Prompt: Does anything need to be approved by anyone? Is it something you can deliver on your own? Do you need to get your approach or plan approved? Are there any consultations needed? Do you work as part of a multidisciplinary team? If so, what type of other professionals are part of that team?
8. In an ideal world, if there were no restrictions (in terms of staffing, support, resources, training, etc.), would you be delivering support or intervention in the same way?
    a. Prompt: If not, what would you do differently?
9. Are there any barriers that you encounter when providing support or intervention for feeding difficulties?
    a. Prompt: What do these barriers look like? (i.e. experience, resources (financial/staffing), families, characteristics of the referred child). When you say x, how does that present a barrier to providing support or intervention for feeding difficulties?
10. From your perspective, what makes for a good support or intervention for feeding difficulties?
    a. Prompt: Is there any specific element or component that you think is particularly important for delivering good intervention or support?
11. In what ways do you think parents and families influence the effectiveness of the supports or interventions delivered?

    a. Prompt: What involvement do you think parents and families have in the success of a support or intervention?

12. Is there anything you think would improve supports or interventions for feeding difficulties?

Research question 3: What working models do professionals have about the development and maintenance of feeding difficulties and how do these working models influence the support or intervention provided to children with learning and/or developmental disabilities and their families?

13. From your perspective, what influences the development of feeding difficulties in children with learning and/or developmental disabilities?
    a. Prompt: What starts them? How do you think behavioural feeding difficulties develop? Anything in particular that starts them? Any thoughts about why feeding issues start? When you say x how does that fit in with the feeding difficulty?
14. What do you think influences the maintenance of feeding difficulties?
    a. Prompt: What keeps them going? How do you think behavioural feeding difficulties are maintained? Why do you think they keep happening?
15. In what ways does your understanding/interpretation of feeding difficulties influence the support or intervention that you provide?
    a. Prompt: How does your understanding of feeding difficulties translate into the supports or interventions you deliver?
16. Is there anything else about feeding difficulties you would like to add?

Appendix U

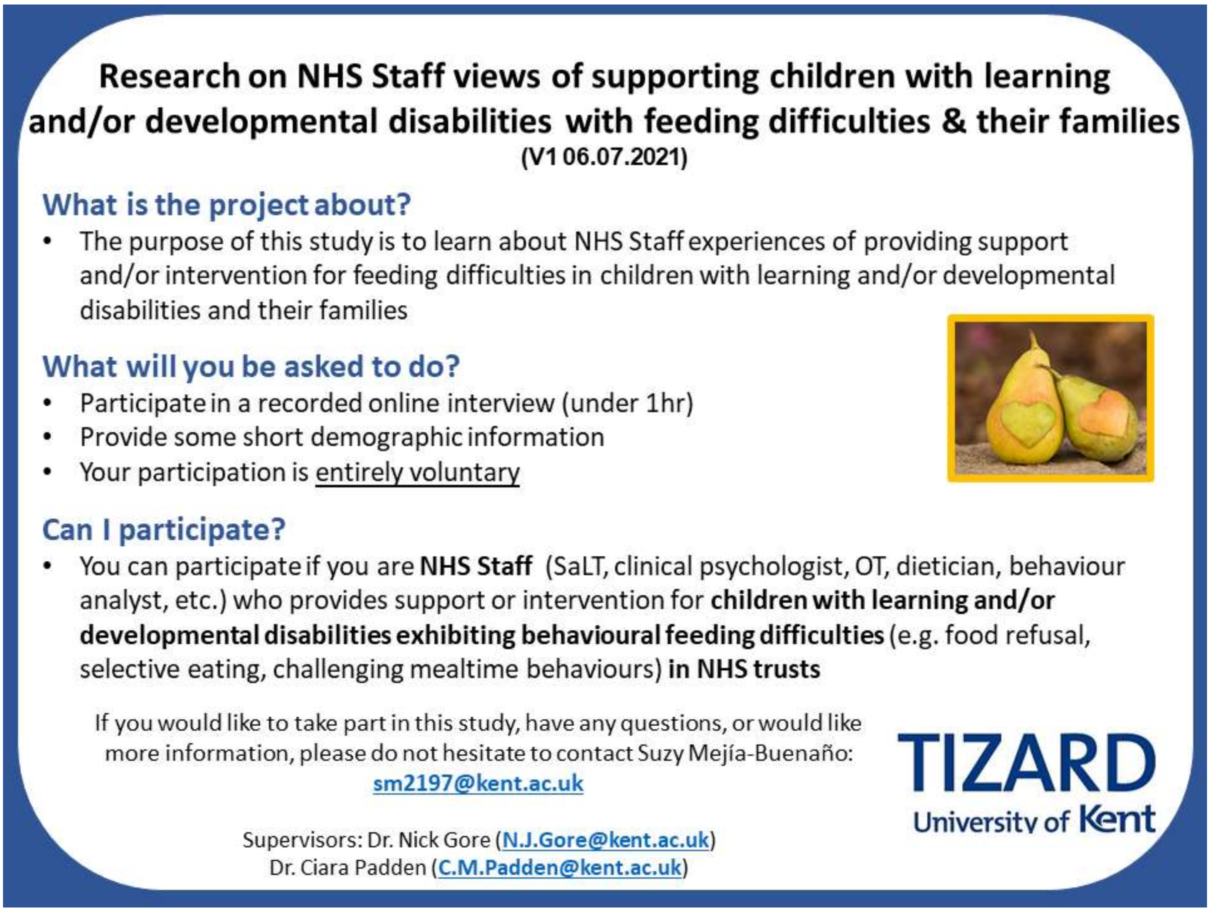
NHS Clinician Study Support Resource

Project5 Resource for NHS Clinicians

https://www.project5.org/

Appendix V

NHS Clinician Study Research Poster



Research on NHS Staff views of supporting children with learning and/or developmental disabilities with feeding difficulties & their families

(V1 06.07.2021)

What is the project about?

- The purpose of this study is to learn about NHS Staff experiences of providing support and/or intervention for feeding difficulties in children with learning and/or developmental disabilities and their families

What will you be asked to do?

- Participate in a recorded online interview (under 1hr)
- Provide some short demographic information
- Your participation is entirely voluntary

Can I participate?

- You can participate if you are **NHS Staff** (SaLT, clinical psychologist, OT, dietician, behaviour analyst, etc.) who provides support or intervention for **children with learning and/or developmental disabilities exhibiting behavioural feeding difficulties** (e.g. food refusal, selective eating, challenging mealtime behaviours) **in NHS trusts**

If you would like to take part in this study, have any questions, or would like more information, please do not hesitate to contact Suzy Mejía-Buenaño:
sm2197@kent.ac.uk

Supervisors: Dr. Nick Gore (N.J.Gore@kent.ac.uk)
Dr. Ciara Padden (C.M.Padden@kent.ac.uk)

TIZARD
University of Kent

Appendix W

NHS Clinician Study Participant Information Sheet

V1 06.07.2021

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LR
Researcher : Suzy Mejia-Buenano
E-mail : sm2197@kent.ac.uk
Supervisors : Dr. Nick Gore and Dr. Ciara Padden
E-mail : n.j.gore@kent.ac.uk and c.m.padden@kent.ac.uk

Staff information sheet (V1 06.07.2021)

Title: **NHS staff views of supporting children with learning and/or developmental disabilities exhibiting feeding difficulties and their families**

Dear Sir/Madam,

You are being invited to participate in a research study conducted by Suzy Mejia-Buenaño, a PhD student at the Tizard Centre, University of Kent. Her supervisors are Dr Nick Gore and Dr Ciara Padden. You are receiving this information sheet as you have expressed interest in learning more about this study. This study has been reviewed and approved by Tizard Ethics Committee at the University of Kent and approved by the Health Research Authority. Before you decide if you want to participate, it is important for you to understand why the research is being conducted and what it will involve, therefore some background information has been provided below.

Purpose of the study

This study will examine NHS staff views and experiences of providing support or intervention for children with learning and/or developmental disabilities with feeding difficulties and their families. We are also interested in hearing about staff interpretations of feeding difficulties. This study is part of a series of studies and will help us with our next step of developing a staff and family informed intervention for children with learning and/or developmental disabilities.

Why you are being asked to participate?

You are being asked to participate because you have expressed interest in this research, and you are an NHS staff member providing support or intervention for feeding difficulties in children with learning and/or developmental disabilities in an NHS Trust.

Your participation is entirely voluntary. If you decide to volunteer your time, you can provide consent digitally by completing, signing and returning the consent form or providing an email stating that you agree to take part in the study. You are free to withdraw your participation at any time without giving a reason.

What you will be asked to do

If you agree to take part, you will need a computer, laptop, tablet, or mobile phone with internet connection. You will be asked to participate in an online, video-recorded interview with me (Suzy) through Microsoft Teams. The interview will be video-recorded by Suzy through Teams and saved in Stream. Only the research team will have access to your video-recorded interview. The interview should not take longer than 1 hour. You will be asked questions about your job delivering support and/or intervention for feeding difficulties. You do not need to download any software or applications for this interview; a link will be provided. The interview can be arranged around your schedule, including outside of normal working hours. You also will be asked to complete a short demographic questionnaire.

What are advantages or disadvantages of participating

Your experiences will help us develop a staff and family informed intervention approach to feeding difficulties in children with learning and/or developmental disabilities which will be beneficial to many people. You might have limited time to participate; the short questionnaire will provide us with information so your interview can be targeted and quicker. I also have flexible availability and will work around your schedule. If at any point you become uncomfortable throughout the interview, I will ask you if you would like to end the interview or continue another day.

What will happen to your information

If you wish, after the interview, you will be given the opportunity to review your interview transcript, and once the study is finished, I will contact you with information about our findings.

Your information will be kept confidential, stored securely, and all your responses will be anonymised as quickly as possible after data collection. This means that any information that could either directly or indirectly indicate who you are will be removed and replaced with a pseudonym. Your name or that of your workplace will not be used in transcription or in later reporting of research results in academic publications or conference presentations. Only myself and my research supervisors at Tizard will have access to completed material (i.e. transcripts, questionnaire). Data will be stored securely for 5 years, at which point it will be destroyed. For additional information about the University's Privacy Notice for Research (GDPR), please click here.

Limits to confidentiality

There are limits to the degree of confidentiality possible since myself and my research supervisors will have access to your recorded interview, we will know your identity and may be able to recognise you. Nobody beyond us will be able to identify you. Another limit to confidentiality is that myself and my supervisors have the obligation to report something that indicates a child you support is at risk of harm or disclosure of a harmful practice. If this occurred, you would be informed that myself and my supervisors would be contacting the relevant child protection services.

What happens if you wish to make a make a complaint?

You will be given a form at the end of your involvement, so that you can give feedback or make a complaint if you wish. In addition, at any time, you can contact my supervisors, Nick Gore or

Ciara Padden by email: N.J.Gore@kent.ac.uk or C.M.Padden@kent.ac.uk. Alternatively, you can contact the Coordinator of Tizard Ethics Committee by email: lssjethics@kent.ac.uk.

Thank you for taking the time to read this information sheet.
I am available via email or phone to answer any questions you might have.

Yours sincerely,

Suzy Mejia-Buenaño

Appendix X

NHS Clinician Study Consent Form

CONSENT FORM (V1 06.07.2021)

Title: ***NHS staff views of supporting children with learning and/or developmental disabilities exhibiting feeding difficulties and their families***

Researcher: Suzy Mejia-Buenano
Email: sm2197@kent.ac.uk
Supervisors: Dr Nick Gore and Dr Ciara Padden
E-mail: n.j.gore@kent.ac.uk and c.m.padden@kent.ac.uk

	Please initial
I confirm that I have read and understood the information sheet (V1 06.07.2021) attached for the above project.	☐
I have had the opportunity to ask any questions and these have been answered to my satisfaction.	☐
I understand that I will participate in an online, video recorded interview about my job providing support or intervention for children with learning and/or developmental disabilities exhibiting feeding difficulties.	☐
I understand that my participation is voluntary and that I do not have to take part.	☐
I understand that I can choose to withdraw before, during or after the interview (it will not be possible to withdraw after data analysis has taken place), without giving a reason.	☐
I understand that all of my responses will be made confidential (anonymised) and neither myself nor my place of work will be identifiable from data that may be presented in academic publications, or conference presentations.	☐
I understand the limits to confidentiality, specifically that the interviewer and the research team will know my identity and personal details.	☐

I understand the limits to confidentiality (i.e. if any disclosures were made that indicated that anyone was at risk of harm). I understand that I would be informed that the relevant child protection service was being notified if such a situation arose. ☐

I understand that a video and audio recording will be made of the interview and this will be stored securely for 5 years, at which point it will be destroyed. ☐

I understand that information I give will be shared with research supervisors. ☐

I would like to participate in this research. ☐

Name of Participant:_________________________

Signature:____________________________

Date:________________

Completed copy: 1-participant copy; 1-site file.

Appendix Y

NHS Clinician Study Demographic Form

PARTICIPANT DEMOGRAPHIC INFORMATION (V1 06.07.2021)

Title: ***NHS staff views of supporting children with learning and/or developmental disabilities exhibiting feeding difficulties and their families***
Researcher: Suzy Mejia-Buenano
Email: sm2197@kent.ac.uk
Supervisors: Dr Nick Gore and Dr Ciara Padden
E-mail: n.j.gore@kent.ac.uk and c.m.padden@kent.ac.uk

You can choose to complete the form digitally and return it or answer the following questions verbally before your interview. You can also opt to skip these questions if you wish to do so.

Age: ____________________________ Gender: ____________________________

Ethnicity: ____________________________ Occupation: ____________________________

Role within the NHS: ____________________________

Length of employment in the above role: ____________________________

Any training related to providing support and/or intervention for feeding difficulties (either as part of NHS role or outside):

Formal training: ____

____

____

____

____

Informal training: ____

____

____

____

____

Name of Participant:____________________________

Date:__________________

Appendix Z

NHS Clinician Study Comments Form & Participant Feedback

Feedback / Comments Form (V1 06.07.2021)

Thank you for agreeing to talk to Suzy Mejia-Buenaño to help with her research about *NHS staff views of supporting children with learning and/or developmental disabilities exhibiting feeding difficulties and their families.*

We hope that everything was alright when you talked to Suzy. We would be interested in any comments you would like to make, positive or negative.

When things go well, we like to encourage researchers by giving them good feedback. But if things don't go well, it will help us to know this.

