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# Reimagining Autism: How drama environments can aid the diagnosis and understanding of autism

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## **ABSTRACT**

Using the practical approaches developed for the research project, *Imagining Autism*, the PhD investigates whether engagement in a play-based drama environment can help aid the diagnostic process and understanding of autism. The research has used drama workshops to see if these can enhance the profile of strengths, difficulties and differences obtained in a more traditional clinical diagnostic assessment. The exploratory study also seeks to see whether the ADOS (the clinical assessment tool) can be completed in a different environment and if there is agreement between the two settings on these scores. In addition to this, what supplementary information may be provided about the individuals because of their engagement in this drama environment. Eight participants (aged 3 – 11 years) were recruited through the NHS and had gone through the clinical assessment. They engaged in the arctic environment twice, where they encountered puppets, props and full-body characters e.g. the slapstick snowman, in play-based interactions with trained practitioners. The sessions were documented and analysis occurred afterwards, using a novel coding framework, and additional information obtained from parents and practitioners. These were then compared to the clinical assessment scores and reports, to test the hypotheses. Both qualitative and quantitative analysis will compare the two sets of information from the different environments, seeking to present a more holistic and rounded view, focusing not only on the difficulties but also on the strengths of the individual.

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# INTRODUCTION

'Whilst the scientific stance is to observe and measure, arts-based approaches are a means to engage and interact, creating knowledge that is not possible through the science on its own' (Shaughnessy 2017b: 80).

This thesis investigates the idea of generating knowledge from the arts to extend scientific understanding, as put forward by Shaughnessy, using an interdisciplinary project to explore how a drama-based environment could enhance the process of diagnosing autism, thus combining the social sciences and humanities. Most of the prevalent research into autism is within the sciences and presents a particular view of autism in terms of deficits, based on the medical model. However, there is an increasing amount of arts-based practices that are providing alternative views and contributing to the understanding of autism that, as Shaughnessy commented, is not possible exclusively within the sciences.

In recent years there has been an increase in the number of interdisciplinary projects that are being developed between the sciences and humanities and that utilise the robust measures of evaluation found within the sciences and the techniques and practices from the humanities (e.g., deLahunta, Clarke and Barnard 2012). Prior to this, within the arts community there had been an understanding and appreciation of the role that arts can have in benefiting and supporting communities, this being recognised within humanities academia (e.g. in applied theatre contexts [discussed later on pages 12 and 13]). The benefits that such projects are having, in particular for the autistic community, are starting to be acknowledged by scientists and the drive to establish more robust evaluative methods in the arts has helped to develop interest in the production of interdisciplinary work. This has been prominent in the use of drama with autistic individuals, as drama-based practices have been found to be beneficial as an

intervention tool for them (e.g., the SENSE Theater Program [Corbett et al. 2017] and SDARI [Lerner and Mikami 2012]; see also O’Sullivan 2015 for a review of drama with autism). This thesis extends the range of possible benefits found in such research by exploring how drama-based practices could affect the diagnostic process.

The following research questions are proposed and explored:

1. Does engagement in a drama environment enhance the profile of strengths, difficulties and differences that are found in autistic children?
2. Can the Autism Diagnostic Observation Schedule (ADOS: Lord et al. 1989; ADOS-2: Lord et al. 2012) be used in a non-clinical setting?
3. How do ADOS-2 scores compare between clinical and drama-based settings?
4. What (if any) additional behavioural information about the participant can be ascertained based on their engagement in the drama-based setting that can help to generate a strengths-based profile of them (additional information not currently tested for in the ADOS-2)?

This introduction will start with a brief exploration of how autism is currently conceptualised, an issue which is further explored in Chapter 2. Following on from this, an outline will illustrate why drama has been found to be a valuable intervention tool with autistic individuals, with a growing shift from the production of work that is presented in case-studies and anecdotal reports to more robust evaluative methods that are akin to scientific methods of evaluation. This will lead into a discussion of the existing drama-based project *Imagining Autism (iA)*, on which this research is based, moving on to how the research developed from this work, introducing the development of the research as it sits across and between the fields of drama and psychology. The introduction will conclude with a short outline of the thesis and a note on the terminology used throughout.

## Introduction to Autism

Autism Spectrum Disorder (ASD) is currently<sup>1</sup> described as ‘a lifelong developmental disability that affects how people perceive the world and interact with others’ (National Autistic Society [NAS] 2017) – there are no cures. Diagnostically it affects individuals in two ways: through difficulties in their social communication and imagination; and through restricted and repetitive behaviours (World Health Organisation [WHO] 1992; American Psychiatric Association [APA] 2013).

The condition was first labelled as a separate clinical entity – ‘autistic disturbances of affective contact’ – by psychiatrist Leo Kanner in 1943 in a study of eleven children.<sup>2</sup> Since then a plethora of research has developed the understanding surrounding it, including the characteristics of autism, the diagnostic label used and what might help an individual once they have received a diagnosis (e.g., an intervention).<sup>3</sup> Although there has been a considerable increase in understanding about autism there is still much that remains unclear, with areas such as the cause of autism remaining largely unknown. This further contributes to a fluid concept of autism and thus to the continual change in diagnostic practices, leading it to be labelled as ‘perhaps one of the most confusing and enigmatic of conditions’ (Trimingham in press). However, it is known to affect a wide range of people of all genders, across races and around the world.

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<sup>1</sup> The term ‘currently’ is used here because knowledge continues to be generated that affects how autism is viewed, labelled and diagnosed, as will be discussed throughout.

<sup>2</sup> Not long after, in 1944, Hans Asperger, another paediatrician, published a paper describing four children who had similar symptoms to Kanner’s children, referring to an ‘autistic psychopathy’. Similarly to Kanner, the behavioural presentations he noted were so distinct that he introduced a new diagnostic label. Asperger’s paper was not translated into English until 1991 (by Uta Frith) and so the extent of the condition in the West has only recently become apparent. While Aspergers is considered to be part of the autistic spectrum, some have argued for it to be its own clinical entity. This will be discussed in more detail later.

<sup>3</sup> Popular interventions include Applied Behavioural Analysis (ABA), ‘a systematic way of observing someone’s behaviour, identifying desirable changes in that behaviour and then using the most appropriate methods to make those changes’ (Research Autism 2017).

The current prevalence rate is thought to be just over one in every hundred (Baird et al. 2006<sup>4</sup>; Brugha et al. 2012) with a reported gender bias of 4:1 to males (Fombonne 2003; Baron-Cohen 2008).<sup>5</sup> However, the gender bias has recently been contested by researchers who suggest that the gender ratio is much closer<sup>6</sup>, with complex issues seen in the diagnosis of females, an underrecognition of symptoms and misdiagnosis suggested (Shattuck et al. 2009; Giarelli et al. 2010; William et al. 2012; Rutherford et al. 2016). Diagnosis occurs across multiple races; however, some studies have found an underdiagnosis in ethnic minorities (Mandell et al. 2007; Waltz 2011; Heejoo et al. 2015; Emerson, Morrell and Neece 2016). Autism is diagnosed around the world although often based on a Western perception of the condition, in particular an Anglo-American one.

The use of the term 'spectrum' refers to the wide range of behavioural manifestations that are present in diagnosed individuals, with the spectrum usually understood to be linear.<sup>7</sup> At one end there are those who appear to be more severely outwardly affected, have higher support needs and who may have additional diagnoses such as intellectual disability (ID). Within the literature these people are sometimes referred to as being 'lower-functioning', which Osteen (2008: 7) has argued 'may create low expectations that foster hopelessness or passivity'. At the other end of the spectrum are those who, at least outwardly appear, to be more autonomous and able to function more successfully, requiring less daily support. These people may be referred to as having high-functioning autism (HFA) or Asperger's Syndrome. However, it has been pointed out that the term 'high-functioning' can also be misleading as an individual

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<sup>4</sup> This was made up of 0.39% diagnosed with childhood autism and 0.77% with other ASDs.

<sup>5</sup> The ratio of Kanner's children was 8:3 and Asperger's children were all male, with Asperger even stating that the 'autistic personality is an extreme variant of male intelligence' (Asperger 1991[1944]: 84).

<sup>6</sup> For example Wing (1981b) found a ratio of 2.6:1 when all children who functioned at a moderate, severe or profoundly intellectually disabled level were considered, regardless of handicaps or behaviour, and a 2.1:1 with those who were 'moderately, severely, or profoundly retarded'.

<sup>7</sup> Although recently this has been challenged with the autism spectrum being instead perceived as a circular representation, e.g. <https://themighty.com/2016/05/rebecca-burgess-comic-redesigns-the-autism-spectrum/>

with 'high' intellectual ability can still be significantly impaired in their social skills (Dover and Le Couteur 2007: 540), which can reduce the perceived impact of the disability on them and the understanding of difficulties for these individuals. As Dr Stephen Shore notes 'if you've met one person with autism, you've met one person with autism', which emphasises the varying behavioural manifestations of the condition and its heterogeneous nature (Spectrum n.d.).

The diagnosis of autism is made problematic by the lack of a single known cause (as will be discussed in Chapter 1) meaning that the diagnosis relies on a range of tools that often attempt to assess and evaluate behaviour through either direct observation or via historic reports of behaviour, with a combination of both sets of information suggested for clinical diagnosis in the UK (National Institute for Health and Care Excellence [NICE] 2011). Because the diagnosis relies on assessment via behavioural methods it is defined as being a 'best estimate'. There are two diagnostic manuals used within the UK and although they now contain similar descriptions of autism, they use different labels, potentially further problematising the condition: the umbrella term 'autism spectrum disorders' (ASD) is used in the Diagnostic and Statistical Manual of Mental Disorders now in its 5<sup>th</sup> edition (DSM-5); and a range of possible diagnoses including autism and Asperger's syndrome in the International Statistical Classification of Diseases and Related Health Problems (ICD), the current revision being ICD-10 (discussed further in Chapter 2). Authorities in different areas in the UK use different manuals, resulting in variation in the label used from county to county. However, despite the different diagnostic systems used there is consensus that the diagnosis should contain both an observational assessment and a historic report of development.

The tools that are deemed to be 'gold standard'<sup>8</sup> are the ADOS (Autism Diagnostic Observation Schedule, see Lord et al. 1989 [ADOS-2 was released in 2012]), an observational

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<sup>8</sup> This term implies that the method 'is the best available, and the procedure by which all similar procedures should be judged' (Matson, Beighley and Turygin 2012: 20).

tool, and the ADI-R (Autism Diagnostic Interview-Revised, see Lord, Rutter and Le Couteur 1994 [for the original version of ADI see Le Couteur et al. 1989]), a historical account involving an interview. The combination of these tools provides a comprehensive perspective on an individual, enabling an experienced multidisciplinary team to make a diagnosis.

Further complications that can confound diagnosis result from the fluid nature of autism research, as mentioned above, which is constantly shifting. Despite the condition first being labelled over seventy years ago, it is only recently that there has been the ‘phenomenal success of autism *diagnoses*’ (Evans 2017: 1) [italics in the original].

## Why Drama?

Drama practices have historically been used in a variety of ways to help various communities. For example, in educational settings, Dorothy Heathcote<sup>9</sup> realised the potential of drama as a powerful learning tool. Controversially she worked *within* the action, working alongside her pupils and learning from them as they learnt from her, as opposed to being a distant and authoritative figure (which was common at the time), with her techniques helping to develop a pedagogy which uses drama as a teaching tool. She acknowledged that drama is a useful tool as it requires co-operation and a common understanding, leads to an enhancement of communicative precision and enables children to work within two worlds simultaneously<sup>10</sup> (fiction and fantasy), among other skills (Heathcote 1984: 203-204). Her work was hugely influential to applied theatre.

The use of drama in educational settings has been extended through applied theatre (although it can still occur within education), an umbrella term for practices that involve

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<sup>9</sup> A drama teacher who started working in the 1950s, and academic.

<sup>10</sup> Additionally, discussed in Sherratt and Peter (2006: 93) in relation to play-drama interventions and autism.

working with communities (e.g., in prisons or war-torn countries) often outside conventional theatre spaces, and can cover a range of theatre practices, for example theatre in education and Theatre of the Oppressed (Johnson and O'Neil [1984]). Nicholson (2014: 3-4) has said that it is a form of drama that seeks to 'benefit individuals, communities and societies' and is 'primarily concerned with developing new possibilities for everyday living rather than separating theatre-going from other aspects of life'. Taylor (2003: xxi) has discussed the social and political potential of the genre by putting forward five key purposes of it: 'raising awareness, posing alternatives, healing psychological wounds or barriers, challenging contemporary discourses, voicing the views of the silent and marginal'. Emphasis is placed on the process of creating theatre with individual members of the communities, with specific communities' stories being central to the work produced (Thompson 2008). The audience often becomes embedded within the performance as participants, both doing and watching (Prentki and Preston 2009) with applied theatre being for, with and by a community (Prentki and Preston 2009: 10).

Drama-based work has also been applied in a therapeutic context through dramatherapy, which evolved in the 1960s in Britain from drama/theatre in education (Meldrum 1994: 12). This is drama that is applied in 'clinical, remedial and community settings with people who are unwell' (Jennings 1998: 12) and is 'aimed at enhancing the well-being of the persons involved' (Pitruzzella 2004: 1).

These drama-based practices (as well as other forms not mentioned here) have been proposed as beneficial to the autistic community, with popularity of the approaches increasing and anecdotal reports and case studies providing a range of support for its use.

The potential benefits of drama may be that the triad of impairments (which proposes that autistic people have difficulties in social communication, social interaction and social imagination [Wing and Gould 1979; to be discussed on page 94]), can be mapped onto the 'drama triad' in which communication, interaction and imagination are essential to the

engagement with drama from both the performers' and audience's perspective. It is therefore conceivable that drama may be useful to help remedy some of the difficulties faced by autistic people. Sherratt and Peter (2002) have suggested that the triad of impairments could in fact be converted into a triad of competencies, as using play-drama interventions with autistic people allows the development of brain functioning that helps with flexible thinking, which in turn can benefit communication and social interaction skills (cited in Peter 2003). As stated by Corbett et al. (2017: 335) 'skills involved in theatre parallel areas in which youth with ASD display deficits: emotion perception, theory of mind, creative thinking, and reciprocal communication', which supports the benefits as reported by Sherratt and Peter. The mapping of the triad of impairments onto the drama triad was of central importance to the conception of the AHRC iA project and was the basis of the hypothesis for that project (Beadle-Brown et al. 2017). Furthermore, this idea of the relationship between the drama triad and the triad of impairments indicates why this kind of work may be beneficial to the autistic community.<sup>11</sup> In addition, the foundation of approaches that use drama with autistic individuals is the recognition that 'drama can be both a means of modelling or rehearsing for interactions in the social world as well as being a means of facilitating self-awareness and self-expression', allowing a variety of practices which can be flexible to suit different aims (Trimingham and Shaughnessy 2016a: 109).

In previous research, the relationship between drama and autism has been explored through dramatherapy (e.g., Johnson 1982; Barrager Dunne 1988) demonstrating some benefits for specific autistic people which can be achieved when drama-based practices are used in a therapeutic approach.

In recent years there has been an expansion in the interest in the relationship between autism and drama, one that extends beyond dramatherapy and practitioners and academics

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<sup>11</sup> Asperger's colleague Sister Viktorine Zak found drama to be beneficial as a means to teach social skills in the clinic where Asperger worked, with Asperger referring to her as a 'genius' (Frith 1991: 8).

working in the arts, with scientists demonstrating an increasing awareness of its value. This has encouraged interdisciplinary research which brings together scientists and artists within projects to help scientifically evaluate the benefits of drama as a practice to work with autistic people. This has partly been due to a recognition that scientists' focus on observation and measurement can be complemented by arts-based approaches which engage and interact, helping to generate knowledge beyond what is possible within the sciences on their own (Shaughnessy 2017b). This was emphasised by researchers in an interdisciplinary project that combined dancers and a neuroscientist:

Science and creativity in artistic practice are often uncomfortable bedfellows. In our own project we have found reciprocal synergies where one enriches the other. In this case, science draws on the richness of practical multimodal experience evidenced in dance expertise while offering back a vocabulary through which difficult to express ideas can be crystallized and exchanged in a different register. (deLahunta, Clarke and Barnard 2011: 250).

Key contributors to this growing interdisciplinary field that focus on a particular drama programme for autistic people include: Blythe Corbett and the SENSE Theater program (Corbett et al. 2011; Corbett et al. 2014a, 2014b; Corbett et al. 2016; Corbett et al. 2017); Matthew Lerner and the Sociodramatic Affective Relational Intervention (SDARI: see Lerner, Mikami and Levine 2011; Hartigan 2012; Lerner and Mikami 2012); the Social Competence Intervention Program (SCIP: see Glass, Guli and Semrud-Clikeman 2008; Guli et al. 2013); and the Hunter Heartbeat Method (Hunter 2015). These projects have been subject to some scientific evaluation which has found a range of measurable benefits for their autistic participants, with Corbett et al. (2017) recently publishing the results of a randomised control trial (RCT),<sup>12</sup> noting reductions in trait anxiety after participation in the SENSE program. All of these programmes have seen improvement in autistic people across a variety of measures after participating in drama-based

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<sup>12</sup> This is perceived to be the 'gold standard' of scientific research. RCTs are studies in which participants are 'randomly assigned to 2 (or more) groups to test a specific drug, treatment or other intervention. One group (the experimental group) has the intervention being tested, the other (a comparison or control group) has an alternative intervention, a dummy intervention (placebo) or no intervention at all' (NICE 2017).

programmes (this will be discussed in more detail in later chapters). Another drama project that has sought to remedy the difficulties faced by autistic people and produced interdisciplinary work with drama practitioners and psychologists is iA, the project that the research in this thesis is based on.<sup>13</sup>

## **Introduction to iA**

iA is a drama intervention<sup>14</sup> that works with autistic children in a play-based, multi-sensory and highly stimulating environment, and which seeks to address the difficulties that autistic individuals have that map onto the triad of impairments. These environments are 'designed to facilitate communication (verbal and physical), social interaction (with practitioners and peers), imagination (participating in fictional frameworks) and creativity (through improvisation)' (Beadle-Brown et al. 2017: 3). The main project<sup>15</sup> was funded by the Arts and Humanities Research Council (AHRC) based at the University of Kent<sup>16</sup> between 2011 and 2014, to work alongside psychologists who could evaluate the project scientifically.<sup>17</sup> This involved working in three specialist schools within Kent (St. Nicholas School in Canterbury, Laleham Gap in Broadstairs and Helen Allison School in Meopham) for ten weeks with two groups (3-4 pupils per group) of autistic participants aged between seven and eleven within each school. Evaluation of the project (see Beadle-Brown et al. 2017) reported positive

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<sup>13</sup> Publications include Beadle-Brown et al. 2017; Shaughnessy 2016a, 2016b, 2017a, 2017b; Trimmingham 2017, in press; Trimmingham and Shaughnessy 2016a, 2016b.

<sup>14</sup> Although the project is referred to as an intervention it is not used to teach skills to autistic individuals, as other interventions aims may be, but instead to help 'facilitate and extend communicative intent and shared attention and to develop and sustain imagination and creativity' (Shaughnessy 2016a: 201).

<sup>15</sup> This version of the project will be discussed at various points throughout the thesis and will be referred to as the AHRC iA project to allow clear differentiation between this and the research completed for this thesis which is a version of iA.

<sup>16</sup> The principal investigator was Professor Nicola Shaughnessy (School of Drama) and the co-investigators were Dr Melissa Trimmingham (School of Drama), Professor Julie Beadle-Brown (Tizard Centre) and Dr David Wilkinson (School of Psychology).

<sup>17</sup> This was developed from a previous joint proposal on 'Play and Autism' (Nicola Shaughnessy) and 'Puppetry and Autism' (Melissa Trimmingham) that was funded by the Ideas Factory and won Kent University Innovative Project of the Year 2010-2011.

indicators, including four children having significantly decreased scores (and therefore demonstrating improvement) on the communication subdomain of the ADOS when using confidence interval analysis<sup>18</sup> (although there was no statistically significant difference in the ADOS scores at baseline and post-intervention). For the participants completing module 3 on the ADOS<sup>19</sup> there was a statistically significant reduction in the reciprocal social interaction domain (and therefore an improvement was demonstrated). On the VABS<sup>20</sup> there was a statistically significant increase in the communication and socialisation domain scores post-intervention, and in the emotion recognition task there was an increase in the correct number of emotions identified. These results constitute statistical evidence of cognitive benefit from this intervention for some children with autism, clearly warranting further investigation.

iA sessions (both the AHRC iA project and the research behind this thesis) occur within 'the pod'<sup>21</sup>, a portable metal structure (3m × 4m × 2.5m) sometimes referred to by participants in the AHRC iA project as the 'tent', which is dressed as an interactive performance installation representing one of five environments. These environments were selected due to their potential for imaginative engagement without the likelihood of encouraging reproductions of popular stories or stereotyped responses, e.g., from Disney and children's television/films (Shaughnessy 2013) (Arctic<sup>22</sup>, Forest, Outer Space, Under the City and Under the Sea) (Shaughnessy 2016a: 187). The pod is covered in blackout material for all of the environments apart from the Arctic which uses white material. The space is filled with theatrical technology (stage lighting, sound and a projector which can accommodate live feeds) that help to support the environments. For example, in Forest dappled light is used to simulate light coming through trees, whereas in

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<sup>18</sup> This refers to the level of confidence on the data.

<sup>19</sup> There are four modules (discussed in Chapter 3) which are based on the communication level of the individual being assessed and affects how they are tested. Module 3 is 'fluent speech, child/adolescent'.

<sup>20</sup> Vineland Adaptive Behavior Scales are measures that assess an individual's personal and social skills.

<sup>21</sup> See Tringham in press for a detailed discussion of the scenography of iA.

<sup>22</sup> The hugely successful Disney film *Frozen* was released after the project started in 2013 and only one participant in the practice sessions for this research referred to this film.

Under the Sea UV light helps to illuminate fish puppets. The technological aspects are controlled within the pod thereby giving participants the opportunity to control these components should they wish to. In addition to this, loose props and elements are scattered around the space to add to the environment, e.g., soil and leaves in Forest and snowballs in Arctic. The practitioners<sup>23</sup> present themselves as larger-than-life characters such as Foxy in Forest or the Snowman in Arctic, or as puppeteers, all of whom contribute towards the playful experience of the pod. The space created within the environments is liminal<sup>24</sup>, located between the neurotypical (non-autistic people, i.e. those who are neurologically typical) and neurodiverse<sup>25</sup> world of participants and practitioners, with Shaughnessy (2017b) suggesting that the practitioners and participants are situated in the 'now/here of nowhere'.

A loose narrative guided the sessions that often involved a journey (e.g., entering a space ship that landed on the moon) which had predetermined events within them such as a storm<sup>26</sup> that altered the environment in some way. The loose narrative could be elaborated or dropped by the practitioners depending on the response of the participants (Trimingham 2017: 185). There was a sense of practitioners not imposing what they *wanted* or what they felt they *ought* to do in order to allow the children authorship (Trimingham 2017: 186). This concept is further emphasised by Ralph Savarese's autistic son DJ who discusses how people should talk to him, 'if you wait patiently and wordlessly, you free me to finally respond voluntarily', which highlights the ways in which such techniques might be particularly useful for nonverbal autistic

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<sup>23</sup> These were specifically trained individuals with experience in working with children with special needs and as performers. There were usually four or five practitioners within each session which meant that there was more than a 1:1 ratio of child to adult. The practitioner training for this research will be discussed in Chapter 3.

<sup>24</sup> Turner (1982: 28) has provided definitions of liminality in which 'anti-structure' is present, meaning that there is a 'dissolution of normative social structures, with its role-sets [and] statuses'. In addition to this 'social relations may be discontinued, former rights and obligations are suspended, the social order may seem to have been turned upside down... liminality may also include subversive and ludic (or playful events) ... in other words, in liminality people, "play" with the elements of the familiar and defamiliarize them' (Turner 1982: 27). This liminal space is very much present within the pod.

<sup>25</sup> This is a social movement connected to the social model of disability, which is discussed in more detail in Chapter 2.

<sup>26</sup> The lights flashed and sounds changed to reflect the storm. Practitioners also responded appropriately.

individuals (Savarese and Zunshine 2014: 23; also discussed in Trimingham in press). The participants within the sessions become co-producers rather than spectators or audience members being performed to, as in models of contemporary performance. This diverges from traditional performance in that it 'stresses liveness, challenging the boundaries between performers and audience by emphasizing presence; being, 'in the moment' as spectators who are conscious of being physically present and actively engaged as partakers' (Shaughnessy 2017b: 65).

## **The iA Methodology**

The methods and techniques used in the AHRC iA project were initially developed organically and through trial-and-error methods based on *Elements of Performance Art* (Howell and Templeton 1977). Connections were created between elements of this work (conditions/body/aural/time/space/equipment/manifestation) and with categories in postdramatic theatre<sup>27</sup> (text/space/time/body/media)<sup>28</sup> as proposed by Lehmann (2006) (Shaughnessy 2016b). The research underlying this thesis uses a version of the AHRC iA project, applying several of the techniques developed from the original work and adapting them to be suited to a diagnostic rather than an interventional setting: play; turn-taking; liveness (or presence); open space; physicality; improvisation; working as an ensemble (Trimingham and Shaughnessy 2016a; Shaughnessy 2016b)<sup>29</sup>; and puppetry. Where appropriate, these techniques will be applied to the wider context of other theatre projects that utilise these skills.

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<sup>27</sup> This is a form of theatre that 'operate[s] beyond drama, at a time 'after' the authority of the dramatic paradigm in theatre' and has a 'simultaneous and multi-perspective form of perceiving... replacing the linear-successive' (Lehmann 2006: 16) In contrast, 'dramatic theatre is subordinated to the primacy of the text' (Lehmann 2006: 21) with the text functioning 'primarily as [a] role script' (Lehmann 2006: 26). Practitioners who have been associated with postdramatic theatre include Jerzy Grotowski, Robert Wilson and the Wooster Group.

<sup>28</sup> See Shaughnessy (2013).

<sup>29</sup> Both papers also put forward shared attention, responding to the other and reading non-verbal cues as other training techniques; however, these will not be explored separately as they fit within the other categories described.

## ***Play***

The iA environment operates with a play-based setting (akin to the ADOS-2, although to a greater degree) in which the participants are encouraged to play with and alongside practitioners and peers. Although the play offered by participants is not necessarily intended as performance (e.g., taking on a role), play is an intrinsic part of performing as it embodies the make-believe (Schechner 2013). By engaging with the play-based environment the participants have some acceptance of the make-believe although it is still clear that it is pretence: ‘they were aware that they were in a place of *pretense* (sic) where the experience was real, but the structure was not real’ (Shaughnessy 2016a: 203) [italics in original]. The participants are therefore given a license to play creatively. This is particularly important for autistic children whose play is often overlooked post-diagnosis (Trimingham and Shaughnessy 2016; Shaughnessy 2013; Shaughnessy 2016b). While difficulties and differences with play skills have been reported among people on the autistic spectrum (Hammes and Langdell 1981; Baron-Cohen 1987; Williams, Reddy and Costall 2001; Rutherford and Rogers 2003; Williams 2003; Lam and Yeung 2012) as well as being part of the diagnostic criteria (APA 2013), some parents report that autistic children have shown abilities to engage in dramatic play through acting, dressing up, entertaining others and mimicking (Kempe 2014). In any case, dramatic play has been found to be a useful tool for development (Guss 2005) and for encouraging ‘co-participation, collaboration and enquiry’ (Gupta 2009: 1051). The concept of cognitive development through play is explored further by Shaughnessy (2016b: 205) ‘the autistic children within our environments are engaging in sensory and experiential encounters that are fundamental to cognitive development, that precede speech, and that may explain why language and communication emerge with and through imaginative engagement in these processes’. Furthermore, the iA environments help to return the participants ‘to a mode of playful exploration that is fundamental to development of language and awareness of self, but is suppressed by autism’s concrete orientation’ (Shaughnessy 2016a: 197). Lillard et al. (2013)

discussed the importance of adults who engage in pretence which in turn encourages children to pretend. By playing together with practitioners (adults who are willing to engage in play) in iA, the participants begin to move into co-creator roles rather than simply being passive audience members. The play is often generated by the participants, who are given the license to do so, allowing them to feel in control and have autonomy, as well as help develop creative skills.<sup>30</sup>

### ***Turn-taking***

A natural way to engage with the participants in the iA environments is through turn-taking, which is often based on imitation of the participant's behaviour, using copying and responding to develop a nonverbal communication between participants and practitioners, aiding social interaction. This in part helped to meet the participants in a liminal space (discussed briefly below). This technique is also employed by Intensive Interaction which is an 'approach to teaching the pre-speech fundamentals of communication to children and adults who have severe learning difficulties and/or autism and who are still at an early stage of communication development' (Intensive Interaction Institute 2017). Although Intensive Interaction does not align itself to any drama practice, its methods do have similarities through the use of body-based work as a means of communication, relying on nonverbal cues. Part of their technique is 'mirroring the autistic person's body language' (Craig 2005); however, Phoebe Caldwell, the inventor of the technique, emphasises that this is not about mimicking the person. In one example she demonstrates how the mirroring of behaviour can lead to natural turn-taking and joint attention which promotes social interaction.

For example, in answer to a sound, 'er-er' I might make the same sound, 'er-er' (imitation). Or I might make the same sound but elongate it, 'eerrr', or shift the pitch up or down, or lift it at the end (a good way of asking a question). I might alter the rhythm. Or I might shift the mode, answering the sound with a tap, or draw the shape of the sound on their arm. All of which gives the brain something it recognises but also, a slight 'jolt' – 'that's something I

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<sup>30</sup> Wyver and Spence (1999) found that play helps with the development of divergent problem solving (or creativity), with Danksy (1980) reporting that sociodramatic play is also useful for this.

recognise but it's slightly different'. (Caldwell n.d.).

A similar practice is also used by the Open Theatre Company, a theatre programme that works with young people with learning disabilities to create 'collaborative drama projects and productions... developing real opportunities for these young people to engage and contribute to the cultural life of their cities' (Open Theatre 2013a). One of the techniques that they use is mimetics a practice drawn from psycho-physical actor training.<sup>31</sup> Mimetics is 'an interactive communication process based on copying and imitation... the term mimetics defines imitation as a live, communicative and dynamic process of imaginative and dialogic interpretation of reality' (Trowsdale and Hayhow 2013: 73). Trowsdale and Hayhow (2013: 78) found that mimetics appeared to have significant value for children with learning disabilities in their 'level of engagement with each other and with learning, in problem solving, taking risks, thinking in new and imaginative ways, as well as in children's readiness to reflect on their behaviour and progress in learning', thus demonstrating the potential benefits beyond the drama workshops. It is noteworthy that different practices have arrived at similar methods that appear to be useful for working with autistic and learning-disabled people, often developing in an organic fashion.

### ***Liveness (or presence)***

Being live, present and in the moment is very important to the practices of iA, requiring performers to be open and responsive to cues given by the participants, as well as the practitioners *being*, not merely acting. This is a technique that was employed by Ting Theatre, a performance art company: 'instead of acting, the performers use exercises to create the possibility of extending their own behaviour into the arena of the action... thus the only drama the performers are involved in is that of their real lives at the time of performance... having both [performers and audience] elucidate the rules and judge how the game may be progressing'

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<sup>31</sup> This is essentially a form of training that works to develop towards developing skills that move away from divisions of mind and body and towards an integration of the two (e.g., as proposed by Michael Chekhov).

(Howell and Templeton 1977: 12). However, the participants in iA are not an audience; instead they move into co-creator and co-performer roles. The focus in iA is the 'practitioners' presence not purpose' which is vital to Lehmann's postdramatic theatre (Trimingham 2017: 187).

Lehmann (2006: 17) discusses this: 'the aesthetic act itself (the performing) as well as the act of reception (the theatre going) take place as a real doing in the here and now'. Shaughnessy (2016a: 195) discusses the concept of presence in relation to the AHRC iA project, 'this stance involves being in the moment with participants, engaging in the theatrical temporality (and rhythm) of a continuous present, and allowing for a suspension of the time and space of the school environment to experience 45 minutes of being in the now and here (of nowhere) of immersive performance'. Additionally, 'for practitioners, being in the moment with participants involves leaving their habitual responses behind in order to be open to developing and discovering a relationship with the experience of autism' (Shaughnessy 2016a: 198) and encourages the practitioners as well as the participants, to work 'intuitively and creatively' (Trimingham and Shaughnessy 2016: 112). This type of presence requires practitioners to improvise and play within the liminal space (as defined on page 18). In addition to this, practitioners employed the idea of 'pretending-to-pretend' which Shaughnessy (2013: 327) describes as where

past and futures coalesce into the presence of the present; a consciousness of being 'in the room' as part of the blurring between the fictional world the participants inhabit within the pod (and help to create through their interactions) and the reality of our awareness of the process of making performance.

There is a clear sense of artifice within the iA environment that is realised within the set and props (e.g., cardboard fish) that further emphasises the idea of pretence to the participants. To support this (and tying in with the concept of being in the moment), the practitioners were able to come in and out of role (e.g., through the removal of costume) to make it apparent to the participants that the practitioners were pretending-to-pretend, opening up possibilities for a range of encounters and actions between participants and practitioners to occur.

## ***Liminal Space***

The pod that houses the iA environment is set within a liminal space (as described on page 18) which is located somewhere between neurotypicality and neurodiversity, with the pod fusing the two worlds together and functioning ‘as a bridge between the social world that the autistic participants struggled to access and their experience of an autistic consciousness’ (Shaughnessy 2016b: 499). In addition this contributes to the liminal temporality which offers a time and space between the two worlds ‘where encounters can take place ‘in the moment’’ (Shaughnessy 2013: 327). Baron-Cohen (2009b: 11) further explores the potential benefits of working in a liminal space for autistic people:

[I]t may be that the methods that are most successful will be those that appeal to the autistic mind. Ethically, this also means that, rather than expecting the child with ASC to join our world, we are adapting the environment to meet him or her halfway.

The pod offers the kind of ‘adapted environment’ suggested by Baron-Cohen, as the practitioners join the participants at the level they are at communicatively and join them in the way they are interacting with the environment, helping to find a mutual connection as opposed to pulling the participants into a neurotypical world. This ties back into the role of imitation and the techniques employed by Intensive Interaction, as well as being demonstrated in other projects, e.g., The Miracle Project, which uses ‘inclusive theater and expressive arts programs’ to help autistic and other disabled individuals to build skills in communication and community, and enhance social skills and self-esteem (The Miracle Project 2017). The Miracle Project also encourages neurotypicals to “‘join in the world”, and thus follow the lead, of youth with ASD, all in the context of theatrical play, performance, and experimentation’ instead of teaching those on the spectrum to ‘follow conventional behavioural expectations’ (Kim et al. 2015: 29). Oily Cart, an English theatre company that specialises in creating theatre productions for children with profound and multiple learning difficulties (PMLDs), autistic children and very young children, employs similar methods. They describe their productions as ‘innovative, multi-sensory and highly interactive’ and a high practitioner-to-audience ratio, means that audiences can be at the

heart of the action (Oily Cart 2017a). One of the key methods that they use is to work with audiences on a very individual basis (Oily Cart 2017b):

performers are trained to respond sensitively to each individual's reaction and to tailor each sensory experience to the young person with whom they are working. Each participant will have a unique experience, precisely reflecting his or her interest and ways of communication.