Please send any comments you have to:

Suzy Mejia-Buenaño *(first option)*
PhD Researcher
Sm2197@kent.ac.uk

Nick Gore or Ciara Padden *(second option)*
Supervisors
N.J.Gore@kent.ac.uk or C.M.Padden@kent.ac.uk

Tizard Ethics Committee *(if still not satisfied)*
Coordinator of the Tizard Ethics Committee
Lssjethics@kent.ac.uk

Thank you once again for helping the Tizard Centre with our research.
Tizard Ethics Committee

Participant Feedback:

“I had a great experience participating in the interview. It was my first time partaking within such a research. I felt at ease and comfortable throughout the interview. I appreciated the semi-structure nature of the interview and how the interviewer acknowledged the points which I shared and used this to continue the conversation. I really enjoyed the experience.”

Appendix AA

NHS Clinician Study Preliminary Set of Open Codes

Open code name	Open code description
Barriers to delivering support for feeding difficulties	Things that professionals describe that make it difficult/challenging/impossible for them to deliver support or intervention for feeding difficulties
Current supports provided	Descriptions of the current support/intervention provided for feeding difficulties
Ideal or good support/ intervention for feeding difficulties from professionals' perspective	Descriptions of what professionals believe would constitute a good support or intervention for feeding difficulties / makes for an ideal support for feeding difficulties
Factors that influence the development and maintenance of feeding difficulties (why do they start? & why do they keep happening?)	Descriptions of what professionals believe influences the development and maintenance of feeding difficulties
Importance of formulation	Descriptions of formulations (understanding of the presenting difficulty/issue) as being very important for delivering support/intervention for feeding difficulties
Clinical judgement/ clinical experience when used providing support or intervention	Descriptions of clinical judgement/ clinical experience used when providing support or intervention for feeding difficulties

Open code name	Open code description
Roles or involvement of other professionals when delivering support or intervention for feeding difficulties	Other professionals they might liaise with when supporting this population & what those roles may look like/the support they contribute
Perspectives of what parents understand about FDs	Descriptions of parents’ understandings of the factors that contributed to the D&M of their child’s feeding difficulty
Recognition of the difficulties families face when dealing with feeding difficulties	Acknowledgement/empathy towards families’ situations & the difficulties families face in relation to feeding difficulties (see families as humans – really empathetic)
Importance of meaning of the feeding difficulty for the families	Awareness/acknowledgement that meaning is important for families
COVID adjustments to support or intervention delivered	Descriptions of changes to support or intervention for feeding difficulties as a result of the COVID 19 pandemic
Parental influence on the success or effectiveness of an intervention	Perceptions of the influence parents have on the success or effectiveness of the support or intervention they provide
Professionals’ experience when supporting children w/FDs & their families	Descriptions of their experiences when supporting children with feeding difficulties and their families – what is it like for clinicians?

Appendix BB

NHS Clinician Study Final Open Coding Framework

Main open code	Subcategory codes
Things about support or intervention delivered for feeding difficulties	• Current supports provided • Barriers to delivering support or intervention for feeding difficulties • COVID adjustments to support or intervention delivered • Roles or involvement of other professionals when delivering support or intervention for feeding difficulties
What would help/what does help?	• Ideal or good support/intervention for feeding difficulties from their perspective • Parental influence on the success or effectiveness of an support/intervention
Things about the development & maintenance of feeding difficulties	• Factors that influence the development & maintenance of feeding difficulties (why do they start? & why do they keep happening?)
Clinician awareness of family situation or experience	• Recognition of the difficulties families face when dealing with feeding difficulties • Importance of meaning of the feeding difficulty for the families • Perspectives of what parents understand about feeding difficulties
Role of clinical understanding/approach to providing support or	• Importance of formulation • Clinical judgement/ experience used when providing support or intervention

Main open code	Subcategory codes
intervention for feeding difficulties	
Professionals' experience (what is it like for them?)	- Professionals' experience when supporting children with feeding difficulties and their families

Appendix CC

NHS Clinician Study Outcome of Matrix queries Demonstrating Relationships Between Codes to Explore

	Meaning of FD for families	Difficulties families face	What do parents understand?	Clinical judgement / experience used	Importance of formulation	Staff experience	Barriers	COVID adjustments	Current supports provided	Roles of other professionals	D&M	Ideal / good supports	Parent influence on intervention success
Meaning of FD for families	-	5 refs, S	7 refs, S	-	1 ref, S	1 ref, S	2 refs, S	-	1 ref, S	-	2 refs, S	2 refs, S	3 refs, S
Difficulties families face	-	-	5 refs, S	4 refs, S	-	12 refs, S	8 refs, S	-	5 refs, S	-	2 refs, S	9 refs, S	7 refs, S
What do parents understand?	-	-	-	-	2 refs, S	-	-	-	-	-	-	1 ref, S	-

	Meaning of FD for families	Difficulties families face	What do parents under-stand?	Clinical judgement / experience used	Importance of formulation	Staff exper-ience	Barriers	COVID adjust-ments	Current supports provided	Roles of other profess-ionals	D&M	Ideal / good supports	Parent influence on intervention success
Clinical judgement / experience used	-	-	-	-	14 refs, S	10 refs, S	3 refs, S	-	35 refs, S	6 refs, S	1 ref, S	13 refs, S	-
Importance of formulation	-	-	-	-	-	-	-	-	11 refs, S	1 ref, S	-	6 refs, S	1 ref, S
Staff experience	-	-	-	-	-	-	18 refs, S	2 refs, S	4 refs, S	4 refs, S	-	13 refs, S	8 refs, S

	Meaning of FD for families	Difficulties families face	What do parents under-stand?	Clinical judgement / experience used	Importance of formulation	Staff exper-ience	Barriers	COVID adjust-ments	Current supports provided	Roles of other profess-ionals	D&M	Ideal / good supports	Parent influence on intervention success
Barriers	-	-	-	-	-	-	-	3 refs, S	8 refs, S	8 refs, S	1 ref, S	21 refs, S	19 refs, S
COVID adjustments	-	-	-	-	-	-	-	-	11 refs, S	-	-	4 refs, S	-
Current supports provided	-	-	-	-	-	-	-	-	-	18 refs, S	-	12 refs, S	11 refs, S
Roles of other professionals	-	-	-	-	-	-	-	-	-	-	1 ref, S	3 refs, S	-

	Meaning of FD for families	**Difficulties families face**	**What do parents under-stand?**	**Clinical judgement / experience used**	**Importance of formulation**	**Staff exper-ience**	**Barriers**	**COVID adjust-ments**	**Current supports provided**	**Roles of other profess-ionals**	**D&M**	**Ideal / good supports**	**Parent influence on intervention success**
D&M	-	-	-	-	-	-	-	-	-	-	-	1 ref, S	2 refs, S
Ideal/ good supports	-	-	-	-	-	-	-	-	-	-	-	-	4 refs, S
Parent influence on intervention success	-	-	-	-	-	-	-	-	-	-	-	-	-

Note. S = significant, NS = not significant, Ref = references (i.e., coded portion of an interview), D&M = development and maintenance, FD = feeding difficulty

Appendix DD

NHS Clinician Study Axial Coding Framework

Axial code	Interpretation of the code
Meaning or understanding of the feeding difficulty for families that are receiving support	The meaning/ understanding of the feeding difficulties for families leads into so many other aspects (what to do next, how it can hold families back, how it can help, it influences how to deliver support, how successful interventions can be, impact on the family with guilt/anxiety, etc.)
Duality between professionals' experiences and families receiving support	Difficult balance between acknowledging the difficulties families face when their child has a feeding difficulty and navigating how to support them while recognising this
Families' role in children's feeding difficulties	Understanding of family influence on feeding difficulties (maintaining it)
Formulation influences the way support is delivered	Having an understanding of the why the feeding difficulty is occurring influences the ways professionals provide support for feeding difficulties (who gets involved, how it's delivered, barriers encountered)
What helps professionals provide support for feeding difficulties?	Factors discussed about what does help/would help them provide support for feeding difficulties
Difficulties faced when delivering support for feeding difficulties	Factors related to the barriers/difficulties they encounter when providing support for FDs (some family related, some related to systems, i.e., NHS)

Axial code	Interpretation of the code
Providing support for feeding difficulties is guided by clinical experience or training	The support provided is guided by their clinical experience/training/ decision making (acknowledgement of own limits/skills, know what intervention to try/suggest, know when to get other professionals involved, etc.)
What would ideal supports for feeding difficulties consist of	Factors discussed of what would make for ideal supports for feeding difficulties
Integral role of families in providing support for a child's feeding difficulty	Strong emphasis on the involvement of parents throughout support or intervention for feeding difficulties

Appendix EE

NHS Clinician Study Checking Relationships Between Axial Codes for Identification of Selective Codes & Study Findings

	Meaning or understanding of the FD for families receiving support	Duality between family experiences and staff providing support	Families' role in children's FD	Formulation influences the way support is delivered	What helps staff provide support for FDs?	Difficulties staff face when delivering support for FDs	Providing support is guided by clinical experience/ training	What would ideal supports for FDs consist of?	Integral role of families in providing support for a child's FD
Meaning or understanding of the FD for families receiving support	-	3 refs, S	1 ref, S	3 refs, S	-	2 refs, S	5 refs, S	1 ref, S	6 refs, S
Duality between family experiences and staff providing support	-	-	6 refs, S	3 refs, S	6 refs, S	18 refs, S	9 refs, S	6 refs, S	14 refs, S
Families' role in children's FD	-	-	-	3 refs, S	-	7 refs, S	5 refs, S	3 refs, S	4 refs, S
Formulation influences the way support is delivered	-	-	-	-	2 refs, S	-	26 refs, S	2 refs, S	14 refs, S

	Meaning or understanding of the FD for families receiving support	Duality between family experiences and staff providing support	Families' role in children's FD	Formulation influences the way support is delivered	What helps staff provide support for FDs?	Difficulties staff face when delivering support for FDs	Providing support is guided by clinical experience/ training	What would ideal supports for FDs consist of?	Integral role of families in providing support for a child's FD
What helps staff provide support for FDs?	-	-	-	-	-	8 refs, S	9 refs, S	-	4 refs, S
Difficulties staff face when delivering support for FDs	-	-	-	-	-	-	10 refs, S	12 refs, S	16 refs, S
Providing support is guided by clinical experience/ training	-	-	-	-	-	-	-	7 refs, S	27 refs, S
What would ideal supports for FDs consist of?	-	-	-	-	-	-	-	-	8 refs, S
Integral role of families in providing support for a child's FD	-	-	-	-	-	-	-	-	-

S = significant, NS = not significant, Ref = references (i.e., coded portion of an interview), FD = feeding difficulty

Appendix FF

Family Feeding Intervention Study Research Poster

Research on working with family carers to support their child with a learning disability/autistic child who displays a feeding difficulty

What is the project about?

- The purpose of this study is to work with family carers to create and put in place personalised supports for feeding difficulties
- We are also interested in hearing about your experiences of going through this process

What will you be asked to do?

- Participate in 7 sessions with Suzy, supporting assessment, gathering information, and putting in place supports at home
- Provide some brief details about you and your child
- You can also decide whether to participate in a short interview about going through this process

Can I participate?

- You can participate if you are the parent of a child with a **learning disability or an autistic child** that is **aged 1½ -7 years old** who has a **behavioural feeding difficulty** (food refusal, selective eating, challenging mealtime behaviours) and can attend all the sessions

If you would like to take part in this study, have any questions, or would like more information, please do not hesitate to contact Suzy Mejía-Buenaño: sm2197@kent.ac.uk

TIZARD
University of Kent

Supervisor: Dr. Nick Gore (N.J.Gore@kent.ac.uk)

Appendix GG

Family Feeding Intervention Study Participant Information Sheet

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LR
Researcher : Suzy Mejía-Buenaño
E-mail : sm2197@kent.ac.uk
Supervisor : Dr. Nick Gore
E-mail : n.j.gore@kent.ac.uk

Family carer information sheet

Title: **Working with family carers to support their child with a learning disability/autistic child who displays a feeding difficulty**

You are being invited to take part in a research project conducted by Suzy Mejía-Buenaño, a PhD student at Tizard Centre, University of Kent. Her supervisors are Drs Nick Gore, Ciara Padden and Peter Baker. The study has been reviewed and approved by the Tizard Centre Ethics Committee at the University of Kent. Before you decide if you want to participate, it is important for you to understand why the research is being conducted and what it will involve. The following information can help you decide.

Purpose of the study

Children with learning disabilities and autistic children often have feeding difficulties (e.g., selective eating, food refusal, or challenging mealtime behaviours). These difficulties can have an impact on the child and their families. There is not much research about feeding difficulties in England.

This project aims to work with family carers to develop individualised strategies for feeding difficulties. Families will be supported to implement interventions for their children. Participants will also be asked about their experiences of this process.

Why you are being asked to participate?

You are being asked to participate because you are the family carer to a child aged 1½ to 7 who has a learning disability or who is autistic and has a feeding difficulty, and you have expressed interest in this research. Your participation is entirely voluntary. If you decide to volunteer your time, you can complete the consent and demographic forms and return them to me (sm2197@kent.ac.uk). Alternatively, you can email me saying that you consent to taking part in this research.

You are free to withdraw your participation at any time without giving a reason.

What will the project involve?

The project will run virtually. You will need a computer, laptop, tablet, or mobile phone with internet connection to participate. You will be asked to record videos of your child's mealtimes at different points in the project. This will be done via MS Teams (see **Video Recordings** below).

The project will involve 3 stages delivered to individual families across 7 sessions as follows:

1. **Baseline**
   We will meet for about an hour, to work together to describe your child's mealtime behaviours. We will complete a questionnaire and you will be asked to do some video observations of your family mealtimes (see **Video Recordings** below for further information).

2. **Intervention**
   We will meet 5 times. Most session will be between 1-1.5 hours, but one may be as long as 3 hours, with a break halfway through. We will work together to assess your child's feeding difficulty, support you to collect information, do some intervention planning activities, and support you through trying these out. Between meetings, you will be asked to complete some activities at home, such as collect information (data) during mealtimes and video record some mealtimes. I will provide you with resources, support, and guidance throughout to do this.

3. **Follow-up**
   We will meet for 1-2 hours. You will be asked to complete a questionnaire and we will review your child's progress. You will be given the option of taking part in a short, video-recorded interview about your experience going through this process.

All sessions will be scheduled at times that are convenient for you.

What are advantages or disadvantages of participating?

The possible benefits include:

1. Receiving bespoke information about how to best support your child with their feeding difficulty
2. Your experiences may help us develop a family carer-informed intervention approach to feeding difficulties in children with learning disabilities and/or autistic children, which will be beneficial to many people

While this research has been carefully designed to minimise any risks and burdens to taking part, there are possible disadvantages involved with participating:

1. There is a risk to you and your child from their behaviour, if, for example, their behaviour during mealtimes involves hurting themselves or others. We will work together to reduce this risk by developing a plan for what to do if your child's mealtime behaviour worsens during the mealtimes in this study.
2. As with any intervention, there is also the possibility that it will not be effective. We hope that by working together, this possibility will be reduced, however it is important to highlight this.
3. Participating in this research will require you to commit to attending the sessions, video-recording mealtimes, and collecting data. We will try to maximise flexibility by scheduling your sessions at a time that is most convenient for you.

4. The topic might be difficult for you to discuss. If this happens, I will ask you if you want to withdraw or continue later and provide you with some support resources.

What will happen to your information?

All your information will be kept confidential, stored securely, and all your responses will be anonymised as quickly as possible after data collection. This means that any information that could directly or indirectly indicate who you or your child or another family member are will be removed and replaced with a pseudonym. You or your child's name will not be used in reporting of research results. Only the research team will have access to your details and information and videos.

In all research studies, there are limits to confidentiality. We have the obligation to report anything that indicates that you or your child is at risk of harm. Where possible, we would speak to you if/when such a situation arose. For additional information about the University's Privacy Notice for Research (GDPR), please click here.

Video recordings

In order to participate in the weekly sessions, you will need to record some mealtimes. You may need to download a Teams application; however, you do not need to create an account. I will send you a link and start the Teams meeting. When you join, I will help you set up your device so there is a good view of the mealtime environment. I will then start the recording and leave the meeting. The recording will continue even after I have left the meeting. Once you finish your mealtime, you will leave the meeting. The video will save automatically in my secure Stream account.

Your option to take part in this project

You do not have to take part in this project. If you are interested in participating, you can complete the consent and demographic forms and return them to me (sm2197@kent.ac.uk). Alternatively, you can email me saying that you consent to taking part in this research.

What happens if you wish to make a make a complaint?

You will be given a form at the end of your involvement, so that you can give feedback or make a complaint. In addition, at any time, you can contact my supervisor, Dr Nick Gore by email: N.J.Gore@kent.ac.uk. Alternatively, you can contact the Coordinator of the Tizard Centre Ethics Committee by email: lssjethics@kent.ac.uk.

Thank you for taking the time to read this information sheet.

I am available via email to answer any questions you might have.

Yours sincerely,

Suzy Mejía-Buenaño

Appendix HH

Family Feeding Intervention Study Manual

Working with family carers to support their children with intellectual and/or developmental disabilities who display behavioural feeding difficulties in England

RESEARCHER MANUAL

Suzy Mejía-Buenaño, BCBA

April 2022

How to use this manual?

This manual is to be used by the researcher to guide the intervention work carried out in this study. It provides an overview of the intervention, and outline of each intervention session.

Baseline Session: What will we focus on?

During the session

In this session, we will meet to discuss the topography of the behaviours of concern (i.e. what the behaviours look like) to generate operational definitions together with the parents. Parents will also be asked to complete the pre-intervention BPFAS during this session. This meeting will likely take 1 hour.

Task analysis for the session

- Start the session
- Introductions
- Answer any questions
- What does/do the behaviour/s of concern look like?
- Prompt as needed for what it looks like topographically
- Parents complete pre-intervention BPFAS
- Any questions?
- Set date for next meeting
- Thanks & bye

Materials needed

- Blank BPFAS
- Prompts about what the behaviour(s) of concern look like
- Blank self-completed checklist for Baseline session
- Data sheet for baseline data collection (from baseline videos)
- IOA calculation sheet for baseline data collection

Prompts about what the behaviour(s) of concern look(s) like?

Tell me what your child’s challenging mealtime behaviour/ food refusal/ selective eating looks like?

What does your child do with their hands when they engage in the challenging mealtime behaviour/ food refusal/ selective eating?

What does your child do with their feet when they engage in the challenging mealtime behaviour/ food refusal/ selective eating?

What does your child do with their head when they engage in the challenging mealtime behaviour/ food refusal/ selective eating?

Does your child make any noises or say any words when engaging in the challenging mealtime behaviour/ food refusal/ selective eating?

After the session

Parents will record one mealtime daily for 2 weeks and give me access to these records, which will serve as a research baseline. Immediately after the session, I will fill out a self-completed checklist to ensure I completed all the necessary steps in this session and to ensure that the session is being delivered consistently across families. A member of the research team (either supervisors, an academic member of staff, or a PhD/MSc student with the relevant experience) will collect inter-observer agreement (IOA) data to ensure reliability of the baseline data collected (Cooper et al., 2020).

Task analysis after the session

- Set up meetings in Teams & send invites for one mealtime daily for 2 weeks
- Fill out a self-completed checklist (y/n) based on task analysis of each session
- Identify who will collect IOA data
- Collect baseline data

Blank implementer self-completed checklist for Baseline session

Implementer name: ___________________________

Date: ___________________________

Baseline session – Implementer checklist		
Session components	**Yes/No**	
Start the session	Yes	No
Introductions	Yes	No
Answer any questions	Yes	No
What does/do the behaviour/s of concern look like?	Yes	No
Prompt as needed for what it looks like topographically	Yes	No
Parents complete pre-intervention BPFAS	Yes	No
Any questions?	Yes	No
Set date for next meeting	Yes	No
Thanks & bye	Yes	No

Baseline Data Collection (Template)

On this data sheet we will be collecting data about the number of times that preferred and unpreferred foods are accepted or refused, and the number of times other mealtime behaviours occur. Please familiarise yourself with the operational definitions, watch the indicated mealtime videos to familiarise yourself with the content, and then use this data sheet to collect data about the target behaviours.

Operational definitions

Preferred food –

Other food –

Acceptance –

Refusal –

Tantrum –

Kicking –

Date:	Observer:	
Time lunch started:	Time lunch ended:	
Food behaviours	**Tally of bites accepted**	**Tally of bites refused**
Preferred food		
Other food		
Other mealtime behaviours	**Tally of occurrences**	
Tantrum		
Kicking		
Notes		

Intervention Session 1: Assessment & how to collect data

During the session

A feeding assessment interview will be carried out with families to gather information about the child's behavioural feeding difficulty and to obtain some informant data about the possible functions of the child's behavioural feeding difficulty. It is estimated that this will take between 45-90 minutes to administer. This assessment will provide targeted information about the child's feeding difficulty, making it more relevant for families than a general FAI (O'Neill et al., 1997). It is estimated that this session will take 2.5-3 hours with a break. During the break, I will look through the feeding assessment interview and identify what those data show. Families and I will then refine our operational definition and identify what we should record on an ABC chart.

Following this, I will train families on how to collect frequency data and other data based on what the families target behaviours are. This will follow a behavioural skills teaching (BST) approach and will involve delivering instructions for how to collect data, modelling what this would look like, practicing with families, and providing feedback. Family carers/parents will be explained that obtaining a clear picture of how frequently/often the behaviour occurs (or equivalent based on relevant DV measure) is helpful and that collecting observational data will help us measure if what we are trying to do throughout the course of the intervention is working. Parents will be given materials (i.e. data sheet, definitions, procedures for data collection outlined) for data collection in this session.

Task analysis for the session

- Start the session
- Hello & catch up
- Feeding assessment
- Break
- During break – I review the data and identify what we should record on an ABC chart (but I will collect this)
- Return from break
- Refine operational definitions
- Review with family what we should record on an ABC chart (but I will collect this data)
- Transition to training portion about how to collect frequency data & other data based on families' goal/needs
- Frequency data
    - Instructions/talk through
    - Model what it would look like
    - Practice
    - Feedback
- Provide parents with all data collection materials
- Any questions?
- Set date for next meeting
- Thanks & bye

Materials needed

- Blank feeding assessment
- Original operational definition
- Training materials on taking frequency data
    - Instructions
    - Modelling materials
    - Practice materials
- Blank ABC charts (for me)
- Blank data sheets for parents & myself
- Blank self-completed checklist for Intervention Session 1
- IOA calculation sheet for intervention mealtime videos

Identifying what we should record on an ABC chart

- Review Feeding Assessment Interview for antecedents & consequences
- Check with family if anything to add or happy with the list of antecedents & consequences

Antecedents to record	Consequences to record

Training parents to collect frequency data

*****Highlight to parents that obtaining a clear picture of how often the behaviour occurs will help us measure if what we are doing throughout the course of the intervention is working.*****

Instructions

We're going to be gathering some information about how often this behaviour happens during mealtimes. We'll be gathering this information on one of these sheets (show data sheet). Explain what information goes where. Fill out the name and date first, read over the definitions (if needed) for a reminder of what we are looking at, start tallying how often the behaviour occurs when the mealtime starts. This is going to give us a picture of how often the behaviour is currently happening during mealtimes.

Modelling

Model data collection using families' own mealtime videos (as that is what the data sheets and operational definitions are tailored for).

Identify 2 videos and the time stamps, have these ready to go for the session.

Video 1:

Video 2:

This is what this looks like, fill out the name and date, time of the recoding/time of mealtime start, review the definitions, start the video and tally the behaviour when it occurs. Talk aloud my thinking process while doing this so that families have some context for what I am doing.

Practice & Feedback

Have 3 family mealtime videos loaded and ready to practice with. Identify 3 videos and the time stamps, have these ready to go for the session.

Video 1:

Video 2:

Video 3:

Have families practice once with one video, provide praise for what was done well, provide any corrective feedback (if needed). Collect data alongside parents to ensure fidelity. Ask if they feel comfortable with this or would like to try another example? Go through the same process. Ask if they feel comfortable with this or would like to try one more example?

Frequency of Behaviour Form

On this data sheet we will be collecting data about the number of times that preferred and unpreferred foods are accepted or refused, and the number of times other mealtime behaviours occur. Please familiarise yourself with the definitions below and place a tally in the correct box when an indicated behaviour occurs during mealtime.

Definitions

Preferred food –

Other food –

Target foods –

Acceptance –

Refusal –

Other challenging mealtime behaviour –

Date:	Observer:	
Time lunch started:	Time lunch ended:	
Food behaviours	**Tally of bites accepted**	**Tally of bites refused**
Preferred food		
Other food		
Target food		
Other mealtime behaviours	**Tally of occurrences**	
Other challenging mealtime behaviour		
Notes		

After the session

I will review the baseline videos with our refined operational definition and collect baseline data from these permanent products. Parents will be asked to frequency data (or other relevant DV data) at home and bring this back to the next session. This data will be collected at mealtimes, and it is anticipated that it may take between 15-30 minutes each mealtime to collect this data. They will be asked to video-record 3 mealtimes (through Teams, described below) so I can collect inter-observer agreement (IOA) data to ensure parents have collected data correctly and provide feedback if the IOA data was low. Interobserver agreement data is used commonly in behavioural research to assess for reliability (Cooper, Heron & Heward, 2020). Collecting IOA data and providing feedback will likely take me 1-2 hours per video (depending on the length of the mealtime video). Additionally, immediately after the session, I will fill out a self-completed checklist to ensure I completed all the necessary steps in this session and to ensure that the session is being delivered consistently across families.

Task analysis after the session

- Set up meetings in Teams & send invites for 3 mealtimes
- Fill out a self-completed checklist (y/n) based on task analysis of each session
- Review baseline videos
    - Check baseline data with new operational definitions
    - 2nd observer collects baseline data
    - IOA calculation
- Review 3 mealtime videos
    - Collect ABC data
    - Collect frequency data
    - Calculate IOA from parent data

Blank implementer self-completed checklist for Intervention session 1

Implementer name: ___________________________

Date: ___________________________

Intervention session 1 – Implementer checklist		
Session components	**Yes/No**	
Start the session	Yes	No
Hello & catch up	Yes	No
Feeding assessment	Yes	No
Break	Yes	No
During break – review the data & see what it shows	Yes	No
Return from break	Yes	No
Refine operational definitions	Yes	No
Identify what we should record on an ABC chart	Yes	No
Transition to training portion about how to collect data	Yes	No
Frequency – Instructions	Yes	No
Frequency - Modelling	Yes	No
Frequency – Practice & Feedback	Yes	No
Provide parents with all data collection materials	Yes	No
Answer any questions	Yes	No
Set date for next meeting	Yes	No
Thanks & bye	Yes	No

Intervention Session 2: Formulation & what have you tried?

During the session

In this session, we will review the data collected by parents as well as the feeding interview assessment discussion to arrive at a shared understanding of the child's behavioural feeding difficulty. This will be a collaborative process with families, guided by the data but also focused on creating a shared understanding with them. **This process will involve looking for patterns in the data with families and ensuring that this formulation makes sense to them and is something that they agree with.** The data will be reviewed from the perspective of drawing together patterns between environmental events and the child's feeding difficulty and thinking about how we might be able to break those patterns. Once we have arrived at a shared understanding, we will discuss strategies or adaptations that families have tried to implement previously to improve their child's behavioural feeding difficulty and discuss these previous strategies in the context of our formulation, as well as think about practicalities for strategies (i.e. what is doable?). It is anticipated that this session will take 1-2 hours.

Task analysis for the session

- Start the session
- Hello & catch up
- Review data collected by parents and feeding interview assessment
- Discuss these data & ABC data to arrive at a shared understanding
    - Look for patterns between environmental events & the child's feeding difficulty
    - Think about how we might break those patterns
- Discuss strategies/ adaptations families have tried previously
    - Consider these in the context of our formulation
    - Think about what is doable
- Ask parents to think about strategies that might work to break down patterns identified & will be feasible for them to implement & bring back to next session
- Provide parents with all data collection materials
- Any questions?
- Set date for next meeting
- Thanks & bye

Materials needed

- Parent data collected (frequency data)
- ABC data portrayed graphically (by me)
- Feeding interview assessment results
- Prompts for discussing strategies/ adaptations families have tried previously (further to what was discussed in the feeding assessment interview)
- Blank frequency data sheets for parents & myself
- Action planning activitiy
- Blank self-completed checklist for Intervention Session 2
- IOA calculation sheet for intervention mealtime videos

Prompts for discussing strategies/adaptations families have tried previously

- What have you tried previously to try to improve/change your child’s feeding difficulty?
- Are there any other strategies or things that you have tried to try to improve your child’s feeding difficulty?
- How did that go?
- What was that like?
- Did it work or did your child’s feeding difficulty change in anyway?