Peter (2003: 23) also advocates for this methodology and the role of shared meanings, suggesting that the appropriate method to engage with autistic children is by meeting the child at their level, then enabling this to be developed: 'having gained a child's *interest*, perhaps initially by joining in a favourite play activity (or including it within a drama), and ensuring the activity is pitched at an appropriate level of conceptual understanding, the adult will need to judge sensitively when to introduce a change' [italics in original] (see also Sherratt and Peter 2006). Similar techniques are also used in the Hunter Heartbeat Method. This is a theatre programme which engages with questions of whether drama (and in particular Shakespeare) can help break through the communicative blocks that are present in autism and if long-term benefits can be shown (Hunter 2015: x). The Hunter Heartbeat Method empowers children and ensures that the instructor 'make[s] engagement possible for the children', adapting the work to suit the participants' needs (Hunter 2015: xiii). Furthermore, this technique is used in dramatherapy with one project noting that 'we [therapist and client] become companions in the shared journey of discovery into the client's world (Porter 2014: 84), thereby demonstrating how a range of drama-based practices utilise this sense of liminal space to help support and facilitate engagement.

### ***Physicality***

The role of physicality became important in iA as it offered an alternative mode of communication that did not rely on the verbal, something which proved to be pertinent when working with nonverbal participants as well as the more verbally capable ones. Language levels were often reduced in the environment by the practitioners, helping to facilitate a different

mode of communication. In addition to this, the use of physicality supported body-based humour (e.g., slapstick) which proved to be a very successful method of engaging with the autistic participants, arguably due to the repetitive action that is often prevalent in this style. Slapstick humour was frequently used in the AHRC iA project (see Shaughnessy 2013: 330; and Trimmingham and Shaughnessy 2016a: 144 for a brief discussion) with the mantra ‘if they laugh, do it again’, which helped to facilitate enjoyable interactions and shared attention between practitioners and participants that contrasts with the widespread perception of a lack of humour in autistic people.<sup>32</sup> Shaughnessy (2013: 330) further emphasises how it can be a ‘means of facilitating understanding of the relationship between self and other’. ‘Finding your clown’ workshops were offered as part of the training to practitioners in both the AHRC iA project and the research for this thesis to further support these body-based skills. Trowsdale and Hayhow (2013: 74) in their work with the Open Theatre also used the clown state to help develop their practice of mimetics, with the clown being open to failure, present, a risk taker and truthful, arguably many of the qualities that were required in the iA practitioners. Additionally, the Open Theatre developed some of their own techniques e.g., shystering, which is an ‘interactive, non-verbal, physical theatre practice’ that helps to draw on the ‘creativity of actors with learning disabilities’ (Open Theatre 2013b).

### ***Improvisation***

As part of the techniques of presence and operating within a liminal space, it became fundamental to use improvisational skills which enabled the participants to offer ideas that the practitioners would work with and develop alongside them. Improvisation facilitates and supports many of the techniques thus far discussed. As mentioned on page 18, a loose narrative guided the action within the pod but this was heavily supported by improvisation to enable the

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<sup>32</sup> In addition to Asperger’s own notes, more recent research has provided evidence for this. For example, it was found that autistic participants choose the correct funny endings less often (Ozonoff and Miller 1996; Emerich et al. 2003) and failed to laugh at jokes based on socially inappropriate acts (Reddy, Williams and Vaughan 2002)

collaboration between practitioners and participants. The process of working within iA has been likened to improvisational jazz, with building blocks of action used to help provide a framework that is accompanied by an openness which allows for improvisation to occur as participants offer contributions that help to facilitate both individual and collective creativity, further allowing the practitioners to be responsive to cues from the participants (Shaughnessy 2016a). The structured play that is offered (in the form of a loose narrative with some action points) has been referred to as a 'guided improvisation' and akin to the 'Drama Structures' approach of Dorothy Heathcote (Shaughnessy 2016a: 190). Additional benefits may be felt by the participants: Trimmingham (in press) discusses how the creative improvisation they experienced may be largely denied to them in everyday living but is released in the pod, allowing an 'extension of ourselves when we are most truly ourselves'.

### ***Working as an Ensemble***

Working in an ensemble is very important in applied contexts as there is an element of the unknown facilitated by the use of improvisation and it requires a keen sense of ensemble to help support the work of the performers as a collective, and with their work with the participants. Britton (2013) has reported key approaches to ensemble training, some of which are very relevant to the work of iA: 'shared training'; 'Here. Now'; 'Psychophysicality and sensitization'. The shared training helped to build nonverbal skills within the ensemble, enabling it to operate effectively in a manner that goes beyond verbal direction. The 'Here. Now' approach helps to enable the practitioners to truly be 'alive' and to react spontaneously and appropriately in the moment to each other and to the participants, enabling them to have agency (Britton 2013: 28). The sensitivity of the practitioners is enhanced and they are able to pick up subtle cues from participants as well as from the other practitioners, enabling the work to successfully progress. Furthermore, this development of sensitivity to the "true impulse' and the ability to react authentically to each moment' helps confirm the sense of aliveness (ibid.). The AHRC iA project involved a company that trained and worked together over an extended

period, helping it to develop a shared vocabulary (see Shaughnessy 2016a), and ensemble driven work was integral to the research for this thesis.

### ***Puppetry***

This technique was developed from the experience of one of the co-investigators of the AHRC iA project as a mother finding it to be a successful method for working with her son (see Trimingham 2010) and was used within the environments (see Trimingham and Shaughnessy 2016b for a case study of Mary and the puppet).<sup>33</sup> The puppet offers a simpler mode of communication in comparison to humans, with reduced facial expressions and gesturing that may be easier for some autistic participants to read than their human counterparts – being ‘*usefully inanimate*’ (Trimingham and Shaughnessy 2016b: 300) [italics in original]. The puppet also becomes a valuable tool for what Trimingham and Shaughnessy term as ‘manipulacting’, whereby a three-way communication occurs which includes the puppeteer ‘splitting off from the puppet, joining in and speaking to or doing actions with the child too as themselves’ (2016b: 300). The benefits of working with puppets are summarised by Trimingham (2010: 263):

They are predictable enough to feel safe, they entertain and amuse, they are funny, and they help a child to make ‘sense’ of the world. Uniquely, because they are objects, the child can focus on them as solid and real, but imbue them with ‘mind’. They have enough ‘redundancy’, unpredictability and deep connections to the ‘real’ to both maintain interest and move the child on in its development. They act as a safe bridge to the less predictable world of other objects and people, helping them deal with that ‘otherness’ and learn (and embody) crucial aspects of it.

It was the experience of the AHRC iA project that bird puppets seemed to work particularly well (Trimingham and Shaughnessy 2016b). The iA environments offered Dennis the Woodpecker (who lived in a tree in the Forest environment) and Purdy, with Purdy being used within the research underlying this thesis.

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<sup>33</sup> See also Shaughnessy (2011) pp. 37-38.

## Research and Thesis Development

The research questions that this thesis explores were developed from the positive results that were found in the scientific measures from the AHRC iA project (Beadle-Brown et al. 2017) as well as the positive behaviours demonstrated by participants that challenged current thinking surrounding autistic individuals. This included the fact that participants successfully navigated and maintained peer and practitioner relationships, in contrast with perceived deficits in social interactions as being one of the core difficulties for autistic individuals. Participants also engaged in and produced comic interactions associated with skills in theory of mind (ToM), again something that is perceived to be problematic for some autistic people (discussed further in Chapter 2). In addition to this, a clinician who had diagnosed several of the participants commented on how the children in the AHRC iA project were displaying very different behaviours within the iA environment to those which she had witnessed in the clinical environment. There is an increasing awareness in research communities of the benefits of projects such as iA, which are gaining increasing momentum and evidence for their effectiveness. Moreover, drama-based projects are moving into the development of interdisciplinary work which combines the sciences with the arts to produce more scientifically robust evidence in support of these practices, helping to validate research beyond arts disciplines. Much of the current research explores drama as an intervention for autism, a way to alleviate some of the difficulties associated with the condition post-diagnosis with ever-increasing research success. However, despite the research which focuses on strengths, differences and potential of autistic individuals, this has not yet filtered down into diagnostic practices. There is an increasing social awareness of viewing differences rather than disabilities; however diagnostic practices primarily focus on the weaknesses of an individual. While it is clear that the consideration of these deviations from the 'normal' is necessary to obtain a diagnosis and the support that this then enables, as society is broadly shifting towards holistic views of disability it is important that the focus of diagnostic practices begins to shift too. This is

where drama may be useful in aiding the diagnostic process of autism: introducing the benefits that have been found from its interventional use into the diagnostic setting. This may help to present a holistic view of the individual that emphasises their strengths and potential as well as the difficulties they experience. In addition to this, the use of drama may also demonstrate the individual's skills or tools that were found to be useful in attaining engagement, and these could then be used by the individuals' families to help support work *alongside* the child after the diagnosis.

As well as extending the role of drama into diagnostic practices in this research, the role of interdisciplinary research was further extended in which, instead of a team of experts from different disciplines working on a research project together an individual (with the support of an expert supervisory team) was required to fully engage with and navigate the research across the disciplines. Concerned as it was with the evaluation of diagnostic process, the research became embedded within both the social sciences (psychology) and the arts (drama), developing a conceptual and theoretical framework that suits both modes of enquiry. The methods used by each field have been adapted to complement the other and, as part of this process, compromises to each field have occurred. This means that there is some deviation from the usual disciplinary standards in both the methodologies presented and in the appearance of the thesis.<sup>34</sup> The social sciences initially supplied a methodological structure from which the basis of the research was developed, and provided tools to develop an analytical and evaluative framework. They were also the source of much of the theoretical literature about autism. Drama provided the practical tools with which the individuals' skills and deficits could be explored differently to what is currently witnessed in the clinical setting. It also provided an additional

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<sup>34</sup> When viewing the methodology differences between the sciences and arts, Rowe and Reason (2017b: 14-15) describes it as follows: 'the scientific method takes aim rather like an archer does to his target; success or otherwise is easy to determine. The arts practitioner invites participants to plunge themselves in an immersive pool of creative experience, trusting that this will have an effect that cannot be fully predicated at the outset and is likely to be difficult to define'. Thus demonstrating the potential difficulties in attempting interdisciplinary projects.

framework to work within and an alternative construction of autism through recent advances in literature and research. This thesis attempts to be at the forefront of interdisciplinarity as it has been written with the intention of being read and understood by researchers within both disciplines.

## **About the Author**

It should be noted that the academic history of the author is within the arts, having completed a drama degree specialising in physical actor training at undergraduate-masters level, with sciences (both biology and psychology) having been studied in further education. A substantial part of the initial research process has been the shift in thinking from that of an artist to that of a scientist, attempting to find a medium somewhere between the two disciplines. In addition to this, the author has professional experience working as a practitioner in iA prior to the start of this research, and as a research assistant in two additional research projects concurrent with it which combined the arts with more scientific methods of evaluation (Liquid Vibrations, analysing the effect of music played underwater on people with special needs<sup>35</sup> and Comedy on the Spectrum, Exploring Humour Production in Adolescents with Autism<sup>36</sup>).

## **Structure of the Thesis**

In Chapter 1 autism is explored through the construction of the condition via three key modes of thinking. The first is the medical and scientific construction, which focuses on the deficits of someone on the autistic spectrum and the cause of autism. The second is the social construction, which provides an alternative mode of thinking via the social model of disability

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<sup>35</sup> <https://www.liquidvibrations.org.uk/research>

<sup>36</sup> <https://autismandcomedy.com/>

and movements such as the neurodiversity movement, which places emphasis on difference rather than deficit. In addition to this there will be a discussion of the media representations of autism that are prevalent within society. The third mode of thinking is an alternative view that is being developed through the arts and which provides conflicting evidence to the perceived deficits of autistic people, promoting a more holistic view of the individual.

In the second chapter a historical account of autism is presented<sup>37</sup> which traces the development of knowledge surrounding autism from its 'discovery' by Kanner in 1943, through it being established as a separate clinical entity and up to the state of understanding at the time of writing. This is supplemented by an exploration of the various diagnostic tools that are used, providing support for and arguments against the use of a variety of them (these are divided into screening tools, scales and interviews, and observational measures). The chapter concludes with an explanation of the diagnostic practices used within the UK at the time of writing.

Chapter 3 presents the methodology of the research, providing information on how it was carried out and justification for this. The tools that were used within this research are discussed, including the established ADOS-2 and the development and testing of a novel tool (the diagnostic performance tool) which provides information additional to the ADOS-2. The design of the research, the participants, the environment in which the research took place, the ethics underlying it and the procedure followed are discussed and justified.

The fourth chapter examines the quantitative results of the research comparing the clinical ADOS-2 to the research ADOS-2, and is composed of two parts. The first part will do this by comparing the two ADOS-2 scores on five levels: the actual diagnosis given; the ADOS-2 classification; the severity level; the comparison score; and the individual ADOS-2 algorithm

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<sup>37</sup> It is acknowledged by the author that this historical account, essentially a literature review, inevitably focuses on science-based accounts. It is beyond the scope of this thesis to include a literature review of applied drama and theatre; however, throughout the thesis, references to drama-based practices are made. Moreover, drama was integral to the practice which underlies this thesis and provides very important opportunities for challenging the current construction of autism.

scores. The second part concentrates on the successfulness of the ADOS-2 completion within the iA environment, exploring this through two of the ADOS-2 modules, 1 and 3, which were the modules used for the participants in this research.

In the fifth and sixth chapters the qualitative data from the research is presented through the discussion of 'alternative information'. This information has been defined as being supplementary to the quantitative data and diagnostic information that is currently supplied in clinical practices. It provides an array of examples of behaviours that have occurred because of the interaction with the drama environment, challenging current understanding surrounding autism and providing further support for the use of drama in the diagnostic process. Chapter 5 explores the qualitative information relevant to 'social interaction' considering behaviours that may be demonstrated within the clinical ADOS-2 but are more fully present within the iA environment. The sixth chapter considers 'performance intent', exploring behaviours that are unique to the drama-based environment. Both chapters provide additional information for diagnostic profiles and extend knowledge surrounding perceived deficits in autism.

Chapter 7 draws together the research results discussed in Chapters 4, 5 and 6 in a discussion which examines the results in relation to existing research, focusing on specific areas that the results contribute to which challenge current scientific understanding and provide further support for arts-based research, indicating the wider importance of these findings. The results are discussed in relation to the aims of the research and the limitations of the work are considered.

This thesis will conclude with a brief summary of results and findings.

## Terminology

When referring to clinical diagnosis in relation to the DSM-5, the term autism spectrum disorder (ASD) will be used, as this is the clinical label given to individuals diagnosed by the National Health Service (NHS) in the geographical location for this research, East Kent. This contrasts with autistic spectrum condition (ASC), a label preferred by some as the term ‘simultaneously acknowledges the disabling aspects of autism and Asperger syndrome, and the fact that the differences in functioning do not lead to *global* disability and may in some individuals even result in talent’ (Baron-Cohen 2008: 14) [italics in the original], which arguably suits a holistic understanding better than the ASD. The diagnostic label given varies across the country and between diagnostic manuals (DSM-5 uses the umbrella term ASD whereas the ICD-10 offers multiple diagnostic labels, e.g., autism, Asperger’s syndrome etc.) The labelling is subject to debate within both the autistic and professional communities about which is the most suitable terminology, with some disagreeing that autism is a disorder. However, the diagnostic manual used by the NHS in the research location has dictated the clinical terminology used here. When not referring specifically to the DSM-5, the term ‘autism’ will be used (a shorthand phrase which covers the autistic spectrum) as well as references to people being ‘on the (autistic) spectrum’. When distinguishing between individuals on the spectrum, if an author of a discussed work uses terminology to describe a specific diagnosis or label within the spectrum, e.g., ‘Asperger’s’ or ‘high-functioning autism’, this will be used. In addition to this, the description of autistic people will avoid phrases such as ‘person with autism’ (a person-centred diagnosis<sup>38</sup>) which implies that autism (or indeed any other disability) is an appendage rather than being ‘an essential part of the self’ (Oliver 1990: xiii). This ties in with how Michael Oliver who ‘named but did not invent’ the social model of disability (discussed in Chapter 2) discusses the language he opted to use in *The Politics of Disablement* (1990). A recent survey (Kenny et al.

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<sup>38</sup> This is placing ‘the whole person rather than the disease at the centre of healthcare’ (Mezzich et al. 2010: 702).

2016) found that autistic adults and parents favoured disability-first terms, e.g., 'autistic person', contrasting with professionals who reported preferences towards person-first language, e.g., 'person with autism', and both groups were comfortable with the terms 'autism' and 'on the autistic spectrum'. Moreover, in informal conversations with autistic adults about favoured terminology, there appeared to be a preference towards the use of 'autistic person'.

## CHAPTER 1: THE CONSTRUCTIONS OF AUTISM

The definition of autism is likely to continue to develop as further knowledge is acquired and diagnostic boundaries change, so the current definition of autism as set out in the Introduction may soon become outdated. Part of the way that autism is defined is through the construction of the condition via a variety of models and modes of thinking: the medical and scientific; the social; and the alternative (which is where the role of drama-based projects and interventions lie). These models provide differing frameworks through which to view autism in particular and disability more generally. The various understandings that will be presented support the way that autism is viewed and experienced which in turn affect the diagnostic criteria, the tools used and the labels given. This chapter will not only explore these constructions but will also demonstrate the breadth of information about the condition that is currently available while illustrating the fluidity in understanding of autism, which affects the constructions presented as well as altering the understanding and perception of autism more generally. This fluidity is likely to prevail within certain areas of research surrounding autism, such as the cause of autism, and this will influence the way the condition is understood by individuals and by society at large.

In discussing the medical and scientific construction, the idea of autism as a series of deficits will be explored. Much of the research within this construction focuses on discovering the cause of autism and some of the key proposed causes will be discussed, divided into biological factors, psychological theories, and environmental causes. These models have been predominant through the history of autism research and operate at the forefront of much of the current research. The social construction will be introduced and analysed through how society impacts disability, exploring the social model of disability and the connected neurodiversity movement, both of which attempt to shift society's perception of autism away from the medical

and scientific models. Finally, the effect of alternative constructions will be discussed, focusing particularly on the influence of the arts and more specifically drama, which has recently had growing research interest. This alternative construction promotes a more holistic view of autistic individuals, providing further contrasts with the medical and scientific mode of thinking, thus moving away from viewing what an autistic individual cannot do and towards appreciating and understanding their skills.