Action planning activity worksheet

The behaviours we are focusing on are:

- Behaviour 1 – operational definition
- Behaviour 2 – operational definition
- Behaviour 3 – operational definition

Our understanding of these behaviours is:

Taken from 'Formulation' section

These are the patterns we have identified that often occur before and after the feeding difficulty:

Before	After
Taken from 'Patterns' section	

For the next section, think about:

- How we might change what happens before the behaviour to stop it from starting/happening
- How we might change what happens after the behaviour so that it is no longer 'effective' for the child
- What else would it be helpful for your child to learn that may help during mealtimes?

Things we can change before the behaviour happens	Things we can change after the behaviour happens	What else would it be helpful for your child to learn that may help during mealtimes?

After the session

Immediately after the session, I will fill out a self-completed checklist to ensure I completed all the necessary steps in this session and to ensure that the session is being delivered consistently across families. Families will continue collecting frequency data. Parents will be asked to record 3 mealtimes so I can collect IOA data. Parents will be asked to think about strategies that might work to break down the patterns identified and that will be feasible for them to implement. I will also do the same, and we will both bring back ideas to the following session. My suggestions will be guided by my behavioural knowledge around the basic principles of behaviour, the side effects of these, and what we know from the literature about applying these evidence-based principles to interventions for feeding difficulties.

Task analysis after the session

- Set up meetings in Teams & send invites for 3 mealtimes
- Fill out a self-completed checklist (y/n) based on task analysis of each session
- Review 3 mealtime videos
    - Collect frequency data
    - Calculate IOA from parent data
- Think about strategies that might work to break down patterns identified & may be feasible for families to implement to bring to next session

Blank implementer self-completed checklist for Intervention session 2

Implementer name: _________________________

Date: __________________________

Intervention session 2 – Implementer checklist		
Session components	**Yes/No**	
Start the session	Yes	No
Hello & catch up	Yes	No
Review data collected by parents and feeding interview assessment	Yes	No
Discuss these data to arrive at a shared understanding of the child's behavioural feeding difficulty	Yes	No
Look for patterns between environmental events & the child's feeding difficulty	Yes	No
Discuss strategies/ adaptations families have tried previously	Yes	No
Consider these in the context of our formulation	Yes	No
Think about what is doable	Yes	No
Ask parents to think about strategies that might work to break down patterns identified & will be feasible for them to implement & bring back to next session	Yes	No
Provide parents with all data collection materials	Yes	No
Answer any questions	Yes	No

Set date for next meeting	Yes	No
Thanks & bye	Yes	No

Intervention Session 3: Creating an action plan

During the session

In this session, both families and I will present ideas we have come up with about how to approach their child’s feeding difficulties. We will synthesise these and put them together, both contributing to this process and develop an action plan for strategies that families will implement. This will be guided by the data that we have collected and discussed and what family feel able to implement. Families will leave this section with an action plan that was developed together. It is anticipated that this session will take 1-1.5 hours.

Task analysis for the session

- Start the session
- Hello & catch up
- Parents ‘present’ their ideas on how to approach their child’s feeding difficulty
- I present my ideas on how to approach their child’s feeding difficulty
- Work together to synthesise them/put them together into an action plan for strategies families will implement
- Provide parents with all data collection materials
- Provide parents with action plan
- Provide parents with self-completed checklist to fill out throughout the week
- Any questions?
- Set date for next meeting
- Thanks & bye

Materials needed

- Worksheet to synthesise parents & my strategy
- Blank frequency data sheets for parents & myself
- Blank action plan template
- Blank self-completed checklist template for parents
- Blank self-completed checklist for Intervention Session 3
- IOA calculation sheet for intervention mealtime videos

Creating an Action Plan Worksheet

We will discuss strategies/ideas we have considered for how to break down the patterns we have identified and what we might need to teach X instead. We will use this worksheet to guide us through this process.

Fill out the table below and consider how the proposed strategies will work, given our understanding of X's food refusal (i.e., in what ways will x strategy break down the pattern we identified?; how will x strategy help change the pattern that is currently in place?).

Pattern identified	Strategy discussed & agreed	Strategy name

Food Refusal Action Plan Template

Overview:

Goal:

Our understanding of X’s food refusal:

Selected strategies

The following strategies have been identified by XX as ones that they would like to try out at home:

<table>
<tr><td colspan="2"><u>Before lunchtime</u>
•</td></tr>
<tr><td><u>During lunchtime</u>
<u>Before the food refusal occurs</u>
•</td><td><u>After the food refusal has occurred</u>
•
<u>After the food acceptance has occurred</u>
•</td></tr>
</table>

Food Refusal Strategy Tracker (Template)

On the table below are the strategies we have selected to try out for the next week to try to create a better mealtime context for X, and increase how likely they will be to try the target foods we have selected. Place a tick mark next to each day that you tried out the strategies below. This will let us see what is easiest/more commonly being tried, and we can discuss this at our next session.

Daily agreed strategy	Date:								Total days:

Occasional agreed strategy	Date:								Total days:

After the session

Immediately after the session, I will fill out a self-completed checklist to ensure I completed all the necessary steps in this session and to ensure that the session is being delivered consistently across families. Families will be asked to implement these strategies at mealtimes and videorecord 3 of these mealtimes (through Teams). Families will also be asked to continue to collect data on the identified DVs and record at least 3 of these so I can collect IOA data from the recorded videos to ensure parents are collecting data properly. Families will fill out a self-completed checklist made up of a list of the strategies that we discussed and tally how many times each of the strategies is implemented, so we can look at that together at the next session to support in reviewing reasons for why families have or have not implemented certain strategies (i.e. why trying these and not the others? Is there something about the other strategies we need to change?) so we can continue to work on contextual fit for families.

Task analysis after the session

- Set up meetings in Teams & send invites for 3 mealtimes
- Fill out a self-completed checklist (y/n) based on task analysis of each session
- Review 3 mealtime videos
    - Collect frequency data
    - Calculate IOA from parent data

Blank implementer self-completed checklist for Intervention session 3

Implementer name: ___________________________

Date: ___________________________

Intervention session 3 – Implementer checklist		
Session components	**Yes/No**	
Start the session	Yes	No
Hello & catch up	Yes	No
Parents ‘present’ their ideas on how to approach their child’s feeding difficulty	Yes	No
I present my ideas on how to approach their child’s feeding difficulty	Yes	No
Work together to synthesise them/put them together into an action plan for strategies families will implement	Yes	No
Provide parents with all data collection materials	Yes	No
Provide parents with action plan	Yes	No
Provide parents with self-completed checklist to fill out throughout the week	Yes	No
Answer any questions	Yes	No
Set date for next meeting	Yes	No
Thanks & bye	Yes	No

Intervention Session 4: Trying it out Part 1

During the session

In this session, we will review the data that parents have collected after implementing the action plan, review the self-checklist, and discuss the family's experience of implementing this action plan. This session will be focused on checking if what families are being asked to implement is changing the child's behaviour and if families feel they are able to cope with what they are doing (i.e., does it have contextual fit for them). If the strategies are not working or families do not feel happy about what they are trying out, we will think together about how we can change the strategies to work better for the child or the family. Any necessary changes will be made; the action plan will be adjusted to ensure contextual fit of the action plan to the family's situation. It is anticipated that this session will take 1-1.5 hours. Families will be given revised strategies or advised to continue what they are doing (if it is working and they feel confident to continuing these).

Task analysis for the session

- Start the session
- Hello & catch up
- Review frequency data after implementing action plan
- Review self-checklist data to see what strategies parents are implementing most
- Discuss with families if they are able to cope with what they are doing
    - Are the strategies working?
    - If families not happy, discuss how to change the strategies to make them better for the child/family
- Provide parents with all data collection materials
- Provide parents with action plan (amended, if necessary)
- Provide parents with self-completed checklist to fill out throughout the week
- Any questions?
- Set date for next meeting
- Thanks & bye

Materials needed

- Summary of frequency data after implementing action plan
- Summary of self-checklist data
- Prompts to be able to discuss family's experiences of implementing the action plan (is it working, if not how can we change it, etc.)
- Blank frequency data sheets for parents & myself
- Completed action plan (with updates if necessary)
- Blank self-completed checklist template
- Blank self-completed checklist for Intervention Session 4
- IOA calculation sheet for intervention mealtime videos

Review the week's progress

- Review frequency data after implementing action plan
- Review self-checklist data to see what strategies parents are implementing most
- Discuss with families if they are able to cope with what they are doing
    - Are the strategies working?
    - If families not happy, discuss how to change the strategies to make them better for the child/family
- Prompts to be able to discuss family's experiences of implementing the action plan (is it working, if not how can we change it, etc.)

Prompts of family's experiences of implementing the action plan

How did it go this past week?

What was it like for you implementing the strategies?

I noticed that you used x strategy most often, can you tell me a little about what you preferred about that strategy?

Do you think the strategies are working?

How can we change the action plan to make it better for you?

After the session

Immediately after the session, I will fill out a self-completed checklist to ensure I completed all the necessary steps in this session and to ensure that the session is being delivered consistently across families. Families will continue to collect frequency data and videorecord at least 3 mealtimes through Teams so I can continue to collect IOA data, and complete the self-checklist.

Task analysis after the session

- Set up meetings in Teams & send invites for 3 mealtimes
- Fill out a self-completed checklist (y/n) based on task analysis of each session
- Review 3 mealtime videos
    - Collect frequency data
    - Calculate IOA from parent data

Blank implementer self-completed checklist for Intervention session 4

Implementer name: ___________________________

Date: __________________________

Intervention session 4 – Implementer checklist		
Session components	**Yes/No**	
Start the session	Yes	No
Hello & catch up	Yes	No
Review frequency data after implementing action plan	Yes	No
Review self-checklist data to see what strategies parents are implementing most	Yes	No
Discuss with families if they are able to cope with what they are doing	Yes	No
Discuss if the strategies are working	Yes	No
If family not happy, discuss how to change the strategies to make them better for the child/family	Yes	No
Provide parents with all data collection materials	Yes	No
Provide parents with action plan (amended, if necessary)	Yes	No
Provide parents with self-completed checklist to fill out throughout the week	Yes	No
Answer any questions	Yes	No
Set date for next meeting	Yes	No
Thanks & bye	Yes	No

Intervention Session 5: Trying it out Part 2

During the session

In this session, we will review the further data collected following parent's continued implementation of the action plan developed together and review the self-checklist. We will discuss their continued experience of implementing this action plan. It is anticipated that this session will take 1-1.5 hours. This will be the final intervention session.

Task analysis for the session

- Start the session
- Hello & catch up
- Review frequency data after continued implementation of action plan
- Review self-checklist data to see what strategies parents are implementing most
- Discuss families' continued experience of implementing this action plan
- Any questions?
- Set date for next meeting
- Thanks & bye

Materials needed

- Summary of frequency data after implementing action plan
- Summary of self-checklist data
- Prompts to be able to discuss family's continued experiences of implementing the action plan
- Blank self-completed checklist for Intervention Session 5
- Blank frequency data sheets for parents & myself
- IOA calculation sheet for intervention mealtime videos

Review the week's progress

- Review frequency data after implementing action plan
- Review self-checklist data to see what strategies parents are implementing most
- Discuss families' continued experience of implementing this action plan

Prompts of family's experiences of implementing the action plan

How did it go this past week?

What was it like for you implementing the strategies?

I noticed that you used x strategy most often, can you tell me a little about what you preferred about that strategy?

Do you think the strategies are working?

How can we change the action plan to make it better for you?

What was it like for you implementing the strategies after the changes we made (if relevant)?

After the session

Immediately after the session, I will fill out a self-completed checklist to ensure I completed all the necessary steps in this session and to ensure that the session is being delivered consistently across families. Three weeks after the conclusion of the previous session, families will collect follow-up frequency data on 3 mealtimes on 3 consecutive days (i.e. 1 probe per day for 3 days). These mealtimes will also be video-recorded and I will collect IOA data.

Task analysis after the session

- Fill out a self-completed checklist (y/n) based on task analysis of each session
- Set up meetings in Teams & send invites for 3 mealtimes
- Review 3 mealtime videos
    - Collect frequency data
    - Calculate IOA from parent data

Blank implementer self-completed checklist for Intervention session 5

Implementer name: ___________________________

Date: ___________________________

Intervention session 5 – Implementer checklist		
Session components	**Yes/No**	
Start the session	Yes	No
Hello & catch up	Yes	No
Review frequency data after continued implementation of action plan	Yes	No
Review self-checklist data to see what strategies parents are implementing most	Yes	No
Discuss with families' continued experience of implementing this action plan	Yes	No
Answer any questions	Yes	No
Set date for next meeting	Yes	No
Thanks & bye	Yes	No

Follow-up Session

During the session

This session will occur 3 weeks after the final intervention session. In this session, we will do a follow-up review where we will review the follow up data and make any further recommendations that might support the family in the future (i.e. signposting to further resources, tweaks to strategies, etc.). Families will be asked to complete the BPFAS as a post-intervention quantitative measure. It is expected that this will not take longer than 30-minutes to complete. At this session, families will be given the option of participating in a 20-30-minute-long interview about their experiences of going through this kind of intervention support (i.e. how has this working in your family lifestyle, what worked well, how could this be improved). It is anticipated that this session will take 1.5-2 hours. This session is not considered part of the intervention in research terms, this is an additional session to what would normally occur in clinical practice (like the intervention is trying to emulate), as such this session is geared towards collecting research follow-up data.