## **Autism: The medical and scientific construction**

The medical model and the scientific construction of autism are prevalent in research and literature on autism and focus prominently on the discovery of causes and the diagnostic construction, exploring the symptomatology of the condition. The definition of autism presented in the Introduction, as well as most other definitions, is based on these constructions. The current diagnostic manual, DSM-5, groups the core diagnostic deficits into two areas:

- 1) social communication and interaction;
- 2) restricted and repetitive patterns of behaviour, interest or activities (APA 2013).

The manual lists a series of behaviours (or deficits) of which an individual must present a combination in order to receive an ASD diagnosis, this being established through the use of various diagnostic tools. Although research to date has provided much new information about the condition, contributing to several revisions of the diagnostic criteria, there are still areas of uncertainty within the field which cause much debate. These include the origin of autism, which as research currently stands, has no single known cause, problematising the diagnostic process. If a cause could be determined this could potentially make the diagnostic process more streamlined and arguably more accurate. Currently diagnosis is achieved through observation and reports of behaviour, and can be referred to as a 'best-estimate'. There are many theories of

causation, these broadly fitting into the three categories that will be discussed in turn: biological factors; psychology theories; and environmental causes.<sup>39</sup>

## **Biological Factors**

There are several biological factors that have been linked to autism and it has been argued that there is no longer any doubt for a biological basis (Baron-Cohen 2008). If a biological cause was determined then this could mean a biological test could be used to give an accurate diagnosis, rather than the current reliance on behavioural measures. The focus of this section will be on two of the more prominent and recognised causes: (1) genetics; and (2) abnormalities in brain functioning.

Genetic influences on diagnosis have been supported by family links seen in both twin (Le Couteur et al. 1996; Hallmayer et al. 2011; Nordenbæk et al. 2014; Deng et al. 2015) and family (Gillberg 1991) studies, with parents of autistic children scoring significantly higher than control parents on diagnostic measures (Wheelwright et al. 2010). Behavioural similarities between autistic children and their families were even noted in the original cases of Kanner (1973 [1943]) and Asperger (1991 [1944]). Subsequently, and due to the growing interest in isolating specific genetic causes<sup>40</sup>, a substantial amount of research has been conducted in this area. According to literature reviews, relevant genes have been suggested in seven (Yang and Gill 2007) and sixteen (Aitken 2010) chromosomes. However, other reviews of literature have found many difficulties in highlighting specific causes (Chakrabarti and Baron-Cohen 2013; Geschwind and State 2015; Ziats and Rennert 2016). Although twin studies support some family link, concordance rates of 100%, particularly with monozygotic twins, have not been found suggesting that there are additional factors that may contribute to whether or not someone is diagnosed. As research currently stands there is no single gene or group of genes that has been

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<sup>39</sup> It is beyond the scope of this thesis to explore these individually in detail so only a brief overview will be given, and the author acknowledges that not all causes are discussed.

<sup>40</sup> See Rosti et al. (2014) for an overview of the genetic architecture of ASD.

isolated as a cause of autism and therefore genetic testing is unable to be used for diagnosis, with researchers concluding that autism is an oligogenic<sup>41</sup> condition (Chakrabarti and Baron-Cohen 2013). Moreover, there are serious ethical issues if genetic screening for autism became a possibility, as the selection of embryos that do not contain the 'risky' gene could selectively eradicate ASD from the population.<sup>42</sup>

Another biological factor that has been the subject of a substantial body of research is the role of brain function, with suggestions of differences in both the structure (amygdala dysfunction<sup>43</sup> [Baron-Cohen et al. 2000]; structurally abnormal hippocampi<sup>44</sup> [Schumann et al. 2004]; and differences in grey and white matter<sup>45</sup> [Waiter et al. 2004; Rojas et al. 2006; Bonilha et al. 2008]) and in neurotransmitters (elevated levels of serotonin<sup>46</sup> [Gabriele, Sacco and Persico 2014; Yang et al. 2015]). However, there have been critics who contest the role of particular parts of the brain in autism: Sweeten et al. (2002) found inconsistent results for the link between the amygdala and autism, and although Gabriele, Sacco and Persico (2014) found elevated whole-blood serotonin levels, this only accounted for just over a quarter of those on the spectrum. Moreover, the differences in brain functioning that have been discussed above clearly cannot account for autism in every individual.

The lack of a known aetiology of autism, at least from a biological standpoint, means that there is currently no genetic test, brain scan or blood test that could confirm a diagnosis.

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<sup>41</sup> Suggesting that it is unlikely that there will ever be a single gene mutation that explains all of the features of autism.

<sup>42</sup> Prenatal screening is available for Down's syndrome and studies have found that a prenatal diagnosis has led to 92% termination rates (Mansfield, Hopfer and Marteau 1999). Additionally, despite the prevalence rates increasing, predominately due to an increase in the number of older mothers giving birth, the increased numbers of prenatal screenings and subsequent terminations have meant that the live birth prevalence rate has remained constant (Loane et al. 2013).

<sup>43</sup> This helps to process emotions and influences drive-related behaviour.

<sup>44</sup> This is involved in short and long-term memory, and with spatial navigation.

<sup>45</sup> Grey matter consists of mainly nerve cell bodies and white matter is made up of their axons. Baron-Cohen (2008) simplifies this as follows: grey matter is used for neuronal computation, whereas white matter carries the information.

<sup>46</sup> This affects an individuals' mood, social behaviour and sleep.

However, recent research involving brain scans is providing some promising data that supports the potential use of MRI scans in identifying autism, e.g., Ghiassian et al. (2016) and Chaddad et al. (2017).

Although the genetic basis is widely accepted, the specific gene or group of genes that combine to give an individual a diagnosis is currently unknown; however, there is a higher chance of having autism if a family member is diagnosed. If a biological basis could be found, a biological diagnostic test could be used, bringing about the possibility of a diagnosis that was universally valid.<sup>47</sup>

## **Psychological Theories**

As biological factors are unable to account for all autistic individuals, psychological theories have been proposed as alternative explanations. These theories have been praised for destigmatising autism and viewing it as a different ‘cognitive style’ rather than a disease (which is how the medical and scientific constructions view it) (Baron-Cohen 2009a: 73). This section will introduce four psychological theories in turn: mindblindness; weak central coherence; executive dysfunction; and empathizing-systemizing, which extends into the extreme male brain theory.

The mindblindness theory (Baron-Cohen, Leslie and Frith 1985; Baron-Cohen 2008; Baron-Cohen 2009b) states that autistic people lack a Theory of Mind (ToM) – the ability for an ‘individual [to] impute mental states to himself and to others’ (Premack and Woodruff 1978: 515), which Baron-Cohen (2009b: 6) describes as the ‘cognitive component of empathy’. Support for this theory has been found using false-belief tasks such as the Sally-Anne test<sup>48</sup>,

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<sup>47</sup> As the diagnosis currently relies on behavioural presentations, it is not universally valid, with different countries holding alternative views of autism (discussed shortly).

<sup>48</sup> This is a test which uses two dolls, Sally and Anne. Sally puts a marble into her basket and then leaves the scene. Anne then moves the marble to a box. Sally returns and the participant is asked where Sally will look for the marble. Those with skills in ToM will say the basket, as that is where Sally left the marble and so she believes it is still there. Those with deficits in ToM will say the box, as they are unable to see the situation from Sally’s perspective.

demonstrating difficulties within the autistic community in passing such tests (Baron-Cohen, Leslie and Frith 1985). However, more recent studies have criticised this test (Korkiakangas et al. 2016) and others have found a 50% pass rate for those on the spectrum (Lam and Yeung 2012). There are issues with the passing of tests such as this one as it does not necessarily demonstrate understanding of ToM. Furthermore, the strategies that are used to pass the test are likely to be 'poorly suited' to the person's ability to attribute mental states in 'complex, dynamic real-life social situations', demonstrating the problems with applying the results of such test to real-life situations (Lind and Bowler 2009: 935-936).

Another criticism of this model and, in particular, the perceived issues in ToM and subsequently empathy is the 'double empathy problem': autistic people lack insight into non-autistic people but, equally, non-autistic people 'lack insight into the minds and culture of autistic people' (Milton 2012: 886). This alters perceptions of breakdowns in interactions between autistic and non-autistic people: rather than being seen solely in the mind of the autistic person it seems that the problem is 'largely due to the differing perspectives of those attempting to interact with one another' (Milton 2017). Therefore this makes it

easy to problematise the definition of autism as a 'social deficit' located within an individual's mind. Differences in neurology may well produce differences in sociality, but not a 'social deficit' as compared with an idealised normative view of social reality. Such definitions may help to signpost disability support services, but they are no way of defining autism in any kind of holistic sense. (Milton 2012: 886).

Furthermore, reports of enhanced empathy in which autistic people can 'feel too much' (as discussed shortly) further problematise the use of these tools in the diagnosis of autism.

An alternative theory, the weak central coherence theory, was first proposed by Uta Frith in 1989 and suggests that those on the spectrum focus on detail and have difficulties viewing the bigger picture (Happé 2013). Evidence has been found via a variety of tests that supports this concept (Shah and Frith 1993; Jolliffe and Baron-Cohen 1997; Morgan, Maybery

and Durkin 2003).<sup>49</sup> However, alternative tests have been used and have found that autistic people *are* able to see the bigger picture (Baron-Cohen 2008). The theory has also been criticised by López, Leekham and Arts (2008) who failed to uncover a central mechanism responsible for integrating information. It has been further criticised for implying that the attention to detailed information is a negative trait, suggesting that autistic people will be forever lost in detail, whereas the ‘empathizing-systemizing theory’ (to be discussed shortly) suggests that this may be a positive skill (Baron-Cohen 2009b). Frith (2003) has since developed this theory, suggesting that autistic people can acquire ToM and may have a preference for strong central coherence. Again, the fact that autistic people can view the bigger picture makes tests of weak central coherence problematic for sole use in the diagnostic process.

Another psychological theory that has been proposed is the executive dysfunction theory. Executive function is the ability for a person to control action, with ‘action’ being ‘motor’, (i.e., movements), attention and even thoughts’ (Baron-Cohen 2008: 52). This affects people’s ability to plan, skills in flexibility, working memory, generativity, self-monitoring and an understanding of inhibition (White 2013: 115). Dysfunctions in these areas are commonly found in autistic people. There is some limited evidence for this theory with autistic people taking longer on the Tower of London Test<sup>50</sup> (Baron-Cohen 2008: 52). However, the tests have been criticised with White (2013: 115) suggesting that failing executive function tests is not necessarily indicative of an inability but instead it may be that autistic people are not aware of the purposes. There are also issues with the idea of executive dysfunction being exclusive to autism as several studies have found that these difficulties are also demonstrated by participants with obsessive compulsive disorders (OCD) (Delorme et al. 2007), attention deficit

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<sup>49</sup> For example, in the Navon test in which a letter ‘A’ is made up of several ‘H’s, autistic people are more likely to report seeing the ‘H’ rather than the ‘A’ (Baron Cohen 2008: pp. 54-56).

<sup>50</sup> This is where discs are moved from a starting configuration to the goal configuration using the smallest number of moves possible (it can be done in five) (Baron-Cohen 2008: 52).

hyperactive disorder (ADHD) (Pennington and Ozonoff 1996; Ozonoff and Jensen 1999) and Tourette's syndrome (Ozonoff and Jensen 1999). Furthermore, one study found that impaired executive functioning is a common feature in autistic individuals, but is not universal and is unlikely to cause autistic behaviours (Liss et al. 2001), thereby problematising the sole use of these psychological measures to diagnose autism.

The final psychological theory is the 'empathizing-systemizing theory' which suggests that autistic people have below-average levels of empathy (and thus deficits in ToM) and an average, or above-average level of systemising. This is supported by studies which have found that autistic participants score higher than the general population on the Systemizing Quotient (SQ)<sup>51</sup> test (Baron-Cohen et al. 2003) and lower than matched controls on the Empathy Quotient (EQ)<sup>52</sup> test (Baron-Cohen and Wheelwright 2004). The strengths of the 'empathizing-systemizing theory' have also been discussed and compared to those of mindblindness theory, with the former praised for being able to explain both the social and non-social features of autism (Baron-Cohen 2009b). This theory has been extended to the 'extreme male brain theory'. It has been documented that females tend to be better at empathising and males are better at sympathising (see Baron-Cohen 2002), which has been supported by further studies (Baron-Cohen and Hammer 1997; Goldenfeld, Baron-Cohen and Wheelwright 2005), so this theory could explain the autism gender bias towards males which is currently reported. However, a major flaw to this model is that it fails to account for females on the spectrum, with some suggesting that those autistic people may in fact have a surfeit of emotional empathy (Smith 2009). While the theory might help to contribute to explanations for some autistics' preference for systemising and reduced demonstration of empathy, it cannot explain autism in a substantial

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<sup>51</sup> A self-reporting measure to assess someone's skills in systemising – 'the drive to analyse systems or construct systems' (Baron-Cohen et al. 2003: 361).

<sup>52</sup> A self-reporting measure to assess someone's skills in empathy (see Baron-Cohen and Wheelwright 2004).

number of individuals and it complicates the use of tests for both sympathy and empathy (such as the EQ and SQ) as a diagnostic measure for autism on their own.

As with the biological factors discussed above, although the psychological theories have some support and provide explanation for some parts of the autistic experience, they are unable to account for every individual on the spectrum. This therefore makes the use of any cognitive test for diagnosis, such as the Sally-Anne test, problematic, as passing or failing would not necessarily result in a correct diagnosis and could lead to both incorrectly diagnosed and undiagnosed autistic individuals. Another key issue is that the psychological theories are not specific to autism, e.g., executive dysfunction is also associated with ADHD, which is a significant restriction on using such measures for understanding and diagnosing autism.

### **Environmental Causes**

The causes that are put forward from environmental factors may help to account for the inability of the biological and psychological theories to explain all cases of autism. Weintraub (2011) considered the increase in autism diagnosis and found that 46% of the growth in cases was due to unknown factors, which she suggests may be due to environmental influences. While several theories for environmental causes have been proposed, only two prevalent ones will be discussed: (1) the role of the 'refrigerator mother'; (2) the MMR vaccine. Both theories have since been refuted by research (therefore problematising them for diagnosis) but each gained much traction and became a popular theory of causation.

The theory of the 'refrigerator mother' focused on cold parenting styles that were witnessed in some parents of autistic children. This was initially commented on in an observation made by Kanner, 'they [the autistic children he presented] were kept neatly in refrigerators which did not defrost' (1973: 61). Bruno Bettelheim explored this idea further and proposed it as a potential cause for autism in his book *The Empty Fortress* (1967). He suggested that there was a negative circular relationship between mother and child that causes the child to

withdraw, likening the 'extreme conditions' of autism to those experienced by prisoners in a Nazi camp (Bettelheim 1967: 64). After initially gaining momentum the theory began to be criticised and has since been disregarded, although it caused much damage to the understanding of autism and to families of autistic people, in particular their mothers.

The other prominent environmental origin proposed was that the MMR (measles-mumps-rubella) vaccination could cause autism. This link was popularised after a report investigating the findings of a new gastrointestinal disease proposed a connection between this, the MMR vaccine and autism (Wakefield et al. 1998). Despite the research flaws, the study received widespread publicity (Rao and Andrade 2011), subsequently causing a huge amount of concern and panic among parents in the UK and USA (Begley and Interlandi 2009). However, studies have since been produced which disprove the link (Taylor et al. 1999; Honda, Shumizu and Rutter 2005; Uchiyama, Kurozawa and Inaba 2007; Jain et al. 2015). This resulted in *The Lancet* (the journal in which the article was published) retracting the article in 2010. In addition to this, the authors were found guilty of ethical violations and the *British Medical Journal* has subsequently published a series of articles exposing the fraud, which 'appears to have taken place for financial gain' (Rao and Andrade 2011: 95-96).<sup>53</sup> Despite this there are still some people who believe in the link between MMR and autism and promote the anti-vaccination movement.

Although both theories have achieved some popularity, with the MMR link still discussed, they have damaged the public understanding of autism with some serious consequences, e.g., immunisation rates for MMR dropped to 65%, far below the 95% herd immunity required to prevent an outbreak (S.H. 2008). Using environmental causes as a diagnostic measure is very problematic, particularly when prominent theories have been

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<sup>53</sup> Despite this, Wakefield has recently directed an anti-vaccine film, *Vaxxed: From Cover-Up to Catastrophe* (2016) (see <http://vaxxedthemovie.com/about/>).

subject to much controversy. However, it is possible that there is some currently unknown environmental contribution to autism.

As has been demonstrated in this exploration of the scientific and medical theories, there is considerable focus of finding the cause of autism, as this would help the diagnostic process, although at present none of the theories can account for all cases. These models have influenced understanding of the origins of the condition and have subsequently affected how it is viewed and diagnosed. However, there are issues with the scientific and medical research carried out to date as it is predominantly done in the West but ultimately affects how autism is viewed and diagnosed elsewhere in the world. When looking at lower- and middle-income countries, researchers confirmed that limited research had been carried out on early identification, although it was found that across lower- and middle-income countries there were similarities in age of parental concern, diagnosis and indicators of early identification. However, when compared to high-income countries these were delayed (Samms-Vaughan 2014). Understanding of autism differs between countries as in some it is still a relatively newly diagnosed condition. It was only in the 1990s that it became a prominent condition in the Czech Republic (Eisler 2017), was only recognised in Vietnam around the same time (Ha et al. 2014), and was relatively unknown until recently in China (Volkmar 2005), with autistic people in China being hidden at home which could potential cause a misinterpretation of autism being rare (Huang, Jia and Wheeler 2013). Other countries have been found to have insufficient knowledge about it, e.g., India (Shrestha and Shrestha 2014), with autism slowly becoming 'less shameful' (Grinker 2008: 218), and there is little known about the diagnosis of autism both there and in China (Daley and Sigman 2002). There have been further issues with diagnosis as it has been found to be more likely to be diagnosed as 'reactive attachment disorder' (RAD) or 'lack of love' in South Korea (Kang-Yi, Grinker and Mandell 2012), with blame placed squarely on the mothers (Grinkler 2008: 241).

The diagnostic process also varies, e.g., in Finland the diagnosis usually happens after inpatient care with a multidisciplinary team (Lampi et al. 2010). In the US universal screening is recommended at both 18 and 24 months (Fennell et al. 2014). The most common symptom causing concern in Nepal is delayed language, although the children are most often taken to faith healers and temples before seeing a physician (Shrestha and Shrestha 2014). In addition to this, researchers have suggested that how autism is currently viewed and presented is based on a Western perception, as the image of autism does not fit with the image of children in Taiwan (Pin Yu 2017); less stereotypical behaviour is seen in other countries, e.g., hand flapping in Tanzania (Martinage 2017); high-functioning autism is not recognised or diagnosed in Tanzania (ibid.) or Uganda (Zoanni 2017) and only severe autism is identified and diagnosed in Ethiopia (Roth 2017). In Vietnam autism is socially and culturally constructed as a disease or family problem with the disability seen as a consequence of an ancestor's actions (Ha et al. 2014). These different perceptions of autism obviously affect diagnostic procedures, demonstrating how presently the understanding of autism is tailored to a Western perspective of behaviour and therefore so is its diagnostic testing. However, even within Western countries there are differences in diagnostic approach. For example, France has been found to have lower than average diagnostic rates (around 5-10 compared to 68 in 10,000 in the US) as they have not adopted the same diagnostic standards, instead favouring a psychodynamic approach (Briggs 2017) and it was only in November 2004 that autism was officially recognised as 'a developmental disorder rather than a kind of schizophrenia' and was done so, 'only because parents demanded it' (Grinker 2008: 14). However, one can access services without a formal diagnosis (Chamak and Bonniau 2013), which would affect the need to seek one out. In Australia a diagnosis must be made before six years old to access support (Starling 2014), which is likely to place emphasis on younger diagnosis. This helps to demonstrate that even within Western countries which should be working with similar behavioural expectations, there is still substantial variation in diagnostic practices. Furthermore, Grinkler (2008: 2) notes 'there is

little agreement, even in a single culture, about exactly what it is or how to treat it', further problematising the diagnostic process.

In addition to this, the medical model has been argued to be one rooted 'in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual', placing the emphasis on the individual having the problem (Brisenden 1986: 173). This is where the social construction of autism challenges the scientific and medical models.

## **Autism: The social construction**

Society has influenced the perception of autism and provides a different construction to that presented within the medical and scientific models of autism. This is explored through three modes: (1) the role of alternative models (the social model of disability) and related movements (e.g., the neurodiversity movement); (2) the growing autistic voice, usually presented through autobiographies and online communities; (3) and media representations of autism presented to the general public. While these constructions do not explicitly elicit diagnostic methods they influence how the condition is perceived, which may then affect the diagnostic criteria or methods.

The social model of disability was named by Michael Oliver although the ideas behind it had been previously discussed. In contrast with the individual model which 'sees the problems that disabled people experience as being a direct consequence of their disability' (Oliver 1983: 15), it suggests that there should instead be a 'switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people' (Oliver 1983: 23). Essentially, an environment (or society) can cause a person to be more, or less, disabled. For example, in a building with no ramps or consideration for accessibility, a wheelchair user would be more

disabled than if they were in a building that met high accessibility requirements. Finkelstein (1980: 1-3) has commented on how disability is often seen as a 'personal misfortune' that appears to have a 'social relationship'. This is further supported by Oliver's (1983: 3) suggestion that there is a tendency for people to view disability 'as a personal tragedy or disaster' affecting how society relates to the disabled person. This links to the narrative of social normality 'based upon an unspoken acceptance of the standard being able-bodied normalcy' (Finkelstein, cited in Oliver 1983: 21) and further perpetuates the notion of an ableist society in which 'ableism is described as denoting an attitude that devalues or differentiates disability through the valuation of able-bodiedness equated to normalcy' (Campbell 2008: no pagination). These ideas tie into rhetoric surrounding autism of 'suffering' and the 'politics of sadness' in science, which is caught up in the 'culture of deficit' (Fitzgerald 2017). The social model of disability has been defended by, e.g., Shakespeare and Watson (1997: 264) who propose that it is an alternative view to the psychology and medical model in which the 'psychology [model] individualises disability whilst medical sociology pathologises disability'. Some members of the autistic community have themselves begun to challenge ableism instead pathologising neurotypicals in a parodic fashion, interestingly contrasting with the perceived lack of humour in autistic individuals.<sup>54</sup>

Linked to the social construction of autism is the neurodiversity movement which has gained traction in recent years. The term 'neurodiversity' is defined as a 'neurological difference associated with individual or community identity that is a more or less elective choice of those experiencing neurological difference' (Baker 2006: 15). This can be seen as a natural variation that is 'on par with... homosexuality' (Jaarsma and Wellin 2012: 20). It contrasts with neurological disability, described as an 'impairment of socially determined major life functions caused by observable, diagnosable difference in an individual's brain' (Baker 2006: 15), which is arguably how some of the medical and scientific models view autism. However, a problematic

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<sup>54</sup> See <http://erikengdahl.se/autism/isnt/index.html> for a list of neurotypical symptoms.

aspect of neurodiversity has been pointed out. Those who are 'high-functioning' and do not require support are happy

in the knowledge that they are freed from the burden of having a deficit and may have a better life with non interference. But it may not be so good for low-functioning autists or even high-functioning autists that *do* need care. Acceptance does not 'cure' difficulties with social relationships, social communication, rigidity and sensory issues. (Jaarsma and Wellin 2012: 27) [*italics in the original*].

Some have argued for a shift in emphasis from disease to neurodiversity: moving away from the metaphors of autism being a 'foreign space', those on the spectrum 'arriving from [a] foreign space' (alien); or a 'retreat or withdrawal to foreign space' (Broderick and Ne'eman 2008: 463-465). This shift to a neurodiversity-based approach would help to support 'inclusive education and equal educational, economic, and political opportunities for autistic citizens' (Broderick and Ne'eman 2008: 474). Moving away from perceiving autism as a disease could affect diagnosis and could call into question whether a diagnosis would be needed in a society accepting of neurodiversity. Issues with labelling have been discussed elsewhere and tie in with the social construction of autism. Selfe (2002) has questioned the role of symptoms, suggesting that behaviour that was once deemed eccentric has now been turned into a symptom, and she is consequently resistant to the medicalisation of people. This was also discussed by Hodge (2005) who suggested that the diagnostic process can pathologise individuals, with Timimi (2004: 226) arguing that society can do better than the 'relentless medicalisation of children'. While this takes the concept of removing a diagnostic label to the extreme, arguably devaluing autism and the difficulties that it can produce, it does reflect the opinion of some individuals who, although they may display autistic symptoms, resist the diagnosis partly due to the wish to avoid being medicalised or labelled.

An emerging autistic culture is developing, particularly online (see Davidson 2008) with the Internet being described as 'for many high functioning autistics what sign language is for the deaf' (Dekker 2015). Informal first-hand accounts can be found in the blogosphere, the 'richest habitat' for those on the spectrum (Hacking 2009: 1467). This is reflected by a plethora of blogs

(e.g., the curly hair project<sup>55</sup>), vlogs, forums (e.g., Wrong Planet<sup>56</sup>), discussion spaces and subscription-based email lists (How to Walk<sup>57</sup>), where autistic people can develop their identity and social relationships. These spaces allow autistic people to develop their own online subcultures, as well as offering first-hand accounts of being autistic.

In addition to online content, published first-hand accounts are available which help to give more accurate depictions of the spectrum than typical media representations (discussed below). Popular examples include Dr. Temple Grandin's *Thinking in Pictures* (2006) and Donna Williams's *Nobody Nowhere* (1992), both written by female, 'high-functioning' individuals. The more recently published *The Reason I Jump* was written by Naoki Higashida (2014), a non-verbal boy attempting to explain his experience of autism.<sup>58</sup> These accounts from autistic people are useful in supplementing the knowledge surrounding autism that is published elsewhere (and often by neurotypicals), helping to develop a lived understanding of the condition via people diagnosed with it. However, Osteen (2008: 19) points out that there are problems with the autistic (auto)biographies currently being published as the weighting of publications is towards the 'higher end' of the spectrum, which can fuel 'the misconception of ASDs as a set of temporary, even quaint eccentricities'.

Another way in which society constructs autism is through information obtained about the condition via the mainstream media. There are problems which surround the narrative of disability presented in the media, as discussed by Oliver (1990: 61):

Throughout the twentieth century, whether it be in the novel, newspaper stories or television and films, disabled people continue to be portrayed as more than or less than human, rarely as ordinary people doing ordinary things... These portrayals see disabled people either as

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<sup>55</sup> <http://thegirlwiththecurlyhair.co.uk/>

<sup>56</sup> <http://wrongplanet.net/>

<sup>57</sup> <http://tinyletter.com/katherinemay/archive>

<sup>58</sup> It has recently been announced that the book is being adapted into a site-specific performance <https://www.nationaltheatrescotland.com/production/the-reason-i-jump/>.

pathetic victims of some appalling tragedy or as superheroes struggling to overcome a tremendous burden.<sup>59</sup>

This is further explored by Draaisma (2009: 1477) who discusses how the stereotypes are described as 'either [a] diminished capacity or superhuman capacity, but nothing in between'. Additionally, these stereotyped perspectives of disabilities within society have often presented disability as a negative thing, with the able-bodied majority being continuously exposed to these inaccurate misconceptions (Young 2012: 5).

More popular media representations are found in film and television (both real and fictional) and through novels. Baker (2008: 229) illustrates how these representations shape views on disability:

When the public has no direct experience with a disability, narrative representations of that disability provide powerful, memorable definitions. In films, novels, play, biographies, and autobiographies that depict a character with a disability, the character comes to exemplify with that particular disability – demonstrating how individuals with that disability behave, communicate, exhibit symptoms, and experience life. In short, a character with a disability serves as a lens through which an audience can view and define that disability.

When this is specifically related to autism, Draaisma (2009: 1475) argues that it is vitally important to scrutinise any representations as to whether they are misrepresenting autism as 'much of what society at large learns on disorders on the autism spectrum is produced by presentations of autism in novels, TV-series, movies or autobiographies'. Currently, the more popular representations of autism are stereotyped ones which often promote male, 'high-functioning' individuals, usually with some savant skills. These are 'extraordinary skills not exhibited by most persons' with the most common types involving memory feats (e.g., remembering everything about a given subject), mathematical calculations (calendar memory) or musical or artistic skills (Edelson n. d.). 50% of savants are autistic but only one in ten autistic people have savant skills, thus 'not all autistic people are savants, and not all savants are

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<sup>59</sup> This concept of being superheroes was demonstrated through the advertising surrounding the Rio Paralympics in 2016, which saw advertisements with the slogan 'we're the superhumans' (see <https://www.youtube.com/watch?v=IocLkk3aYlk>) leading some critics to say 'let us be ordinary, let us be every day' (Pepper 2016).

autistic' (Treffert 2014: 565). Famous fictional representations included Raymond Babbit, a male with savant skills in *Rain Man* (Levinson 1988), and Christopher Boone, a high-functioning teenage boy in *The Curious Incident of the Dog in the Night-Time* (Haddon 2003), subsequently turned into a successful theatre production. In addition to this, characters with autistic traits are seen in TV series, the most prominent examples being within comedies, including Sheldon in *The Big Bang Theory*, Abed in *Community* and, more recently (and explicitly autistic), Sam in *Atypical* – all 'high-functioning' males. McGrath (2015) raises issues with some of these stereotypes, expressing his frustration at the lack of 're-thinking of established Asperger-phase assumptions about Autism'. He particularly criticises *The Curious Incident of the Dog in the Night Time* and *The Big Bang Theory* for conveying autism but not naming it, with the writers inviting 'us to gaze, even stare at AS [Asperger's syndrome] – but not to *acknowledge* the condition' (ibid.). However, an autistic character has been introduced to the children's programme *Sesame Street*<sup>60</sup>, going against stereotypes of male autists. Even documentaries and factual programmes promote the stereotyped representations. *The Autistic Gardener* (2016; 2017) documents an autistic award-winning gardener, Alan Gardner, as he uses his alternative autistic perception to transform gardens and provides commentary throughout that illustrate how his autism affects what he does, ultimately enabling him to create his designs (Carruthers and Margett 2017). *Extraordinary People: The Human Camera* (Osei-Tutu 2007) profiles Stephen Wiltshire an autistic artist with savant skills of photographic memory, who can draw cityscapes to high degrees of accuracy after short exposure times. More recently, *Chris Packham: Asperger's And Me* (Russell 2017) documents Chris' experience of being diagnosed as Asperger's and how this alters his perceptions of the world. While the show documents his difficulties, it further perpetuates stereotypes and shows how his special interests have led to a very successful career. Even when a programme takes a more scientific stance (e.g., *Horizon: Living with Autism* [Sage 2014]) and features well-known and respected researchers, the focus is still on those who

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<sup>60</sup> See <https://www.youtube.com/watch?v=dKCdV20zLMs>

are 'high-functioning', such as one individual who has calendrical savant skills while an individual who is more severely affected is given considerably less attention.<sup>61</sup> Baker (2008: 231) argues that Hollywood is attracted to the condition because autism 'becomes a spectacle' in particular when an individual has savant skills and audiences are in awe of these. However 'defining autism primarily as a savant disorder places unreasonable expectations on individuals with autism' (Baker 2008: 236). These representations are problematic as the examples given above fuel misconceptions that autism is a male condition that enhances intelligence or gives someone special skills. This only represents a small portion of the autistic community and the stereotypes present within the general public, inevitably alter social constructions of the condition.<sup>62</sup>

While the social constructions do not offer diagnostic tools (as in the scientific and medical models of autism) they provide a framework through which the condition can be viewed and accepted in society more generally. This can affect treatment and the understanding of the condition, and in turn can affect how disability (or difference) is viewed and the diagnosis is framed.

## **Autism: Alternative construction**

In addition to the medical, scientific and social constructions of autism, alternative models are being offered which view autism through a different framework. These include arts-based models and, in particular, drama and theatre practices and research. The arts can be used in a range of ways: as an intervention, an educational or therapeutic tool, and as a creative practice outlet for those on the spectrum. The information that is obtained from these areas

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<sup>61</sup> See Milton (2014) for a criticism of this.

<sup>62</sup> Other publications, such as *Neurotribes* (Silberman 2015) (an international bestseller, winning several awards) have provided alternative and more factual reviews of autism which have been popular with the general public.

helps to challenge current understanding of autism and provides alternative perceptions of the condition, specifically of the strengths and capabilities of the individuals, or of autistic people more generally. Although the focus will be on drama-based practices in this thesis, various arts-based therapies and interventions for autistic people have been found to help with social skills (Wright et al. 2006; Epp 2008; Müller, Nutting and Keddell 2017) as well as reductions in problem behaviours, hyperactivity and internalising behaviours (Epp 2008) and emotional problems (Wright et al. 2006). The research for this thesis was grounded within the alternative construction which builds on the growing body of information that is being obtained via drama-based practices specifically those that focus on strength- and skill-based approaches rather than the model of deficits seen in the medical and scientific constructions.

This section will start with a brief discussion of autistic practitioners who are using their autism as material for their performances and contributing to this alternative construction. This is an extension of the autobiographical work discussed earlier (e.g., Grandin and Williams), instead using the performative arts as the medium. Following on from this, there will be a discussion of the growing body of research that uses a variety of drama methods for autistic people, which have reported improvements across several areas that are thought to be problematic for autistic individuals. This research is helping to challenge current thinking and is moving towards developing a holistic construction of autism, shifting the focus from deficit-based models such as the scientific and medical construction.

### **Autistic Artists**

One area of drama-based contribution to the alternative construction of autism comes from the growing body of autistic performers who use their work to explore their own autism, sharing experiences and potentially educating others, as well as challenging perceptions of autism. This extends the work of the autistic autobiographies and offers an alternative medium through which autism can be explored. Three artists who are challenging perceptions of autism

through their work will be introduced briefly. Cian Binchy has developed two shows which relate to his autism: *This Misfit Analysis*, which explores a 'journey into the autistic mind' (Clark 2015), and *Madhouse: Catch the Baby*, which explores and criticises the 'historical and current isolation of learning disabled people' (Autism Arts Festival 2017). Annette Foster's<sup>63</sup> *Adventures of a Super Aspie Grrl* explores her coming out as a late-diagnosed autistic person and in her future work she hopes to explore the lives of autistic people who are not stereotypical presentations (such as autistic females and those with complex gender identities) thereby challenging some of the myths present as discussed in media representations (personal communication). Daniel Bendelman explores representations of autism through installation work, challenging stereotypes and the medical model, most recently focusing on the removal of the Asperger's label from the DSM-5. These works contribute to the growing autistic voice and challenge ideas of a lack of imagination and creativity in autistic people, as well as offering alternative constructions of autism. Additionally, they provide autobiographical experiences, giving important insight into the autistic experience for both autistic and neurotypical audiences.

### **Drama and Autism in Research**

Before the link between drama and autism is discussed it would be helpful to discuss certain benefits that have been found within research involving drama and theatre more generally, in non-autistic participants. Firstly, actors have been found to have increased Theory of Mind (ToM) in comparison to their non-acting peers (Goldstein, Wu and Winner 2009-2010; Goldstein 2011), with an increase in ToM skills noted particularly in a children's drama group when compared to other arts and non-arts activities (Goldstein and Winner 2010-2011). Similarly, Guss (2005) found that children were enabled to see and explore others' opinions through drama. These studies demonstrate the potential role that drama could have in

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<sup>63</sup> see <http://nettypage.com/>

developing skills with ToM, thought by some to be a deficit for autistic people. A second area in which drama has been found to be beneficial in the general population is in the development of empathy. Increased empathy scores have been noted in actors (Goldstein 2011) and drama-based approaches have been used to help teach clinical empathy<sup>64</sup> to medical residents<sup>65</sup>, with significant improvements found in empathy scores pre- to post-intervention (Dow et al. 2007). Additional benefits have been noted in imaginative and creative skills in young children (Gupta 2009) in improvement and maintenance in social and oral expressive language for children with learning disabilities (de la Cruz, Lian and Morreau 1998) and as a beneficial communication intervention for children who use augmentative and alternative communication (McCarthy and Light 2001). In addition to this, role play has been noted to be a useful research tool in some situations, with educational drama having the potential to emotionally and cognitively engage people and thereby help to develop ‘felt-understanding’; a type of knowing which results in people taking a potential interest in issues and wanting to effect change’ (O’Sullivan 2011: 510). These studies have illustrated the benefits that drama and theatre can have for people, helping to facilitate skills in ToM, empathy, imagination, creativity and communication. As these are all perceived deficits for autistic people, this suggests that these methods could be potentially valuable for this group.