Task analysis

- Start the session
- Hello & catch up
- Review follow up data
- Make further recommendations that might support the family in the future
    - Signposting to further resources
    - Tweaks to strategies
- Parents complete post-intervention BPFAS
- Give option to participate in interview about their experiences of going through this kind of intervention support
    - If yes, start recording
    - Go through interview schedule
- Any questions?
- Thank you for participating in my research & bye

Materials needed

- Summary of follow up data
- Resources for signposting
- Blank BPFAS
- Interview schedule
- Blank self-completed checklist for Follow up session

Review follow-up data & final recommendations

- Review follow up data
- Make further recommendations that might support the family in the future
    - Signposting to further resources
    - Tweaks to strategies

Blank implementer self-completed checklist for Follow-up session

Implementer name: ___________________________

Date: ___________________________

Follow-up session – Implementer checklist		
Session components	**Yes/No**	
Start the session	Yes	No
Hello & catch up	Yes	No
Review follow-up data	Yes	No
Make further recommendations that might support the family in the future (signposting to further resources, tweaks to strategies, etc.)	Yes	No
Parents complete post-intervention BPFAS	Yes	No
Give option to participate in interview about their experiences of going through this kind of intervention support	Yes	No
(If yes) start recording & go through interview schedule	Yes	No
Answer any questions	Yes	No
Thank you for participating in my research & bye	Yes	No

Appendix II

Family Feeding Intervention Study Consent Form

CONSENT FORM

Title: ***Working with family carers to support their child with a learning disability/autistic child who displays a feeding difficulty***

Researcher: Suzy Mejía-Buenaño
Email: sm2197@kent.ac.uk
Supervisor: Dr Nick Gore
E-mail: n.j.gore@kent.ac.uk

	Please Tick
I confirm that I have read and understood the information sheet attached for the above project.	
I have had the opportunity to ask any questions, and these have been answered to my satisfaction.	
I understand that I will work with Suzy to develop a plan that may help me support my child with their feeding difficulty.	
I understand that my participation is voluntary and that I do not have to take part.	
I understand that I can choose to withdraw from this study at any time without giving a reason.	
I understand how mine and my child's data will be used and stored.	
I understand that all of my data will be made confidential (anonymised) and neither myself nor my child will be identifiable from data that may be presented in academic publications, or conference presentations.	
I understand the limits to confidentiality, specifically that the research team will know my identity and personal details.	
I understand that confidentiality cannot be maintained if I mention something that indicates that I or my child is at risk of harm. I understand that I would be informed that the relevant child protection service was being notified.	

I understand that the videos I provide will be stored securely and any video and audio recordings made in the study will be stored securely.	
I understand that I will be asked if I want to take part in a 20-30 minute interview at the conclusion of the study about my experience in this study and I do **not** have to take part.	
I understand that information I give will be shared with the research team.	
I would like to participate in this research.	

Name of Participant:__________________________

Signature:_____________________________

Date:_________________

Appendix JJ

Family Feeding Intervention Study Demographic Form

PARTICIPANT DEMOGRAPHIC INFORMATION

Title: ***Working with family carers to support their child with a learning disability/autistic child who displays a feeding difficulty***
Researcher: Suzy Mejía-Buenaño
Email: sm2197@kent.ac.uk
Supervisor: Dr Nick Gore
E-mail: n.j.gore@kent.ac.uk

You can choose to answer the following questions verbally on the telephone before the first session, or return the completed form to sm2197@kent.ac.uk.

Family carer's age(s): ____________________________

Gender/Sex: ____________________________

Race/ethnicity: ____________________________

Number and ages of children in your household **with** learning disabilities or that are autistic:

____

Number and ages of children in your household **without** learning disabiltiies or that are autistic:

____

Name of Participant:____________________________

Date:__________________

Appendix KK

Family Feeding Intervention Study Detailed Overview of Study Sessions

	Session	Aim of session	During and post-session activities
STAGE A: BASELINE	Baseline session (1hr)	Identify what mealtime behaviours we will focus on as part of the intervention.	*During the session* Pre-intervention BPFAS. Discussion of the topography of the mealtime behaviours of concern. *After the* session Video-recordings of mealtimes (recordings procedures described below) from which baseline data will be collected by myself. A member of the research team (either supervisors, an academic member of staff, or a PhD/MSc student with the relevant experience) will collect inter-observer agreement (IOA) data to ensure reliability of the baseline data collected (Cooper et al., 2020).
STAGE B: INTERVENTION	Intervention session 1 (2.5-3 hours with a break)	Assessment of the feeding difficulty & training parents on how to collect data.	*During the session* Feeding interview assessment to gather information about the child's behavioural feeding difficulty. Review and discuss assessment results with family & identify what we should collect direct assessment data on. The methods used to collect direct assessment data will be flexible, to reflect the specific needs of each family. For example, if a family reports that a child takes too long to consume food after being presented with a bite, we would collect direct assessment data on latency (i.e., time between presentation of the demand, and the start of the behaviour). If a family reports that a child takes bites too slowly, we would collect direct assessment data inter-response time (i.e., the time between one bite and another). ABC data would be collected if there is a discrete behaviour (i.e., a clear start and end). These are examples to provide context for direct assessment methods and are not exhaustive, as mentioned, the specific methods used would be tailored to each family's need to make it more appropriate for families. Training families on how to collect frequency data. Parents provided with all data collection materials. *After the session* Parents will be asked to collect frequency data at home during mealtimes and bring this back to the next session. I will collect direct assessment data from the recorded mealtime videos, thus reducing the burden off families. It is anticipated that it may take between 15-30 minutes each mealtime to collect this data. They will be asked to video-record 3 mealtimes and I will collect IOA data from these.

	Intervention session 2 (1-2 hours)	Formulation (to arrive at a shared understanding of the child's behavioural feeding difficulty) and identifying what families have previously tried for their child's behavioural feeding difficulty.	*During the session* Review data to arrive at a shared understanding of the child's behavioural feeding difficulty by looking for patterns in the data and ensuring the formulation makes sense to them and is something they agree with. Discussions with families about how we might be able to break the patterns identified. Discussions with families about strategies or adaptations they have tried previously to improve their child's feeding difficulty. *After the session* Families will continue collecting frequency data and videorecord 3 mealtimes so I can collect IOA data. Parents will be asked to think about strategies that might work to break down the patterns identified and that will be feasible for them to implement. I will also do the same, and we will both bring back ideas to the next session. My suggestions will be guided by my knowledge around the basic principles of behaviour, the side effects of these, and what we know from the literature about applying these evidence-based principles to interventions for feeding difficulties.
	Intervention Session 3 (1-1.5 hours)	Creating an action plan together to address their child's mealtime behaviours.	*During the session* Discussion of ideas on how to approach their child's feeding difficulties and synthesis of these to develop an action plan for strategies that families will implement. Families will leave this section with an action plan that was developed together. *After the session* Families will implement these strategies at mealtimes and videorecord 3 mealtimes. Families will continue collecting frequency data and I will collect IOA data. Families will fill out a self-completed checklist made up of a list of the strategies that we discussed and tally how many times each of the strategies is implemented, so we can look at that together at the next session to support in reviewing reasons for why families have or have not implemented certain strategies so we can continue to support contextual fit.
	Intervention Session 4 (1-1.5 hours)	Reviewing families' implementation of the action plan Part 1.	*During the session* Review together the data that parents collected during their implementation of the action plan, the parent self-checklist, and discuss the family's experience of implementing this action plan. Discussions around if what families are implementing is changing the child's behaviour and if what families are implementing has contextual fit. If not, then think together about how we can change the strategies to work better for the child/family. Families will be given revised strategies or advised to continue what they are doing (if it is working and they feel confident to continuing these). *After the session* Families will continue to collect frequency data, self-checklist and videorecord 3 mealtimes through Teams so I can collect IOA data.

	Intervention Session 5 (1-1.5 hours)	Reviewing families' implementation of the action plan Part 2.	*During the session* Review the further data collected following parent's continued implementation of the action plan and review the self-checklist. Discussion around their continued experience of implementing this action plan. *After the session* Three weeks after the conclusion of the previous session, families will collect follow-up frequency data on 3 mealtimes on 3 consecutive days (i.e. 1 probe per day for 3 days). These mealtimes will also be video-recorded and I will collect IOA data.
STAGE C: FOLLOW-UP	Follow-up session (1.5-2 hours)	Review of progress after 3-weeks and collection of follow-up data.	This session will occur 3 weeks after the final intervention session. Review the follow up data and make any further recommendations that might support the family in the future (i.e. signposting to further resources, tweaks to strategies, etc.). Families will be asked to complete the BPFAS as a post-intervention quantitative measure. It is expected that this will not take longer than 30-minutes to complete. At this session, families will be given the option of participating in a 20-30-minute-long interview about their experiences of going through this kind of intervention support.

Appendix LL

Family Feeding Intervention Study Comments Form & Participant Feedback

Feedback / Comments Form

Thank you for agreeing to work with Suzy Mejía-Buenaño to help with her research about *working with family carers to support their child with a learning disability/autistic child who displays a feeding difficulty.*

We hope that everything was alright when you worked with Suzy. We would be interested in any comments you would like to make, positive or negative.

When things go well, we like to encourage researchers by giving them good feedback. But if things don't go well, it will help us to know this.

Please send any comments you have to:

Suzy Mejía-Buenaño *(first option)*
PhD Researcher
Sm2197@kent.ac.uk

Nick Gore *(second option)*
Supervisor
N.J.Gore@kent.ac.uk

Coordinator of the Tizard Ethics Committee *(if still not satisfied)*
Lssjethics@kent.ac.uk

Thank you once again for helping the Tizard Centre with our research.
Tizard Centre Research Ethics Committee

Participant feedback:

“Thanks so much for all your support and training over the last 3 months, you have been fantastic and I have seen really positive changes in xxx's eating. We will miss you.”

Appendix MM

Modified Functional Assessment Interview

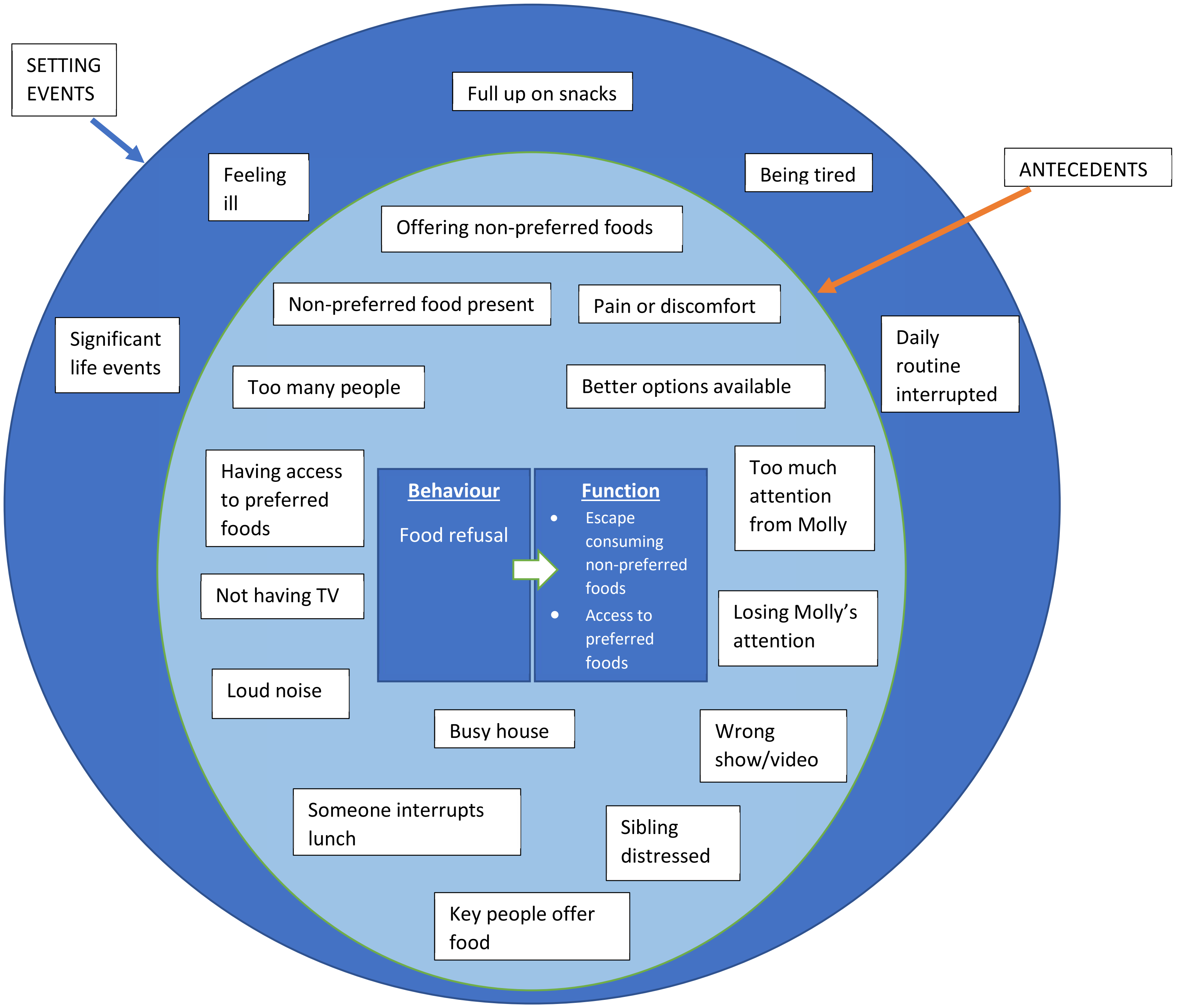
[REDACTED]

Appendix NN

Max's Formulation Map

Events outside the mealtime that influence food refusal	**Events within mealtime that influence food refusal**	**Refusal behaviour**	**Outcome of the behaviour**
• Being tired • Being ill • Having had snacks • Having his daily routine interrupted • Significant life events • Key people are not home	Situation • Offering Max food that is not preferred or he does not want • Experiencing pain or discomfort • Too many people around • There are better options available • Not having access to preferred foods • Too much attention Disruptions in mealtime routine • Losing Molly's attention • Not having TV during lunch	When presented with a spoon of food, Max turns face away, pushes away the spoon, moves to a different part of the room or walks away from the food, this may also be accompanied by negative expressions or 'eww' 'blech' noises. When self-feeding, Max moves a piece of food off his plate/away from him or pushes the plate of food away from him. If	• Escapes consuming the non-preferred food • Gets access to high-preferred foods

	• Wrong show/video during lunch • Someone interrupts lunch • Loud noise • Movement in the house • Sibling distressed People • Who is feeding	refusal goes on for a long period, then it may also include kicking. If Max was presented with a non-preferred food mixed in with a preferred food, he will isolate it and spit it out/take it out (e.g., if a pea was on a bite of his beans and toast and Max did not notice and put it in his mouth, he would identify the pea, and take it out of his mouth, and consume the bite of beans on toast).	