Drama (in its broadest sense) has been used by a range of individuals and groups who work with autistic individuals in a multitude of ways. O’Sullivan (2015) enumerates the three areas in which drama is used:

- 1) theatre and performance: creating theatre to be shown to others;

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<sup>64</sup> ‘The skills of recognizing a patient’s emotion status and responding, in the moment, to the unique needs of the patient to promote better clinical outcomes’ (Dow et al. 2007: 1114).

<sup>65</sup> This is part of medical training, where a graduate is placed under the supervision of another physician while the resident practices medicine.

- 2) drama in education (DIE) and process drama: the process of developing performance is emphasised with people often working in a fictional scenario and with participants improvising;
- 3) drama therapy and psychodrama: drama is used as a therapeutic method, with methods being applied in a clinical setting.

In addition to this, the author of this thesis proposes a fourth category, that of 'theatre and audience' in which there is noted to be an increase awareness of the needs of those on the spectrum when viewing performance, for example through relaxed performances<sup>66</sup> (e.g., see Kempe 2014). The above methods all have different approaches and outcomes, demonstrating the range of drama work that is accessible to those on the spectrum. Successful outcomes which have been achieved in working with autistic communities may be partly due to the flexible approaches that drama offers. This chapter will explore how a range of drama methods have contributed to and challenged current understanding of autism, offering an alternative construction that demonstrates strengths in areas that are generally considered to be problematic for autistic people including social interaction ToM, imagination, play, empathy, and shared (joint) attention.

### ***Social Interaction***

The medical and scientific construction of autism emphasises issues with social interaction in autistic people, these being considered a core deficit of autism, reflected in the diagnostic criteria (APA 2013; WHO 1992), with the DSM-5 listing 'persistent deficits in social communication and social interaction' as one of the two key diagnostic areas, with subheadings noting deficits in social-emotional reciprocity, nonverbal communication, and developing, maintaining and understanding relationships (APA 2013: 50-51). Therefore, deficits in social

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<sup>66</sup> These are performances in which 'adjustments are made to sound and light effects and the operating conditions of the auditorium in order to reduce surprises or tensions that may trigger adverse reactions... Other adjustments are made 'front of house''. (Kempe 2014: 262).

interaction have become a central component in diagnostic tools. These difficulties have been observed in research (Lord et al. 1993; Lord et al. 2000; McConnell 2002; Müller, Schuler and Yates 2008; Deckers et al. 2014; Szatmari et al. 2016).

Theatre projects have been found to be beneficial for autistic participants, with skills in social interaction being demonstrated that challenge these perceived deficits, helping to develop the alternative construction of autism. These benefits have shown to help gain understanding of social constructs (Peter 2003), to help develop key social skills (Corbett 2016), and to practice these social skills (Kempe and Tissot 2012). A wide range of theatre interventions have recently been found to increase social skills on a variety of measures. Improvements have been noted in social competence (Peter 2009; Corbett et al. 2016; Corbett et al. 2017), social cues and interaction (Portman Minne and Semrud-Clikeman 2011), social-relationships (Andersen-Warren 2013), social referencing (Corbett et al. 2011), social skills (Guli et al 2013; Wilmer-Barbrook 2013) and interpersonal relationships, positive interactions and parental-reported seeking-out of friendships (Guli et al. 2013).

One reasonably well researched theatrical intervention based in the USA is SENSE (Social Emotional NeuroScience Endocrinology) Theatre, which is a 'theatrical intervention research program designed to improve the social and emotional functioning of children with autism and related neurodevelopmental disorders' (Sense Theater 2017).<sup>67</sup> This is an intervention that allows participants to explore and practice their skills in social interaction in a supportive and safe environment (Corbett et al. 2014a: 4). Several research projects have been conducted on this theatre intervention and have found increases in social skills on a variety of measures: improvements were noted in social awareness (Corbett et al. 2014a), social cognition (Corbett et al. 2014a; Corbett et al. 2016), social competence (Corbett et al. 2016; Corbett et al. 2017) and social referencing (Corbett et al. 2011). These social communication gains were

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<sup>67</sup> see [www.sensetheatre.com](http://www.sensetheatre.com)

translated into the home and community settings with reciprocal communication scores maintained at two months and social competence increases reported on both behavioural and neural measures (Corbett et al. 2016). In addition to this, there appeared to be a growing awareness of peer interaction with typically developing (TD) children's knowledge of autism increased (mean increase of 17%) between the first and last day of training (ibid.), as well as an important factor that came out of another project (although not quantified) that empathy from the TD children towards the ASD participants appeared to increase (Corbett et al. 2011). The studies demonstrate that this drama intervention helps support social skill development or demonstrates the social skill possibilities in autistic participants that contrasts with medical views of deficits.

Another US drama-based intervention, the Socio-Dramatic Affective Relational Intervention (SDARI), is a group, game-based intervention that helps 'participants [to] develop and practice social skills in a fun environment', in which the activities are constructed on a 'variation of dramatic improvisation-based games' (Lerner, Mikami and Levine 2011: 24). Lerner refers to this as 'performance-based training [which] assumes that [the] students know how to perform in social situations, but they just can't produce appropriate behavior when necessary' and this theatre project provides them with an opportunity to practice these skills. In one study it was found to reduce social problems in autistic adolescents, demonstrating its application as an effective intervention in the development of social skills (ibid.), with Lerner commenting that 'for the first time that summer all of the kids who had been aggressive with each other got along... In the context of the theater games, they began using some socially appropriate skills' (Hartigan 2012: 30). Improvements were also noted in peer interaction when comparing the SDARI to Skillstreaming<sup>68</sup>, with the SDARI group reported to interact with and

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<sup>68</sup> This is a social skills intervention that is focused on reinforcing fifty target skills which are used to help teach the correct behavioural steps to use within specific social situations (Goldstein and McGinnis 1997; described in Lerner and Mikami 2012).

like each other more after the first session, both groups demonstrating significant improvement in reciprocated friendships (Lerner and Mikami 2012), adding to the understanding of social interaction skills in some autistic people.

Further support for the use of theatre projects to develop social skills in autistic participants was provided in the form of anecdotal reports concerning theatre classes offered as part of the Social Competence Intervention Program (SCIP), which suggested that the autistic children could successfully engage in social interactions within the study, with some participants demonstrating skills in the classes that they were not able to elsewhere (Glass, Guli and Semrud-Clikeman 2000). This work was extended and a larger number of participants was compared to a clinical control group in a 16-week programme (Guli et al. 2013). Interpersonal relationships and positive interactions were found to improve, as well as improvements in the seeking-out of friends as reported by parents. The significant increases demonstrated by the theatre group were in three of the four subcategories that explored social behaviour.

The alternative construction of autism has been further supported by other theatre-based programmes which had been found to benefit autistic people. For example, the Hunter Heartbeat Method reported benefits, with improvements measured in social functioning<sup>69</sup> for the autistic participants who experienced the workshops in comparison to a control group (Hunter 2015). A preliminary investigation was conducted with autistic students who participated in a 10-week programme culminating in a final performance – the focus was placed on the creative process (Reading et al. 2016). Despite the programme not specifically targeting social skills, the theatre participants had higher levels of social responsiveness after participating in the theatre program when compared to the control group who demonstrated no gains in this area. Moreover, there appeared to be a growing awareness of peer interaction, with Loyd (2013) reporting that when interviewing autistic adolescents after they had participated

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<sup>69</sup> In addition to this, benefits were noted in language skills and overall adaptive functioning.

in drama classes, 40% of the participants identified peer-work as being important to drama. One participant even commented that the main thing he had learned from the classes was ‘the ability to work with people I don’t like’ (Loyd 2013: 12). Other drama-based techniques have been developed to support peer interaction by using scripts. One study found an increase and improvement of interaction with peers when using sociodramatic scripts with TD and disabled children (Goldstein and Cisar 1992) and positive peer benefits were found when autistic participants used scripts (Krantz and McClannahan 1993). Furthermore, improvements were found in adaptive social behaviour in drama classes for children, as opposed to participation in music classes and a control group (Schellenberg 2004). Theatre work was also found to reduce social problems (Lerner, Mikami and Levine 2011). In addition to these positive gains, other drama interventions have found those on the spectrum became more successful in their social engagement (Glass, Guli and Semrud-Clikeman 2000), there was a positive impact on their comfort with others (Kim et al. 2015) and that these helped with peer relationships (Schuler 2003). Drama interventions have also noted to be a space to practice and help with social skills (Kempe and Tissot 2012; Godfrey and Haythorne 2013).

These results have extended into the role of drama in a therapeutic context. Studies which have investigated the use of dramatherapy have reported a development in social skills, as well as overwhelming support from the parents/carers and teachers of the participants for the use of this method (Godfrey and Haythorne 2013), an increase in participant-reported social and communication skills (Wilmer-Barbrook 2013), dramatherapists reporting an improvement in social relationships, with one client commenting that there was a ‘value [to] being supported in relationships with peers’ (Andersen-Warren 2013: 13), and an increase in friendship skills (Miller 2005). A successful collaborative relationship was established between a dramatherapist and an autistic client in one study (Porter 2014). Moreover, a study interviewing autistic adults found that most participants described some form of creative or

improvisational outlet that they used to either reduce social anxiety or to help practice social skills, such as participating in theatre groups (Müller, Schuler and Yates 2008: 185).

Improved skills in social interaction have been noted in the AHRC iA project through both quantitative and qualitative methodologies. In the communication subdomain of the ADOS there was a significant decrease in scores in confidence interval analysis and a decreasing trend in scores for reciprocal social interaction, specifically with the module 3 participants who had a statistically significant decrease<sup>70</sup> (Beadle-Brown et al. 2017). Additionally, on the VABS communication domain, a significant increase was reported.<sup>71</sup> A parental report demonstrated an increase in communication with one participant, Matthew, having a 'conversation for 15 minutes for the first time' with his parents (Trimingham and Shaughnessy 2016a: 411) who were 'floored' by the level of communication he displayed after participating in a session (Shaughnessy 2016b: 498; see also Trimingham and Shaughnessy 2016b: 93). Within the sessions this same participant established relationships with characters, building an alliance with the Snowman to chase the dog away (see Trimingham and Shaughnessy 2016a: 114). Another participant, Harry, used his camera to establish a relationship with the dog (Trimingham and Shaughnessy 2016b). These examples particularly contrast with the perceived social skill levels of these participants and provide further validation for the alternative construction of autism based within the arts.

### ***Theory of Mind (ToM)***

ToM has been noted within the medical and scientific constructions to be problematic for some people on the autistic spectrum (e.g. Baron-Cohen, Leslie and Frith 1985; Baron-Cohen 1989 [advanced levels of ToM]; Baron-Cohen 2008). This plays an important role in social cognition and may well contribute to the difficulties experienced by autistic people with social

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<sup>70</sup> These decreases in scores are positive and indicate an improvement in social skills.

<sup>71</sup> This increase is positive and further indicates an improvement in social skills.

interaction, due to issues in reading cues and understanding what other people may be thinking. Research has supported this, with autistic participants performing worse on ToM tasks (Burnside, Wright and Poulin-Dubois 2017) and having lower scores than their TD counterparts on understanding emotional and mental states from photographs of eyes, and lower scores on the 'believe' and 'emotions' part of the comic strip test<sup>72</sup> (Pino et al. 2017).

Interestingly, gains in ToM skills have been reported in drama and theatre programmes with non-autistic participants (as discussed on pages 56-57). This was further supported by Goldstein and Winner (2012) who found an increase in the development of ToM insights in true-to-life and naturalistic tasks in the theatre programme participants in comparison to their arts training (visual arts and music) counterparts. Furthermore, Guss (2005) acknowledged that the use of drama with children in helping to see and explore others' opinions is predicated on skills in ToM, and this idea was also demonstrated in dramatherapy, with the participants being able to demonstrate skills in understanding the actions, feelings and thoughts of another character (Porter 2014). These research projects which demonstrate ToM skill development in non-autistic participants suggest the potential value of using these approaches with autistic participants.

In contrast with the medical and scientific constructions which view a ToM deficit in autistic individuals, ToM skills have been reported in drama and theatre programmes (Corbett et al. 2011; Godfrey and Haythorne 2013; Lewis and Banerjee 2013; Loyd 2013; Corbett et al. 2016). The SENSE program found some improvements in ToM skills in autistic children with statistically significant differences pre- and post-test (Corbett et al. 2011) and significant improvements in ToM skills that helped to increase perspective taking, with the 'acting exercises with peers creat[ing] the opportunity for the children with ASD to take on the

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<sup>72</sup> This is a test in which individuals 'are shown three pictures which tell a social story, after which they are presented with two pictures containing alternative endings to the story, and asked to select the one that they think best completes the story. One option indicates a lack of understanding of others' mental states... the other indicates a presence of such understanding'. (Pino et al. 2017: 2746).

perspective of another through action thereby setting the stage for different shared points of view' (Corbett et al. 2016: 688). Loyd (2013) interviewed autistic adolescents who had participated in drama education and found that: (1) there was a clear understanding that some of the participants were playing a role; (2) one participant showed an awareness of how her performance would affect another. Both findings demonstrate ToM.

Furthermore, the use of drama within a therapeutic context has been found to be beneficial in ToM skills with documented gains in ToM tests (Lewis and Banerjee 2013). In one reflection on dramatherapy, Hodermarska (2013: 70) reported that her autistic son could activate his ToM in multiple role play (between Superman and a villain), and how he was able to 'play with both his subjective and objective experience of self as well as with his perception of others' objective and subjective experience of him'.

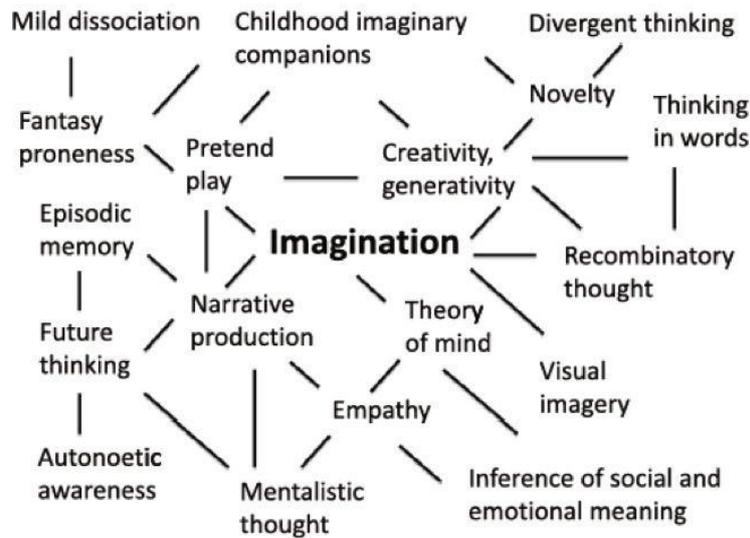
Within the AHRC iA project numerous examples of ToM were displayed which further challenge the medical and scientific view of deficits in ToM and provide support for ToM skills being demonstrated when engaging in the drama environment. Trimmingham (2013) provides evidence in her discussion of one participant, Mary, who used ToM to help with the meaning of wearing the Foxy costume and the responses this might elicit (see also Trimmingham 2017).

All of these drama-based examples show how such projects are able to demonstrate ToM skills and/or an improvement in these skills after engagement, which contrast with ideas of ToM deficits noted in medical and scientific constructions, thus supporting an alternative construction of autism through the arts.

### ***Imagination***

The definition of imagination can be problematic as it is among the most 'slippery [of] phenomena' that fall within the scope of psychology (Roth 2008: 146) and although it unites the creativities of the human mind, 'we also have a very poor understanding of exactly what it means' (Foley 2007: xvii). It essentially 'denotes a cluster of related phenomena including

pretense and fantasy, metaphorical thinking (in “as if” mode), counterfactual thinking (in “what if?” mode), creative thinking and imagery’ (Roth 2008: 147) (see figure 1 for a diagram of neurotypical imagination). Currie and Ravenscroft (2002) have noted that an obvious function of imagination is to enable ‘us to project ourselves into another situation and to see, or think about, the world from another perspective’ (Currie and Ravenscroft 2002: 1), and identify two types of imagination: creative and recreative. Creative imagination is defined as when ‘someone puts together ideas in a way that defies expectation or convention’ (Currie and Ravenscroft 2002: 9). In contrast, recreative imagination is the imaginative capacity that ‘underpins perspective-shifting’ (ibid.). This links back to issues with ToM in autism: the difficulties with social competence and communication are based on social tasks depending on mind-reading skills, for which autistic people find it more challenging to know what people think and want, due to a difficulty in imaginatively putting themselves into someone else’s shoes (Currie and Ravenscroft 2002: 145). Roth argues that the multiple roles and definitions of imagination still have in common ‘a reference to the human mind’s capacity to elaborate concepts, images, and ideas that do not correspond to current or past reality, and that may never be actualized. In this sense, imagination appears fundamental to the mental apparatus that differentiates humans... from other species’ (Roth 2007b: xx-xxi). This contributes to its role as ‘a central facet of human social evolution and cognition’ and therefore the implications of deficits in imagination have far-reaching impacts (Crespi et al. 2016: 181).