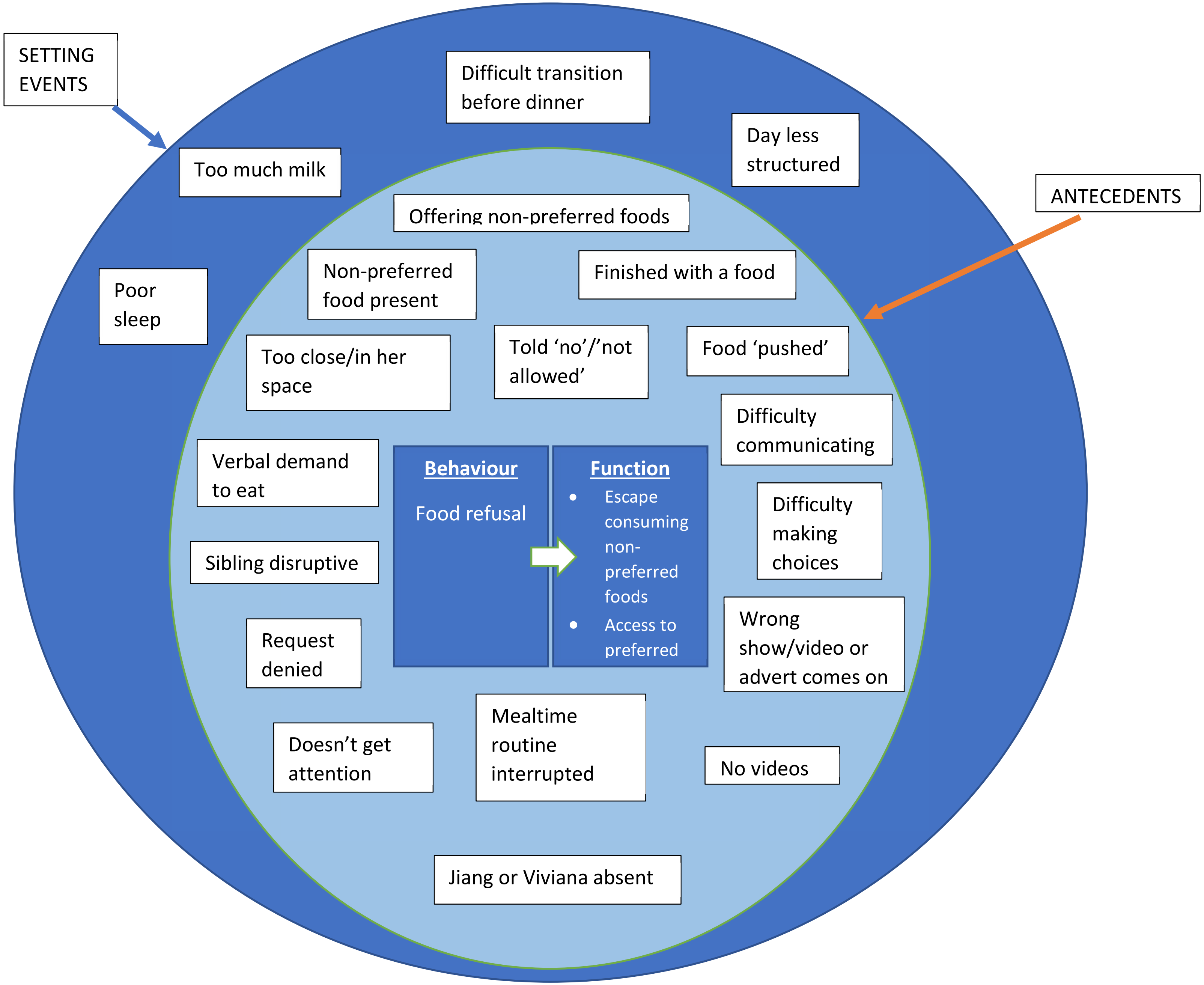

SETTING EVENTS
Full up on snacks
Feeling ill
Being tired
ANTECEDENTS
Offering non-preferred foods
Non-preferred food present
Pain or discomfort
Significant life events
Daily routine interrupted
Too many people
Better options available
Having access to preferred foods
Behaviour
Food refusal
Function
Escape consuming non-preferred foods
Access to preferred foods
Too much attention from Molly
Not having TV
Losing Molly's attention
Loud noise
Busy house
Wrong show/video
Someone interrupts lunch
Sibling distressed
Key people offer food

Appendix OO

Adina's Formulation Map

Events outside the mealtime that influence food refusal	**Events within mealtime that influence food refusal**	**Refusal behaviour**	**Outcome of the behaviour**
• Too much milk • Difficulty transitioning out of a preferred activity before mealtime • Day less structured • Poor sleep	Situation • Offering Adina food that is not preferred or that she does not want • She is finished with a food • Milena (sister) is next to her and being loud or disruptive • A food is presented multiple times and has been refused • Being told 'no' or 'not allowed' • Given a verbal demand related to eating • Being too close to her or in her space	If self-feeding, when Adina has a piece of food/bowl/utensils in front of her, she throws the piece of food/bowl/utensils, so they are no longer in front of her (count each individual throw as an instance of refusal, i.e. if Adina throws 3 raspberries, make 3 tally marks), pushes the food away or moves the food off her tray. If being fed, when presented with a spoon/fork of food, Adina turns face away, pushes	• Escapes or avoids consuming the non-preferred food • Gets access to high-preferred foods • Gets attention

	• When she has a request denied • When she wants attention and does not receive it • Difficulty communicating • Difficulty making choices • Having round food • Being placed in the highchair • Playing with food is interrupted <u>Disruptions in mealtime routine</u> • Mealtime routines are interrupted • Not having laptop with videos during dinner • Wrong show/video or an advert comes on during dinner <u>People</u> If Jiang or Viviana are absent	spoon/fork of food away or shakes her head. In some situations, if refusal continues to happen, it may escalate into a tantrum (i.e., Adina hits her head with her hand with an open fist. Also includes instances where Adina arches her back and bangs her head on the back of the seat, this may also be accompanied by swinging her feet forward. Used to band head on tray previously.)	


SETTING EVENTS
Difficult transition before dinner
Day less structured
ANTECEDENTS
Too much milk
Poor sleep
Offering non-preferred foods
Non-preferred food present
Finished with a food
Too close/in her space
Told ‘no’/’not allowed’
Food ‘pushed’
Difficulty communicating
Verbal demand to eat
Behaviour
Food refusal
Function
Escape consuming non-preferred foods
Access to preferred
Difficulty making choices
Sibling disruptive
Wrong show/video or advert comes on
Request denied
Doesn’t get attention
Mealtime routine interrupted
No videos
Jiang or Viviana absent

Appendix PP

Max's Food Refusal Action Plan

Before lunchtime

- Prepare Max for interruption in the daily routine
- Sign on door outside TV room
- Helps prepare the meal
- Turn TV on before Max comes down for lunch

During lunchtime

Before the food refusal occurs

- Reduce number of bites presented if ill, tired, full on snacks, daily routine has been interrupted (or let self-feed @ own pace)
- Scattered attention provided when adult needs to do other things/pay attention elsewhere
- If Katie (sister) is distressed, wait until calm before presenting food or let self-feed @ own pace
- Consistent embedded opportunities to self-feed, mixed in spoon-feeding
- Try eating in a different setting
- Feed others the same meal
- Someone else (other than Molly, Christopher (dad), Grandma) offers the food
- Select long video/DVDs to play during lunch

After the food refusal has occurred

- Leave non-preferred food in sight after refusal
- Continue to provide attention but change tone based on what Max tries (non-preferred or preferred)
- Opportunity to ask for next bite after refuses food

After food acceptance has occurred

- Provide special reinforcers when Max tries non-preferred food (e.g., YouTube sounds cheering, peppa pig cheering, etc.).
- Encourage other adults to praise Max when he tries non-preferred food from them

• Model eating the non-preferred food with positive facial expressions and verbal statements (can be before or after food refusal)	

Appendix QQ

Adina’s Food Refusal Action Plan

Before dinner

- Following her lead to start eating
- Following her lead to transition out of preferred activity into dinner
- Following her lead to go up in the highchair
- Prepare food in advance
- Food cut in different shapes
- Sanitising the environment before dinner
- Round food adjustments
- Adina helps prepare the meal

During dinner

Before the food refusal occurs

- Sporadic attention
- Physically present
- Increase distance between Adina & Milena
- If Milena is loud/disruptive, wait until calm before presenting food or let self-feed @ own pace
- Eat the same food as Adina
- My turn, your turn game
- Play downloaded favourite video rotation

After the food refusal has occurred

- If food was refused, wait before re-presenting it
- De-escalation
- Continue to provide attention but change tone based on what Adina tries (non-preferred or preferred)
- Model eating the non-preferred food with positive facial expressions and verbal statements

After the food acceptance has occurred

• Reduce number of bites presented if difficult transition prior to dinner, day less structured, has had poorer sleep than usual • Ensure preferred foods are available for Adina during dinner • Reminder to eat/take a bite when Adina is focused on her videos and not eating • Round food adjustments • Avoid creamy foods • Follow through with Adina’s ‘routines’ where possible • Encourage placing food on tray • Model eating the non-preferred food with positive facial expressions and verbal statements	• Provide special reinforcers when Adina tries non-preferred food • Continue to provide attention but change tone based on what Adina tries (non-preferred or preferred)

Appendix RR

Supplementary Data & Report about Acceptance/Refusal of Preferred Food

Response definitions:

Each child's preferred foods (i.e., the most consistent ones that they usually ate during the specified mealtime) were identified for the study. Max's preferred foods were: beans on toast (or any variation, beans only, toast only). His target foods were: courgettes, spaghetti Bolognese, peas and carrots. Adina's preferred foods were: pasta, couscous, orzo, chicken nuggets, ham and soup. Her target foods were: cucumber, tomato, pepper, and broccoli.

Table 1

IOA information about food acceptance.

			Preferred food	
	Stage	**Number of sessions (%)**	**Average IOA %**	**Range of IOA**
Family One	**Baseline**	4/11 (36.4%)	98.3%	96.4-100
	Intervention	11 / 22 (50%)	94.95%	87.5-100
	Follow-up	3/3 (100%)	98%	93.3-100
Family Two	**Baseline**	4/13 (30.8%)	93.5%	86.7-100
	Intervention	10 / 24 (41.7%)	89.29%	71-100
	Follow-up	3/3 (100%)	92%	87.5-98.1

* Indicates IOA that was lower than the outlined standards.

Table 2

IOA information about food refusal.

			Preferred food	
	Stage	**Number of sessions (%)**	**Average IOA %**	**Range of IOA**
Family 1	**Baseline**	4/11 (36.4%)	77.5%*	50-100
	Intervention	11 / 22 (50%)	87.88%	50-100
	Follow-up	3/3 (100%)	100%	-
Family 2	**Baseline**	4/13 (30.8%)	95%	80-100
	Intervention	10 / 24 (41.7%)	62.78%*	0-100
	Follow-up	3/3 (100%)	93%	80-100

* Indicates IOA that was lower than the outlined standards.

There were graphs created for food acceptance or refusal of preferred food. Figure 1 illustrates the way in which Max's and Adina's acceptance and refusal of their preferred foods progressed throughout the study. These foods were identified at the baseline session, thus they were tracked throughout the baseline, intervention, and follow-up stage of this research. There is a phase change line that can be seen between the baseline and follow-up stages, indicating where the clinical baseline period ended, and the implementation of strategies began (i.e., the families were implementing the strategies outlined in their action plans).

Figure 1 shows that Max experienced a decrease in the acceptance of his preferred food, while Adina showed an increase in the acceptance of her preferred foods. Acceptance of preferred foods for Max during the research baseline stage was variable, with high rates and no trend, and this was the same for the clinical baseline stage, with the exception that the high rates were lower compared to the research baseline stage. During the intervention stage, acceptance of preferred foods for Max was variable and showed a slight decreasing trend, and during follow-up, this was variable with no trend and low rates. Acceptance of the preferred foods for Adina during the research baseline stage was variable, with high rates and no overall trend, though there was a decreasing trend at the end of this stage. This was the same for the clinical baseline stage, with the exception of no decreasing trend at the end of this stage. During the intervention stage, acceptance of preferred foods for Adina was variable, with high rates and no trend, and during follow-up, this was stable, with high rates and an increasing trend.

Refusal of preferred foods remained the same throughout with slight changes for both Max and Adina. Refusal of preferred foods for Max during the research baseline stage was variable, with low rates and no trend, and this was the same for the clinical baseline stage. During the intervention stage, refusal of preferred foods for Max was variable, with low rates and no trend overall, though there was a decreasing trend at the end of this stage, and during follow-up this was variable, with no trend and low rates. Refusal of preferred foods for Adina during the research baseline stage was variable with low rates and no trend, and during the clinical baseline stage this was stable with low rates and no trend. During the intervention stage, refusal of preferred foods for Adina was stable with low rates and no trend, and this was the same during follow-up. Max's refusal of his preferred foods remained on average the same throughout the study. Although Adina's frequency of refusal of preferred foods decreased slightly in level throughout the conditions of this intervention (see Table 3), this was low to begin with. Table 3 provides an overview of the changes in level (mean) across conditions for Max and Adina.

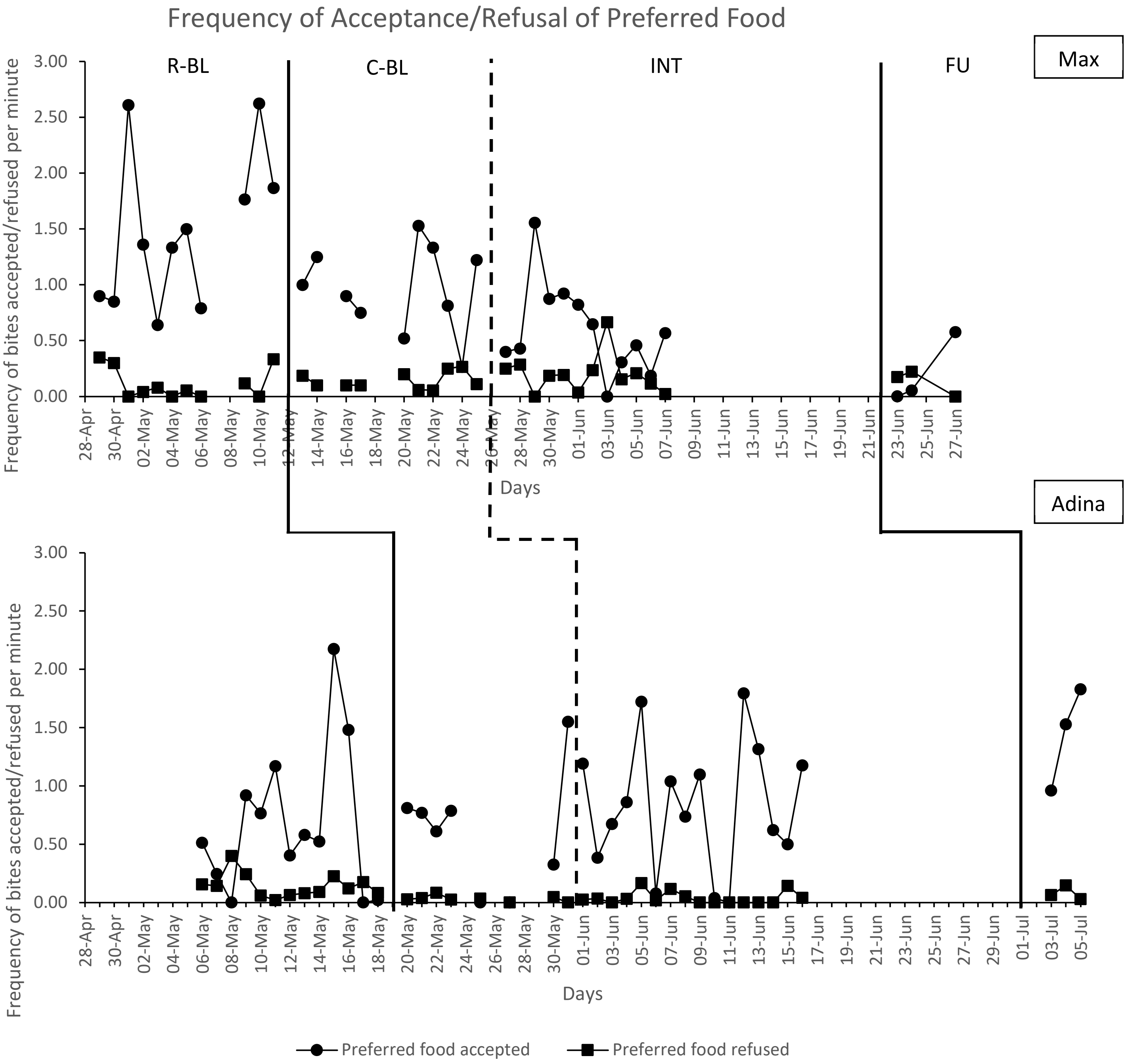
Table 3

Level of acceptance and refusal per minute of preferred foods for Max and Adina across conditions.