*Figure 1 Imagination in neurotypical cognition, which demonstrates how it relates across different skills (Crespi et al. 2016: 182). Reproduced with kind permission from the author.*

The medical and scientific construction of autism emphasises deficits in imagination, with the diagnostic criteria for autism reflecting this across several areas. Crespi et al. (2016) suggests that deficits in imagination are a contributory factor in the core deficits of autism. This refers both to social imagination and creative imagination. As social interaction (and therefore imagination) has already been discussed, this section will focus on creative imagination. Kempe (2014) has been explicit in noting the distinction between the two. Deficits in imagination have been noted in research studies, with a reduced engagement in imaginative activities in autistic participants when compared to a language disorders group (Barrett, Prior and Manjiviona 2004) and a preference for fact (encyclopaedia entries) over fiction (social stories), indicating a lack of desire to engage imaginatively (Barnes 2012).

Imagination is difficult to assess, although several studies have tested it in autistic people through drawing tasks and found deficits in this area which supports the medical and scientific construction (Scott and Baron-Cohen 1996; Craig and Baron-Cohen 1999; Craig,

Baron-Cohen and Scott 2001; Low, Goddard and Melser 2009; Eycke and Müller 2015). Scott and Baron-Cohen (1996: 280) reported that across three drawing tasks there were ‘deficits in the representation of real objects’, autistic participants were significantly impaired when asked to draw unreal combinations (e.g., half-fish, half-mouse) and an ‘impossible man’ (Craig, Baron-Cohen and Scott 2001), and they had overall impairments in both the autism and Asperger’s group when using standardised tests of creativity (Torrance Test of Creative Thinking<sup>73</sup>), demonstrating less imaginative creativity and fewer responses. When using a modified version of Karmiloff-Smith’s drawing task<sup>74</sup>, autistic participants had reduced imaginative content<sup>75</sup> compared to TD participants over three attempts<sup>76</sup> (Low, Goddard and Melser 2009). Further support was found by Eycke and Müller (2015) who reported that autistic children drew less imaginative features in the same drawing tasks.

However, interestingly, studies grounded in the medical and scientific models have produced results that run contrary to the idea of deficits in imagination in autistic individuals, perhaps challenging the testing methods used and showing further complexities with evaluating imaginative skills. No differences were found between autistic and TD children in their abilities to create stories from a fantasy- or reality-based starting point, or were demonstrated in story length, elaboration or the use of emotional states (Dillon and Underwood 2012). No group effects were reported on any measures in the drawing of ‘real’ and ‘impossible’ images which contrasts with Scott and Baron-Cohen’s (1996) findings (Leevers and Harris 1998).

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<sup>73</sup> A creativity test which assesses fluency, flexibility and originality.

<sup>74</sup> This is a task in which the children are asked to draw a house, person and animal that exists, and then one that does not (Karmiloff-Smith 1990). The modified version was as follows: ‘Participants were first shown a picture of people walking towards a sparkling door that opened on to a path leading to a distant planet in space. The scene was set as follows. ‘These people are walking through a magic door that sends them to live on a faraway different planet in space. When people walk through the door, they get magically changed into funny, strange looking people that no one has ever seen before. Draw as many pictures as you can of what people coming out of the door would look like, making the changed people look as funny and strange looking as you can’ (Low, Goddard and Melser 2009: 431).

<sup>75</sup> As measured based on scoring criteria in which the number of imaginative features were divided by the total number of features within the drawing.

<sup>76</sup> 59% v. 93%; 100 v. 68%; 100% v. 73%.

Additionally, Angus et al. (2015) found no differences in autistic children compared to TD children in imaginative abilities, autistic children were found to complete drawing templates as well as learning-disabled children although they struggled with spontaneity (Allen and Craig 2016); autistic participants were also able to draw as many features as their counterparts, suggesting that imaginative difficulties may be in social imagination (Eycke and Müller 2015). This was supported by Lim and Slaughter (2008) who noted less sophisticated human drawings from the autistic group but similarities in the drawings between the autistic and TD groups when comparing drawings of houses and trees. It was further reflected in Lee and Hobson (2006) who found individual differences in depictions of house but not when drawing themselves and others. Even within studies that generally report deficits, a large proportion (66.7%) of the autistic participants passed the tests and no significant differences could be found in other examples (Craig, Baron-Cohen and Scott 2001). These examples all provide evidence to challenge the perceived notion of deficits in imagination in autistic people, evidence further supported by arts- and drama-based projects.

The perception of deficits in imagination has been contradicted by work grounded within arts and drama practices wherein autistic participants have demonstrated skills in imagination (Kempe and Tissot 2012; Godfrey and Haythorne 2013; Lewis and Banerjee 2013; Pimpas 2013; O'Sullivan 2016). When research was conducted into autistic poetry, it was found to share characteristics of non-autistic poetry, as well as the autistic poets using significantly more language derived from their own emotions, desires and thoughts than the neurotypical poets, running contrary to perceptions of deficits in imagination (Roth 2008). Kempe and Tissot (2012) were surprised by the creative imaginary skills of their participants, with the authors suggesting that despite the perceived difficulties in this area for autistic individuals, drama could be a useful tool to help support this skill. One of the ten core objectives of the SENSE programme is to help participants engage in imaginative play, therefore helping them to develop their imagination skills (Corbett et al. 2014b). Child-initiated and teacher-directed

drama experiences have been found to allow imagination and creativity to be explored (Gupta 2009). Again, these skills have been discovered within therapeutic contexts in which imaginative skills were demonstrated in a dramatherapy group through the participants' use of story, with all participants using imaginative play and structure in their stories and authors commenting that the 'data refute[s] the hypotheses of an absolute inability to pretend and inability to use story, inherent in some constructions of autism' (Lewis and Banerjee 2013: 29). One dramatherapy client commented 'I love dramatherapy because now I know I have a good imagination' (Andersen-Warren 2013: 7). This was further identified in parental interviews in another study, with one parent commenting that their child had 'loads of imagination' (Kempe 2015: 6).

Several examples of imagination<sup>77</sup> were demonstrated by participants in the AHRC iA project and reported qualitatively. Three participants in particular demonstrated clear examples of skills in imagination: Matthew, Harry and Chloe. Matthew developed 'poems' and 'raps' about his experiences in the pod ranging from discussing SpongeBob SquarePants to stating "I know I see the world now. Don't let it change the past." (see Shaughnessy 2013; Trimmingham in press). This was particularly surprising considering his low level of communicative language.<sup>78</sup> His increase in imagination was supported by his parent after participating in the project: 'he has gained in his imagination' (Trimingham and Shaughnessy 2016a: 115). Harry explored the world of the pod through his camera and would construct photos, taking many and selecting the ones to keep. The chosen photographs were striking, with 'beautiful studies of light, texture and shape' (Trimingham, in press). Another imaginative moment came from Chloe who had stood in front of a projection of the moon during the 'space' week in the pod. She crumbled 'moon rock' and repeated, half-singing, half-chanting 'picnic on

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<sup>77</sup> See Trimmingham (in press) for a focus on creative imagination, as defined by Currie and Ravenscroft (2002).

<sup>78</sup> Discussed further in the 'Play' section of this chapter.

the moon' (Shaughnessy 2013: 327 [the subject is called Emily]; Trimmingham, in press). Another moment which tested the imaginative abilities of participants was during the Under the City week in the final school. An alarm sounded causing the practitioners to 'play dead' and then see how the participants would respond. They produced several imaginative responses to try to wake the practitioners up, e.g., banging on dustbin lids and blowing on the practitioners (see Shaughnessy 2016b: 502 for a brief description). Furthermore, when puppets were used, participants frequently engaged imaginatively with them (Trimingham 2013). It is interesting to note that the creative and imaginative instances displayed by participants in the AHRC iA project have thus far been discussed almost exclusively in arts-based publications in qualitative measures, and although imagination was tested to some degree through part of the ADOS and parental/teacher questionnaire, it is particularly difficult to measure scientifically. This is also true of the other research studies discussed in this section which mainly had small numbers of participants and were based on qualitative description. As measures of imagination and creativity are particularly limited within scientific research, the results are unlikely to filter into the scientific and medical construction of autism and this may be where drama-based approaches can significantly contribute.

These examples demonstrate how the notion of deficits in imagination in autistic people has been challenged in the arts and help contribute towards an alternative construction of autism, moving away from deficit-based views. The research has shown that there is potential for imagination in autistic people that can be displayed in specific creative environments. Not only has the research demonstrated skills in imagination, but it has also shown problems with the tests for imagination.

### ***Play***

Play has been described as 'notoriously difficult to define' (Baron-Cohen 1987: 139) and 'because of its essential spontaneity and unpredictability, [play] has presented significant

challenges to researchers' (Whitebread 2009: 40). Piaget (1972: 147) noted that 'play is not a behaviour *per se*, or one particular type of activity among others. It is determined by a certain orientation of the behaviour', with criteria characterising it including that it is: an end in itself; spontaneous; pleasurable; lacking organisation; and free from conflict. He enumerated six stages of play, starting with play being purely reflex adaptations and developing into pretence or make-believe, as the 'ludic symbol is dissociated from ritual and takes the form of symbolic schemas' (p. 95). Other definitions have incorporated the role of imagination, e.g., Vygotsky's which states that play is 'understood as the imaginary, illusory realization of unrealizable desires' (Vygotsky 2016: 7) and can be categorized as 'essentially wish fulfilment' (Vygotsky 2016: 8). Burghardt (2011: 17) offers five points of definition:

Play [1] is incompletely functional in the context in which it appears; [2] is spontaneous, pleasurable, rewarding, or voluntary; [3] differs from other more serious behaviors in form (e.g., exaggerated) or timing (e.g., occurring early in life before the more serious version is needed); [4] is repeated, but not in abnormal and unvarying stereotypic form (e.g. distressed rocking, pacing); and [5] is initiated in the absence of acute or chronic stress.

The definition of play is further complicated by the different types of play that exist.

Burghardt (2011: 10) enumerated twelve different types (although these are not mutually exclusive): 'large-motor play, small-motor play, mastery play, rule-based play, construction play, make-believe play, symbolic play, language play, playing with the arts, sensory play, rough-and-tumble play and risk-taking play'. Play has been further categorised into groups to help identify it (Baron-Cohen 1987: 142):

Sensorimotor: 'banging, waving, sucking, throwing, rolling, 'twiddling', or sniffing objects, with no attention paid to their 'function''

Ordering: 'a more 'intelligent' behaviour involving the child imposing some *pattern* onto the objects, such as lining them up, piling them up, putting one inside another, arranging them in systematic ways, but still with no regard for their 'function''

Functional: 'using the objects 'appropriately', that is, according to their intended function'

Pretend Play: 'child uses an object *as if* it is another object, *or* attributes properties to an object which it does not have, *or* refers to absent objects as if they were present'.

Play has been argued to be an important part of development (e.g. Vygotsky 1978)<sup>79</sup>, with benefits including the development of skills in co-operation (as play is essentially social in its origins [Rakoczy 2008]), socioemotional development (Ashiabi 2007) and the development of creativity and problem-solving skills (Danksy 1980; Wyver and Spence 1999; Whitebread et al. 2008). Moreover, links between play and ToM have been noted with Leslie (1987: 422) suggesting that 'pretend play is thus one of the earliest manifestations of the ability to characterize and manipulate one's own and others' cognitive relations to information', which could help to explain the difficulties in ToM in autism.

In relation to autism, play is regarded to be a problem, with the diagnostic criteria noting difficulties in sharing imaginative play (APA 2013) and deficits in play more generally, this being supported by research in the scientific and medical fields (e.g., Hammes and Langdell 1981; Baron-Cohen 1987; Rutherford and Rogers 2003; Lam and Yeung 2012). When viewing different types of play, deficits in functional play (Sigman and Ungerer 1987; Williams, Reddy and Costall 2001 [although this did not reach significance]), symbolic play (both spontaneous and cued) (Sigman and Ungerer 1987), and, particularly, in pretend play (Charman et al. 1997; Jarrold 2003; Rutherford and Rogers 2003; Rutherford et al. 2007; Hobson et al. 2013; Strid, Heimann and Tjus 2013 [this study noted particular problems in nonverbal autists]), specifically spontaneous pretend play (Baron-Cohen 1987; Charman and Baron-Cohen 1997; Charman et al. 1997; Rutherford and Rogers 2003; Rutherford et al. 2007), have been noted.

Questions have been raised about whether the deficits in pretend play<sup>80</sup> are due to a competence or performance deficit (Jarrold and Conn 2011). If they were due to a competence deficit this would suggest that autistic individuals have a 'fundamental deficit in the ability to

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<sup>79</sup> See Lillard et al. (2012) for a review of studies into pretend play in children, in which authors conclude that there is not enough evidence to support the view that pretend play is crucial for development. Also for a criticism of the role of play in developing ToM skills and creativity.

<sup>80</sup> Lillard et al. (2012) have argued that deficits in pretend play may be an Anglo construction, as pretend play is not as prominent in non-Anglo cultures.

produce pretence in any situation' (Jarrold and Conn 2011: 317) (e.g., Leslie's explanation [1987]). In contrast, if the issue were a performance deficit, this would suggest that autistic individuals 'have the capability to pretend, but struggle to show this in free play situations' (ibid.) (e.g., Piaget 1972). The hypothesis that a performance deficit is responsible is further strengthened by research showing that pretend play is improved when it is supported, e.g., with instructions or scaffolding (Charman and Baron-Cohen 1997; Jarrold 2003). Furthermore, research has suggested that the perceived 'deficits' within play are actually due to differences in the kinds of play that are engaged in by autistic people. Ungerer and Sigman (1981) found that autistic children had a wide range of different play behaviours, with equal amounts of time being spent between mature and immature play and less play with dolls. Boucher (1991: 1) has also argued that it is not that autistic children do not play, it is just that they do so 'in their own particular way'. In addition to this, Schuler (2003: 465) suggested that the difficulties with play are perhaps an outcome of social isolation as opposed to a fundamental incapacity, which also challenges the view of deficits in play and ToM. These examples illustrate the potential problems with the assumption of deficits in play in autistic individuals as well as more general difficulties with the medical and scientific constructions. Outside these frameworks, research within drama has contributed to an alternative construction of autism, seeing some strengths in play skills and the potential benefits of play-based interventions.

Interestingly (and similar to the ethos of iA), Sherratt and Peter (2006) have suggested converting the 'triad of impairments' into a 'triad of competencies', which would fit into this alternative construction of autism as well as aligning with the social construction. The play-drama intervention 'offers a structured approach to developing children's symbolic understanding and use of pretence... [enabling] socially challenged children to associate pleasurable and satisfying play experiences with other people' (Peter 2003: 22). Play structures are useful with this 'socially challenged' group as the child's affected and cognitive responses can be integrated, allowing for an activity that has personal relevance and perceptual interest,

further giving them the opportunity to operate flexibly within a narrative framework. This allows the children to connect their understanding and knowledge of the world in a coherent and meaningful way: 'crucially, drama offers children a reflective window on their play behaviour: the possibility to explore, review and reflect on the implications of their actions and behaviour and those of others in the make-believe context, and to make connections with the real world' (Peter 2003: 23). In her research, Peter found that all of the participants were liberated by the play structure (Peter 2009). Additionally, the role of play has become central to the SENSE Theatre programme, as two of its ten core objectives are linked to play: 'to create an enjoyable environment ([that] facilitate[s] play)'; and 'to engage in imaginative play (develop[ing] imagination)' (Corbett et al. 2014a: 14).

The benefits of peer-based play (both social and imaginary) have already been noted. These models allow more competent peers to work with those on the spectrum so that they can fine-tune their skills and development within social domains can be nurtured (Wolfberg, Bottem-Beutel and DeWitt 2012). This is supported by research in sociodramatic play (Dauphin, Kinney and Stromer 2004). The benefits of play on social interaction have been supported by other theatre research in which improvements in positive interactions and a decrease in solitary play were found when using the SCIP (Guli et al. 2013). This may partly be due to drama helping the autistic children see and explore others' opinion, again linking back to ToM (Guss 2005). Corbett (2016: 1234) suggested that the theatrical setting is 'distinctive' and may be where autistic people can thrive due to 'the supportive context, active role-playing, and dynamic learning environment' which helps to foster and develop key social skills. Teachers have also reported an increase in play after children engage in mimetics (Trowsdale and Hayhow 2013). Kempe (2014) has questioned the perception that autistic people may struggle to engage with drama due to deficits in social communication, relationships, play and flexibility in thinking and behaviour, with the participants parents' in his study refuting a 'lack of ability to engage in

dramatic play with all of them stating that their children variously enjoyed acting things out, mimicking, dressing up and entertaining others' (Kempe 2014: 270).

Qualitative data from the AHRC iA project concerning the role of play provides further evidence for strengths that have been demonstrated by autistic participants in drama sessions. Some participants spontaneously began to play 'What's the Time Mr. Wolf?' with Foxy, developing sustained peer play that was initially introduced in the 'getting to know you session' (Trimingham 2017: 189). The participant Matthew also demonstrated imaginative play by playing with his speech and language as he developed 'poems' (Shaughnessy 2013; 2016b):

His voice was breaking and he experimented with its different registers, playing with the sounds of words through a form of onomatopoeic sound painting that sounded like descriptive setting, even though the language was emergent as he produced a range of speech sounds rather than words, with a storytelling intonation. (Shaughnessy 2016b: 499).

Matthew's growing demonstrations of imaginative play were noted by his mother: 'for the first time in his life when he plays figures are talking to each other and he is making up a story. Imaginative play with toys is a breakthrough. He started to play with related toys after sessions e.g. space toys.' (Trimingham and Shaughnessy 2016a: 115). Shaughnessy (2013: 331) emphasised the importance of using 'modes of play' as being 'crucial to the response we elicited as this [play] is often neglected post-diagnosis in favour of skills-based and behavioural approaches to 'therapy'.

The skills demonstrated in play by the drama-based research discussed above (particularly the links to social skills and ToM) help to contest the notion of deficits in this area as promoted within medical and scientific understanding, further contributing to alternative constructions of autism and moving away from a focus on deficits.