		Research Baseline	Clinical Baseline	Intervention	Follow-up
		Mean (Range)			
Acceptance					
	Max	1.4 (0.64-2.63)	0.96 (0.27-1.53)	0.6 (0-1.56)	0.21 (0-0.58)
	Adina	0.68 (0-2.18)	0.61 (0-1.55)	0.83 (0-1.79)	1.44 (0.96-1.83)
Refusal					
	Max	0.12 (0-0.35)	0.14 (0.06-0.27)	0.18 (0-0.67)	0.13 (0-0.22)
	Adina	0.14 (0.02-0.4)	0.03 (0-0.08)	0.04 (0-0.17)	0.08 (0.03-0.15)

Figure 1

Frequency of acceptance/refusal of preferred foods.



Appendix SS

Behavioural Paediatrics Feeding Assessment Scale (Word Version)

[REDACTED]

Appendix TT

Family Feeding Intervention Study Interview Schedule

Questions about the process

1. How have you found this process?
    a. Prompt: What was participating in this intervention like for you?
2. What have you enjoyed about this process?
    a. Prompt: Are there any aspects you enjoyed about this process?
    b. Prompt: (If nothing) Can you tell me more about why you didn't enjoy the process?
3. What would you change about this process?
    a. Prompt: How can this process be improved?
4. Have you noticed any changes in your child's behaviour during mealtimes?
5. Have you noticed any changes in your own behaviour during mealtimes?
6. Is there anything else you would like to add about this process?

Questions about social validity

1. Were the treatment goals for your family important and acceptable?
    a. Prompt: Did we focus on the right thing/the most important thing during your involvement in this process?
2. Was working with someone in this way an acceptable way to address your child's mealtime behaviour?
    a. Prompt: Did id work for you working with someone in this way to address your child's mealtime behaviour?
    b. Prompt: Did you find it appropriate to work with someone in this way to address your child's mealtime behaviour?
3. Were the action plan strategies important and acceptable?

   a. Prompt: Did you find the strategies acceptable to try out?

4. Were the changes you noticed in your child’s mealtime behaviour important and acceptable?
5. Were the changes you noticed in your own behaviour during mealtimes important and acceptable?

Appendix UU

BPFAS Participant Areas of Concern Responses

Table 1

BPFAS Indicated Areas of Possible Concern Pre- and Post-Intervention for Molly and Max.

Pre-Intervention Areas of possible concern	**Post-Intervention Areas of possible concern**
• Eating fruits • Enjoys eating • Will try new foods • Eats meat and/or fish • Takes longer than 20 minutes to finish a meal • Comes readily to mealtime • Gets up from table during meal • Whines or cries at feeding time • Eats vegetables • Tantrums at meal • Spits out food • Would rather drink than eat • Refuses to eat meals but requests food immediately after the meal • Tries to negotiate what he/she will eat • I feel confident in my ability to manage my child’s behaviour at mealtime • If my child does not like what is being served, I make something else	• Eats meat and/or fish • Takes longer than 20 minutes to finish a meal • Comes readily to mealtime • Gets up from table during meal • I coax my child to get him/her to take a bite • If my child does not like what is being served, I make something else

Table 2

BPFAS Indicated Areas of Possible Concern Pre- and Post-Intervention for Jiang and Adina.

Pre-Intervention Areas of possible concern	Post-Intervention Areas of possible concern
• Eating fruits • Will try new foods • Eats meat and/or fish • Takes longer than 20 minutes to finish a meal • Drinks milk • Comes readily to mealtime • Eats junky foods but will not eat at mealtime • Eats vegetables • Tantrums at meal • Eats starches • Has a poor appetite • Spits out food • Would rather drink than eat • Refuses to eat meals but requests food immediately after the meal • Tries to negotiate what he/she will eat • I feel confident my child gets enough to eat • I feel confident in my ability to manage my child's behaviour at mealtime	• Eating fruits • Will try new foods • Takes longer than 20 minutes to finish a meal • Eats vegetables • Tries to negotiate what he/she will eat • If my child does not like what is being served, I make something else

• If my child does not like what is being served, I make something else	

Table 3

BPFAS Indicated Areas of Possible Concern Pre- and Post-Intervention for Viviana and Adina.

Pre-Intervention Areas of possible concern	**Post-Intervention Areas of possible concern**
• Eating fruits • Will try new foods • Eats meat and/or fish • Takes longer than 20 minutes to finish a meal • Drinks milk • Comes readily to mealtime • Eats junky foods but will not eat at mealtime • Eats vegetables • Eats starches • Has a poor appetite • Would rather drink than eat • Refuses to eat meals but requests food immediately after the meal • Tries to negotiate what he/she will eat • I get frustrated and/or anxious when feeding my child	• Eating fruits • Will try new foods • Takes longer than 20 minutes to finish a meal • Drinks milk • Eats junky snack foods but will not eat at mealtime • Eats vegetables • Would rather drink than eat • Tries to negotiate what he/she will eat • I feel confident my child gets enough to eat • If my child does not like what is being served, I make something else • I feel that my child's eating pattern hurts his/her general health

- I coax my child to get him/her to take a bite
- I feel confident my child gets enough to eat
- I feel confident in my ability to manage my child’s behaviour at mealtime
- If my child does not like what is being served, I make something else
- I feel that my child’s eating pattern hurts his/her general health

Appendix VV

Social Validity Qualitative Data Overview

	Goals	Intervention	Outcomes
Participant			
Molly	• Acceptable and important goals that we had agreed on • Goals focused on Max being comfortable and less anxious for mealtimes & Max is widening his diet, which is what Molly was hoping to get • Important to work together to ensure researcher and family are working together for the same goal • Good to work together to ensure goals are achievable	• Still have a long way to go but helped move in the right direction • Data-based approach made sense to Molly • Good to try to understand Max • Have lots of simple strategies • Nothing 'dodgy' in strategies, strategies were appropriate	• Max has enjoyed it, not been upset, has coped well – the most important thing • Max has reintroduced things that he wasn't eating previously • Can understand why things go wrong and don't get upset with self if meals go wrong now – has helped Molly emotionally
Jiang	• Goals were fine but depends on how high you want to aim,	• Good to have combination of different strategies &	• Adina is less afraid and anxious

	Goals	**Intervention**	**Outcomes**
	when in a bad situation sometimes any help is good • Goals established were reasonable • Goals should be a positive mealtime experience, not getting the children to eat vegetables ○ Reflects a change in thinking about what is a realistic goal	be able to pick – allowed for experimenting (trying some out and testing the response) • Creating a positive environment during dinner is likely to have other benefits for Adina (more likely to go to sleep, play, like her parents)	• Learned to identify any cues and de-escalate or avoid any problems • Things feel easier now that Viviana is less stressed at dinner • Dinner has become a bonding experience with Adina • Therapeutic effects were not just on Adina but on the family as well
Viviana	• Felt like they had a misunderstanding of goals with initially trying to increase Adina's food consumption, rather than learning about Adina	• Joint working with families is the solution because professionals can't implement anything without the family ○ Described as hard work but worth it	• Didn't achieve Adina eating vegetables but learned to analyse her, understand her and put in place long-term strategies • Lifestyle changing – have learned about Adina and can adapt

Goals	Intervention	Outcomes
	• Discussing strategies together was good – and realising they knew what to do all along, just needed some support (advice and analysis) to do so • Easy to implement at home • All the strategies implemented were acceptable to them	to other situations (like travel) • Not feeling anxious at dinnertime anymore, feeling confident and comfortable • Adina doesn't throw food on the floor anymore or at Viviana – moves it off her tray to the table, or says no, or shakes her head • Adina's mealtime experience is more pleasant for her • Adina is more likely to touch the food or have it in front of her rather than rejecting immediately • Adina no longer has tantrums

Goals	Intervention	Outcomes
		• No longer getting mad or angry at Adina (used to previously), more patient and tolerating with Adina because understand her better & respect her choices more • Don’t feel guilt of being a bad parents because Adina is not eating • Implementing the strategies creates an environment for Adina where she is happier and behaves • Jiang and Viviana work better as a family

Appendix WW

Participant Experiences Qualitative Data Overview

	Positive Experiences	Negative Experiences	Suggestions for improvement
Participant			
Molly	Things about understanding why Max was refusing food • Helped to understand all the factors that influence Max's eating Things about the process • Getting to know the researcher • Nice to have support • Researcher was adaptable in scheduling & worked around the family • Data sheets simple & easy to use • Keeping paperwork light • Feedback keeps you going • Cooking different foods (for the intervention) • Reflecting on own actions during mealtimes	• Challenge trying to keep to the schedule when have lots going on at home ○ Described the effort as "worth it"	Materials • Some materials took a long time to prep – would be helpful to have some templates or strategies ready to go Intervention period • More regular sessions during implementation of action plan & spreading them out • A face-to-face meet with the child that might facilitate the development of strategies (by virtue of the

	Positive Experiences	Negative Experiences	Suggestions for improvement
	• Feel like strategies are helping • Strategies are not difficult to implement Things about Max • Being more present in mealtimes with Max • Max is more relaxed and happier during mealtimes • Max is more interested in what family is eating & asking for larger variety of food • Max has not been distressed at any point		researcher interacting with Max) • Breaking meetings up into shorter sessions because need to arrange childcare • Long sessions tricky – especially with an autistic child
Jiang	Things about the process • Have structure with the sessions & following a plan • Helpful observations provided by researcher & helpful to have someone observe	• Difficult to quantify the bites consistently	Materials • Doesn’t need to be a paper format – could have input the data straight into Excel

	Positive Experiences	**Negative Experiences**	**Suggestions for improvement**
	• Saw the benefits of the strategies • Individualised and tailored, so more likely to agree with the intervention & nothing recommended was unfeasible • Good and open way of exchanging ideas freely • What parents suggest was valued unlike with other health-care professionals • Remote worked well – parents didn’t have to spend extra time commuting and related expenses • Feel like self and Viviana work better as a team now due to roles during intervention		
	Things about Adina		

	Positive Experiences	Negative Experiences	Suggestions for improvement
	• Realised benefits of spending time with Adina during dinner • Helpful to reflect on the progress – see a different child now		
Viviana	Things about understanding why Adina was refusing food • Supported in understanding why Adina was refusing food – developing this understanding was the key • Learning Adina needs a different environment to make her happier and more willing to eat • Learning to analyse the environment and set it up in a more pleasant way for Adina Things about the process	• Difficult to stick to a schedule with dinner recordings because while also trying to be more led by Adina about when she was ready for dinner	Intervention period • Need longer than 3 months to see an improvement • Longer process, more follow-ups, and more spread out

	Positive Experiences	Negative Experiences	Suggestions for improvement
	• Learned about self as a parent and learned about child • Empowered knowing that they knew what to do all along • Helpful to have someone else for accountability • Learning that other fields (e.g., behaviour analysts) can provide support around food, different to nutritionist's support/role • Individualised approach – saw how unique Adina was • Researcher being patient with parents • Built own confidence in offering Adina non-preferred foods • Impressed that they were able to be supported and see benefits when researcher		

	Positive Experiences	Negative Experiences	Suggestions for improvement
	never met Adina or family in person		

Appendix XX

Overview of NHS Services, Intervention Process and Length

Interview 1: Clinical psychologist working in community child health in an acute hospital trust

Referral

- Internal referral
  - Paediatrician in the trust approves referrals (can come from therapists within Trust)
- External referral (dietitians, Great Ormond Street Hospital, Evelina)
  - Paediatrician in the trust approves referrals
- Paper referral (no email)

Waiting list

- One year
- Families informed they are on the waiting list, no further contct until offered appointment

First appointment

- Assessment, organic and led by family needs
- Full developmental history
- Looking for presenting problem, evolution of the presenting problem, parent and carer understanding and interpretations of what happened
- Share formulation to enable shared understanding with family

Support or intervention

- Approach is based on formulation (i.e. based on the presenting situation/need)
- 6 sessions spread out over a year
- Set goals and tasks with family and review periodically
- Identify the approach as PBS for families

Interview 2: Outreach worker working in a specialised tier three service

Referral

- Referred by professionals (school, GP, paediatrician, community services like OT/dietitian/SaLT)
- Complete referral form
- Review referral form and accept or reject it

Telephone triage

- Initial contact with the family
- Assess concerns and see what support might be needed

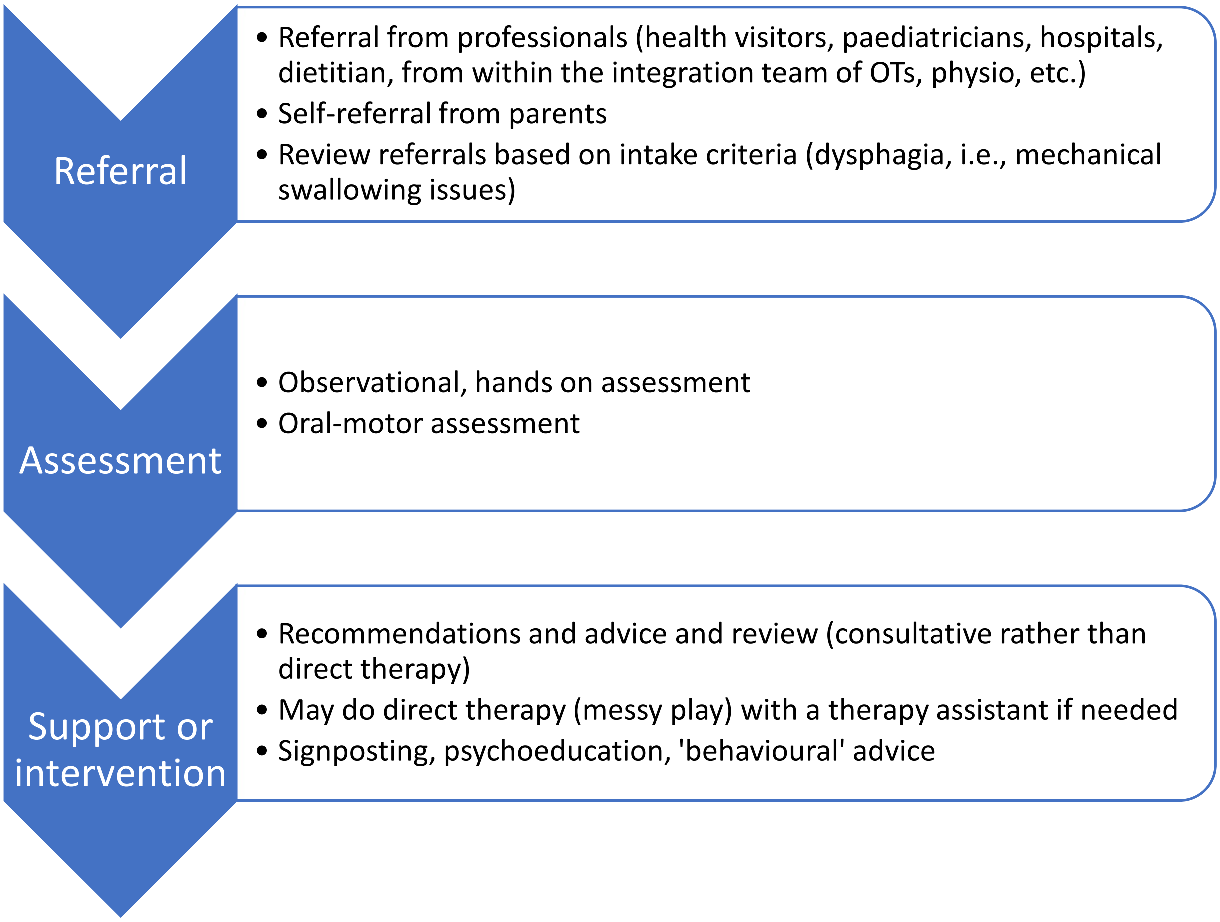
Initial assessment

- Set concrete goals around what family would like to work on
- Allocated to a clinician, depending on what would suit family's needs best

Support or intervention

- Functional behaviour assessment or equivalent, ask parents to collect information at home, setting expectations
- Behavioural intervention: psychoeducation, behavioural strategies, modeling
- Systemic work if indicated
- What is provided is influenced by what families need, flexible approach to support provided throughout
- 6-8 sessions initially then review
- Feeding group or individual feeding allocation

Interview 3: Specialist speech and language therapist in a community service



Referral

- Referral from professionals (health visitors, paediatricians, hospitals, dietitian, from within the integration team of OTs, physio, etc.)
- Self-referral from parents
- Review referrals based on intake criteria (dysphagia, i.e., mechanical swallowing issues)

Assessment

- Observational, hands on assessment
- Oral-motor assessment

Support or intervention

- Recommendations and advice and review (consultative rather than direct therapy)
- May do direct therapy (messy play) with a therapy assistant if needed
- Signposting, psychoeducation, 'behavioural' advice

Interview 4: Behaviour analyst in children's mental health in a tier three service

Referral

- Referral from a professional (dietitians, paediatricians, etc.)
- Require family to have already accessed community esrvices

Triage

- Check referral information correct and current
- Assess current needs and risks and check they are the right service
- Either go to priority or waitlist for an intial assessment

Support or intervention

- Gather up to date understanding of the presenting concern
- Functional behaviour assessment
- Looking to develop a formulation and intervention plan from that
- Group allocation (5 therapeutic sessions, 2 review) or individualised allocation (flexible)
- Short-term goals based service

Interview 5: Lead learning disability nurse in Learning Disability Children and Adolescent Mental Health Services

Referral

- Referred from other professionals (GP, paediatrician, social worker, special schools, other health professionals)

Assessment

- Functional assessment to formulate plans and inform recommendations

Support or intervention

- Intervention depends on formulation
- PBS principles and plans used, PBS strategies recommended
- Short-term, goals-led service

Interview 6: Principal speech and language therapist in community services

Referral

- Referral from other professionals (specialist hospital, local hospital, tertiary hospitals in London, paediatrician, GP, community paediatrician, nurseries, school)

Triage

- Looking at impact of problems mentioned, try to only see organic dysphagia, but behavioural feeding difficulties also get seen because nowhere else for them to be seen

Assessment

- Case history form, overview of the history of the feeding difficulty and presenting problem, and impact on the family

Support or intervention

- Parent workshop on fussy eating & invited to drop-in video feedback (if clearly only behavioural feeding difficulty), focused on parent education. Usually delivered through groups, currently just giving out written presentation
- SOS principles
- 1 session, 2 hours long

Interview 7: Highly specialist clinical psychologist in community paediatrics

Referral

- Referred through generic community paediatrics and the feeding clinic
- Referral reviewed if appropriate for clinical psychologist input (intake criteria)

Waitlist

- In order of referral, priority service in rare cases

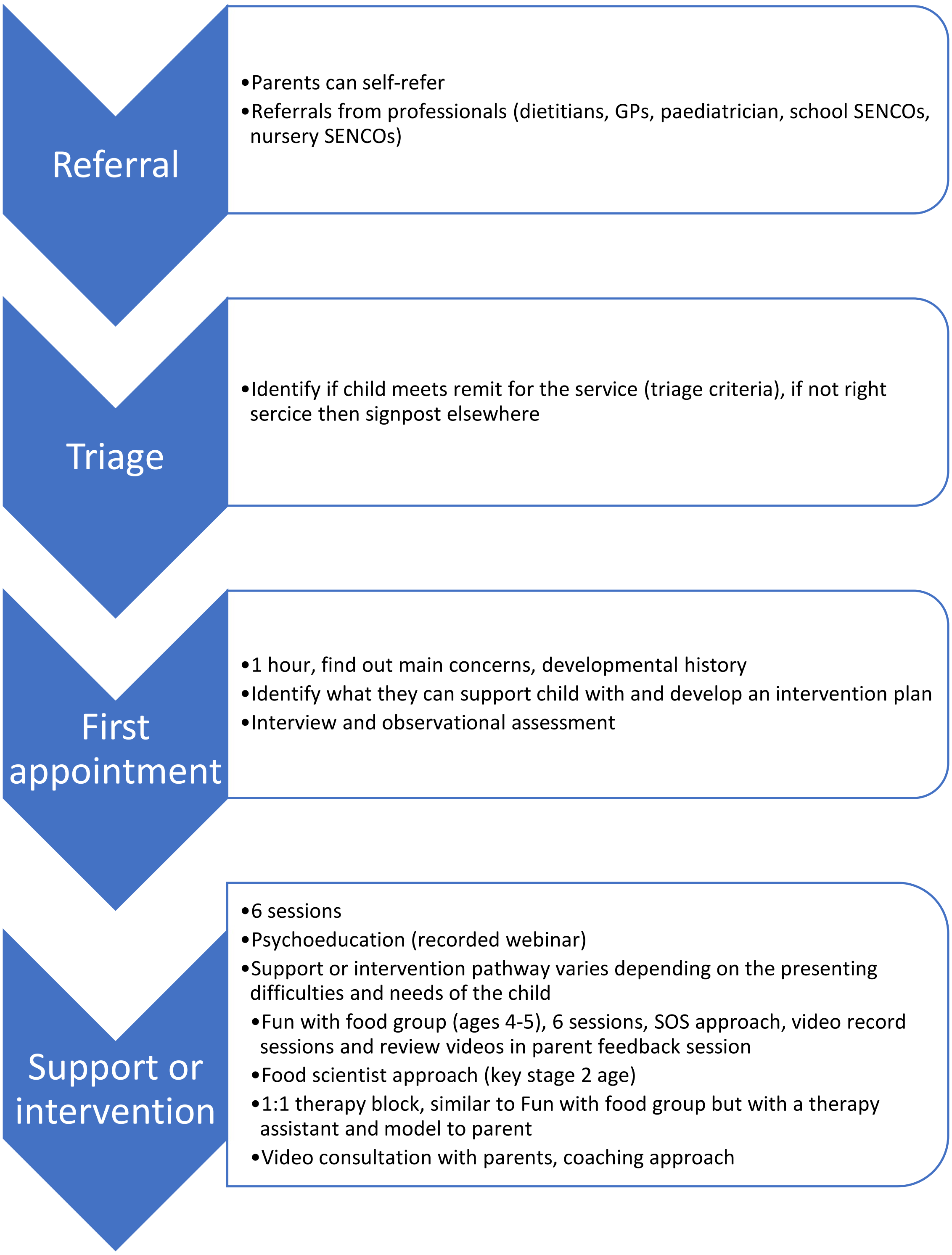
Assessment

- Initial assessment, general paediatric psychology assessment with a focus on feeding difficulties
- Developing formulation, ask about goals

Intervention

- Holding families and supporting in acceptance of where they are
- Psychoeducation, behavioural strategies, theoretical understanding (division of responsibility)
- Individual interventions, 4-6 sessions approximately
- Recommendations, action plan/homework

Interview 8: Occupational therapist (children and young people & clinical lead for feeding)



Referral

- Parents can self-refer
- Referrals from professionals (dietitians, GPs, paediatrician, school SENCOs, nursery SENCOs)

Triage

- Identify if child meets remit for the service (triage criteria), if not right sercice then signpost elsewhere

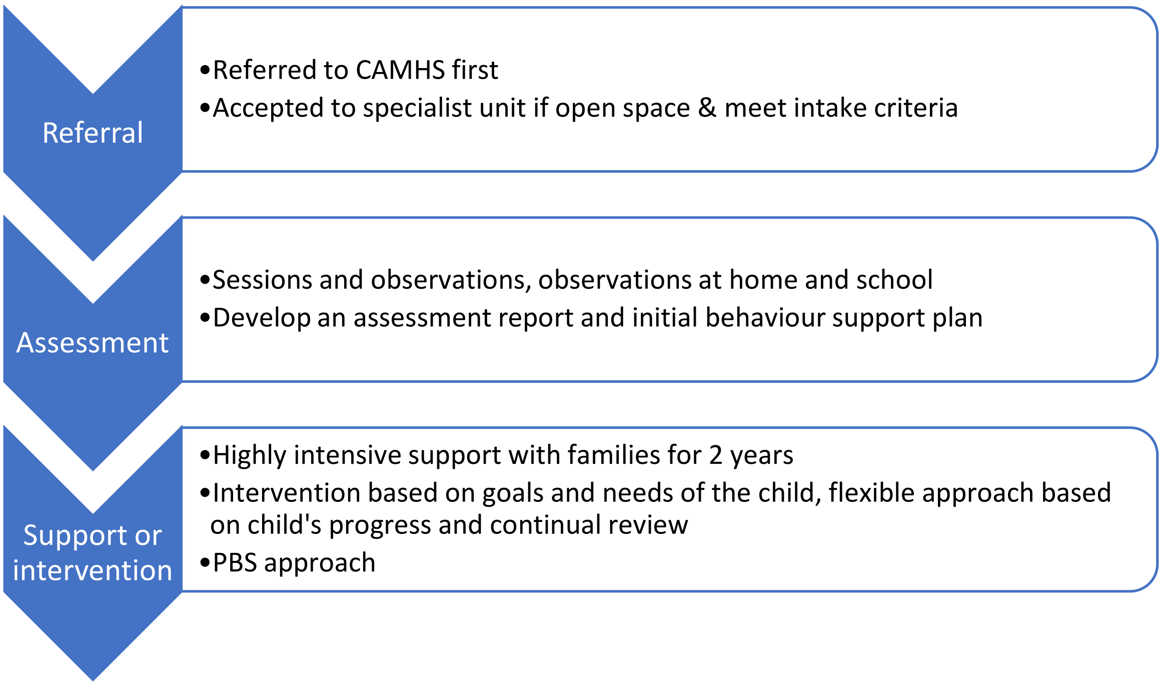
First appointment

- 1 hour, find out main concerns, developmental history
- Identify what they can support child with and develop an intervention plan
- Interview and observational assessment

Support or intervention

- 6 sessions
- Psychoeducation (recorded webinar)
- Support or intervention pathway varies depending on the presenting difficulties and needs of the child
  - Fun with food group (ages 4-5), 6 sessions, SOS approach, video record sessions and review videos in parent feedback session
  - Food scientist approach (key stage 2 age)
  - 1:1 therapy block, similar to Fun with food group but with a therapy assistant and model to parent
  - Video consultation with parents, coaching approach

Interview 9: Assistant psychologist in specialist unit of Learning Disability Children and Adolescent Mental Health Service



Referral

- Referred to CAMHS first
- Accepted to specialist unit if open space & meet intake criteria

Assessment

- Sessions and observations, observations at home and school
- Develop an assessment report and initial behaviour support plan

Support or intervention

- Highly intensive support with families for 2 years
- Intervention based on goals and needs of the child, flexible approach based on child's progress and continual review
- PBS approach

Interview 10: Assistant clinical psychologist in a feeding team

Referral

- Referred by professionals (GP, SaLT, etc.)

Assessment

- Parent workshop (psychoeducation around feeding difficulties and what they do in the feeding clinic)
- Reviewed by physical health for organic difficulties, general assessment
- Parents have option to opt in for futher support

Support or intervention

- 3 sessions online work with parents, parent-led approach, identify a goal, formulation, SOS approach, strategies recommended based on current needs and limitations of the child
- If need further support, stay on, varied by child and need