### ***Empathy***

This is the 'drive to identify another person's emotions and thoughts, and to respond to these with an appropriate emotion. Empathising allows you to predict a person's behaviour, and

to care about how others feel' (Baron-Cohen 2002: 248).<sup>81</sup> Empathy is characterised as involving three components: cognitive, emotional and motor (Bons et al. 2010). Cognitive empathy is 'the ability to rationally understand the emotional state of others'; emotional empathy refers to 'the experience of emotions consistent with and in response to those of others'; and motor empathy refers to 'unconsciously mirroring the facial expressions of another, which is suggested to induce shared representations of perception and emotional contagion' (Bons et al. 2010: 109).<sup>82</sup>

Deficits in empathy have been noted in the autistic population (e.g., Baron-Cohen and Wheelwright 2004) which is predicated on difficulties with ToM, leading to the possible application of the 'empathizing-systemizing theory' and 'extreme male brain theory' of autism (as discussed earlier in this chapter). Furthermore, this links to difficulties with emotion recognition (Uljarevic and Hamilton 2013) and as empathy is the 'most powerful way of understanding and predicting the social world', it could help to explain the social difficulties that autistic people have (Baron-Cohen 2002: 248). These deficits have been noted in scientific research. Goldenfeld, Baron-Cohen and Wheelwright (2005) found that the Asperger's/High-Functioning Autism (HFA) group had a lower combined score on the EQ and SQ; although they outperformed participants from the general population on the SQ, their EQ scores were much lower. This was replicated by a group of Japanese participants with the ASC group scoring significantly higher on the SQ and lower on the EQ than the controls (Wakabayashi et al. 2007). Moreover, Asperger's and HFA participants scored significantly worse than TD participants on the 'reading the mind in the eyes test' (Baron-Cohen et al. 2001a). Impairments were also reported in autistic children on empathy tasks (Charman et al. 1997).

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<sup>81</sup> This contrasts to systemising, which 'is the drive to analyse the variables in a system, to derive the underlying rules that govern the behaviour of a system. Systemising also refers to the drive to construct systems. Systemising allows you to predict the behaviour of a *system*, and to control it' (Baron-Cohen 2002: 248) [italics in the original].

<sup>82</sup> See Bons et al. (2010) for a review of research into these three types of empathy.

Drama can be used to increase empathy within the general population as acting is predicated on the ability to empathise with others in order to play different roles.<sup>83</sup> As discussed previously in the chapter, actors have been found to have increased empathic skills and scores (Goldstein 2011; Goldstein and Winner 2012) which led authors of one study to suggest that ‘training in acting – may lead to growth in the social cognitive skills of empathy and theory of mind’ (Goldstein and Winner 2012: 32). In addition, drama has been used as a tool to help teach clinical empathy to medical residents (Dow et al. 2007).

The benefits of drama for the development of empathy in autistic people have been documented in drama-based research. For example, after autistic individuals had participated in the SCIP, parental feedback noted improvements in empathy and compassion, as well as the use of more expressive faces (Guli et al. 2013), and in another project one teacher commented that she ‘never thought [she would] see so much empathy’ after children participated in mimetics (Trowsdale and Hayhow 2013: 77). Additionally, empathic skills have been demonstrated in dramatherapy patients (Lewis and Banerjee 2013) and in one interview, an autistic individual commented that theatre had helped him to gain empathy (Alexander 2017).

There were a few examples of empathy in the AHRC iA project that have been reported qualitatively.<sup>84</sup> These include the participant Lizzie demonstrating sorrow with Dennis the woodpecker when Foxy was trying to steal his eggs (Trimingham 2017: 189). Additionally, during one session in the pilot project the Snowman was shivering and one participant responded by giving him a scarf (Shaughnessy 2011: 44). Support was further found in the quantitative analysis which showed a statistically significant increase in the amount of correct emotions identified by participants in the AHRC iA project, based on emotion recognition tasks (Beadle-Brown et al. 2017).

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<sup>83</sup> This is intrinsically linked to ToM.

<sup>84</sup> See Shaughnessy (2011) for a discussion of theatre and empathy.

The examples discussed above illustrate how participants are capable of demonstrating empathy within some drama environments. This challenges scientific and medical constructions of autism that hypothesise deficits in empathy predicated on difficulties in ToM.

### ***Shared (Joint) Attention***

Shared or joint attention is a shared focus on something by two people. Attention is drawn to the particular point of focus via nonverbal behaviours such as eye-gaze or pointing. Shared attention has been shown to develop social relationships. Issues with the sharing of interests, emotions and affect are noted within the DSM-5, as is the sharing of imagination which could be used for shared attention (APA 2013). These difficulties with joint attention are reflected in research (e.g., Mundy, Sigman and Kasari 1994; Charman 2003b; Kasari et al. 2008) with few gaze switches demonstrated by autistic participants (Charman et al. 1997), fewer joint attention behaviours exhibited by autistic children (Mundy, Sigman and Kasari 1994; Osterling and Dawson 1994), a low frequency of attention-sharing behaviours (Sigman et al. 1986) and deficits in indicating skills, e.g., pointing, showing and using eye contact (Mundy et al. 1986). Deficits in joint attention are used as part of some screening tools (and therefore within the medical construction). Checklists have employed assessments of joint attention to help screen for autism in young children, e.g., the CHAT (see Baird et al. 2000). Research into checklists supports the assessment of joint attention behaviours to identify autistic people: these behaviours collectively constitute one of three key items that when sufficiently lacking, indicate a high risk of autism in the CHAT (Baron-Cohen et al. 1996), are one of the largest discriminatory functions in developing the M-CHAT (Robins et al. 2001) and are regarded as among the 'earliest signs of the disorder' (Charman 2003b: 315).

Contrasting with the views of autistic people's difficulties in shared attention, drama-based research has reported skills in shared attention, often noting improvements which suggest that such projects could be useful for developing skills: the understanding of nonverbal

cues and use of more expressive faces (Guli et al. 2013), improvement in face-processing skills (Corbett et al. 2013), improvement in face identification and face-matching tests (Corbett et al. 2011), and increased awareness of nonverbal cues through awareness of body language (Corbett et al. 2016).

In the AHRC iA project, qualitative data supported the hypothesis of improved skills in shared attention among autistic participants. When Harry was photographing the environment, there was some joint attention between him and the dog, with the camera becoming the object of attention that was shared (see Trimmingham and Shaughnessy 2016b: 298-300). His skills in shared attention were extended and he later initiated the joint action, by encouraging one of the practitioners and the assistant educational psychologist to jump with him while he documented this (see p. 299). Another example was between a practitioner, Gemma, and a participant, Mary, when they worked alongside Dennis the woodpecker puppet (see Trimmingham and Shaughnessy 2016b: 302). Working with the puppet through joint attention enabled Mary to develop her social skills and knowledge, as well as to gain an understanding of ToM. Furthermore, Shaughnessy (2011: 42) elaborates on how shared attention relates to theatre more generally through the 'triadic structure of shared communication is also fundamental to theatre and the interaction between actor, the staged event and the spectator'. Although the boundaries between actor and spectator are blurred within iA, joint attention was still achieved through the 'staged event', be it through work with the camera or with a puppet.

As was demonstrated above, there is an increasing number of published research papers that emphasise the potential importance of drama for autistic people and that could help to shift perspectives away from deficits, as seen in the medical and scientific construction, by contributing to the development of an alternative construction that also sees skills and strengths. This expansion of the published literature also demonstrates a growing awareness

within academia of the benefits of drama as a methodological approach. However, there are still issues that the arts face in much of the research as, despite a wealth of anecdotal evidence and observational studies that support the effectiveness of such work, there have been very few rigorous clinical investigations, and many of the arts-based studies are case studies with small sample sizes (Mirabella 2015). Although the evaluative methods used are providing evidence for the value of such practices, this methodology and analysis restricts its relevance across disciplines, especially in the sciences. Much of the current drama and autism research is either in the form of case studies/illustrations (Schuler 2003; Peter 2009; Kempe and Tissot 2012; Hodermarksa 2013; Pimpas 2013; Porter 2014; Kempe 2015; Trimmingham 2017, in press; Trimmingham and Shaughnessy 2016) or qualitative data (Portman Minne and Semrud-Clikeman 2011; Andersen-Warren 2013; Godfrey and Haythorne 2013; Guli et al 2013; Lewis and Benerjee 2013; Loyd 2013; Kim et al. 2015; Trimmingham and Shaughnessy 2016).

Some of the more recent research into drama and autism, including the AHRC iA project and the research for this thesis, is moving beyond a reliance on anecdotal or case-study evidence towards more rigorous and scientific testing measures. Although this may not meet rigorous research testing standards as defined within the scientific community, it contributes to an alternative construction of autism and further supports the wealth of evidence supporting the use of drama practices for the autistic community.

While qualitative data provides an important narrative for autism in order to alter perceptions, particularly within the scientific and medical constructions, it is important to extend this research to embrace more rigorous methods (e.g., Corbett et al. 2011) and randomised experimental designs (Corbett et al. 2011; Corbett et al. 2017), with larger groups of participants recruited (above 11 participants) (Lerner, Mikami and Levine 2011; Lerner and Mikami 2012; Corbett et al. 2014a; Kim et al. 2015; Corbett et al. 2016; Beadle-Brown et al. 2017; Corbett et al 2017). Within the sciences there is a push towards research using the 'gold

standard' of randomised control trials (RCTs), although this has been criticised. John Zeisel sent a petition to President Obama criticising the role of RCTs and arguing for a 'champion of nonpharmacological approaches' for the National Alzheimer's Project Act. This petition was signed by researchers from a wide range of subjects within university departments and research centres stating that (Ziesel 2011) <sup>85</sup>:

Much existing research is discounted by policymakers, researchers, and others because they are convinced that the only evidence worth counting is generated by double-blind randomized controlled trials (RCTs). RCTs represent one important way to generate knowledge; but only one way. Other methodologies contribute substantially to our knowledge of nonpharmacological interventions and need to be taken seriously. It makes little sense to discredit a large body of knowledge that could immensely help policy and decision-making.

This illustrates a major problem for arts-based research, which often does not easily fit into the 'gold standard methods' of research. The methodologies of the creative process are filled with 'disorderliness', which tends to give rise to a circular or spiral process of research, as opposed to a linear type of model which arguably would be more likely to be found within the sciences (Trimingham 2002: 56; see article for discussion). Furthermore, it has been argued that RCTs 'are not capable of capturing the sensory, affective and embodied experience of arts engagement' (Rowe and Reason 2017a: 50). Therefore, it is important not to be dismissive of the knowledge gained through research that does not fit these rigorous methodologies, as this has helped to shape the alternative construction of autism, which challenges current understanding and moves towards a strength-based rather than a deficit-based model. This alternative construction of autism is where the research for this thesis lies, although focusing on the diagnosis (therefore the scientific and medical model) takes a strengths-based approach, seeking to explore what skills engagement within drama-based practices can reveal in autistic children. Although the practical side of this research is still open to some of the 'disorderliness'

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<sup>85</sup> See (Jones 2012: 121) for a brief discussion on this.

that Trimingham (2002) refers to, a more scientific approach has had to be taken, both in the practice and the evaluation, to help strengthen the interdisciplinary value of the work.

As has been explored in this section, drama and theatre have an important role in contributing to alternative constructions of autism, challenging preconceived notions of autism and particularly the scientific and medical model of it. The constructions in turn influence diagnostic labels and practices, which are currently located in the scientific and medical model. Recent research studies have demonstrated that involvement in these alternative models such as the arts not only improves skills but also reveals capabilities present for social and imaginative skills, as well as examples of ToM, empathy, play and shared attention. This helps to move away from the deficits model, focusing more on the skills and capabilities present within individuals on the spectrum. The research for this thesis builds on earlier work carried out on the relationship between drama and autism. Going further, it considers how drama could help with the diagnostic process, supporting the medical model of autism at diagnosis, and starting to incorporate strengths-based approaches.

## **CHAPTER 2: A HISTORICAL ACCOUNT OF AUTISM DIAGNOSIS**

Chapter 1 explored three different constructions of autism. This chapter will review the history of the diagnosis of autism from the identification of the condition to knowledge believed correct at time of writing, focusing on the labelling and the diagnosis of the condition. As discussed in Chapter 1 the lack of a known cause has meant that most diagnostic tools are based on observable behaviour, either via direct observation or report, although research continues to search for the 'holy grail of unequivocal diagnosis' which could potentially lead to a more effective biological test (Bristol-Power and Spinella 1999: 436).

This historical account is separated into two parts: labelling and diagnostic criteria; and diagnostic tools. These are intrinsically linked and inevitably affect each other. The first part will start from the original use of the term 'autism' when it was conceived to be a symptom of another condition, continuing up to current diagnostic practices in which it is its own established clinical entity, exploring its introduction into the diagnostic manuals and how the symptoms and definitions have subsequently been revised. This exploration will demonstrate the fluid nature of both the labelling and diagnostic criteria, which have continually altered as more information has been gained, understanding has changed and awareness has increased. As would be expected, the diagnostic tools have similarly evolved to reflect these changes, although they still refer to the original criteria as set forth by Leo Kanner in 1943. This section will evaluate the various tools and conclude by summarising where knowledge stands on the process of diagnosis at the time of writing. This historical reflection will also emphasise some of the gaps that are present within the diagnostic process, gaps which the research for this thesis was carried out to investigate.

## Labelling and Diagnostic Criteria

Key periods in the history of the diagnosis and labelling of autism will be used to guide the reader through this section, pivoting on the identification of autism as a distinct clinical entity by Kanner in 1943.<sup>86</sup> Kanner will be the focus of this section, as opposed to Hans Asperger (although Asperger will be briefly mentioned) because it was only much later, in 1991, that Asperger's work was translated and made available to an English-speaking world. These periods will be labelled as 'Pre-Kanner', 'Kanner's Autism', 'Post-Kanner' and 'Inclusion in the Diagnostic Manuals and Beyond'. The section will conclude with the current status of autism diagnosis as it stands at the time of writing.

### Pre-Kanner

Although autism was not labelled as a separate clinical entity until 1943, the term was initially used to describe a specific type of thinking that was considered to be a symptom of schizophrenia. The term 'autistic thinking' was coined by Bleuler in 1911<sup>87</sup> and was one of the 'four A's'<sup>88</sup> believed to be symptomatic of schizophrenia (McGlashan 2011).

It is seen most prominently in dementia praecox [schizophrenia]... in the day dreams of the hysterical and normal... [it] is governed by the instinctive trends...The immediate result of autistic thinking is therefore the creation of pleasant images and the suppression of unpleasant ones. *The primary function of autism is wish-fulfilment.* But where a negative mental attitude is present, the trend of autistic thinking may be negative... in dementia praecox its finished products are apt to appear as hallucinations, primary elusions and falsifications of memory... pure autism has its value as mental discipline, just as physical play on the bodily side. (Bleuler, in Wells 1916: 436-437) [italics in the original].

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<sup>86</sup> It is likely that symptoms of the condition existed prior to the identification as a separate clinical entity by Kanner, emphasised by Grinker (2008: 64) who argues that 'neither Kanner nor Asperger truly *discovered* autism. They *described* it' [italics in the original]. Further supported by Frith (2003: 34) who argues that 'autism is not a modern phenomenon, even though it has been recognized only in modern times', later conducting a retrospective diagnosis of historical figures.

<sup>87</sup> This was the first written use of the term but Bleuler had previously used it at a conference in 1908.

<sup>88</sup> The other A's were affectivity, association and ambivalence (McGlashan 2011: 1101). However, McNally (2009) has said that Bleuler never used the term and this mnemonic came about later.

Further uses of the term were found, in relation to the personality system (Lasswell 1929; Krout 1937) prior to Kanner's use, and post-Kanner as a type of thinking (T.V. Moore in McHugh 1944; Murphy 1945), before autism was widely accepted as its own clinical entity.

Before discussing Kanner's original studies in detail it is important to acknowledge that at the time of his publication child psychiatry was still a relatively new concept, with issues in psychiatry perceived to be phenomena found only in adults. Henry Maudsley included a chapter entitled 'Insanity of Early Life' in his textbook *Physiology and Pathology of Mind* (1867) attracting much criticism for suggesting that insanity could be found in children (Kanner 1973: 154) and Kanner was the first to separate child psychiatry from child psychology and child psychoanalysis (Evans 2017: 70). He was the first director of the child psychiatry department at Johns Hopkins Hospital in the USA and the first researcher to write a whole textbook on the subject in 1935, further demonstrating the relative infancy of the concept (MacKinnon n.d.).

### **Kanner's Autism**

In his paper "Autistic Disturbances of Affective Contact" Kanner wrote about eleven children (eight boys and three girls) he had seen 'whose condition differs so markedly and uniquely from anything reported so far' (Kanner 1973: 1). These behaviours were so distinct that he created a new clinical entity and labelled it 'autistic disturbances of affective contact'. He discussed the cases in detail and the similarities in their symptoms (Kanner 1973: 33):

These characteristics form a unique "syndrome," not heretofore reported, which seems to be rare enough, yet is probably more frequent than is indicated...it is quite possible that some such children have been viewed as feeble-minded or schizophrenic...The outstanding, "pathognomonic," fundamental disorder is the children's *inability to relate themselves* in the ordinary way to people and situations from the beginning of life...This is not, as in schizophrenic children or adults, a departure from an initially present relationship; it is not a "withdrawal" from formerly existing participation. There is from the start an *extreme autistic aloneness* that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. [italics in the original].<sup>89</sup>

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<sup>89</sup> Asperger ([1944]1991: 38) discussed the connection between autism and schizophrenia, explicitly stating that the term autism 'derives from the concept of autism in schizophrenia'.

Kanner further described common behaviours which he had found in these children and assembled the first list of symptoms for autism (adapted from Kanner 1973: 33-40):

- inability to relate to themselves
- extreme autistic aloneness
- failure to assume at any time an anticipatory posture
- ability to speak either at the usual age or after some delay
- excellent rote memory
- delayed echolalia
- literalness
- personal pronouns are repeated just as heard (and therefore are confused)
- intrusions are found in food, loud noises and moving objects
- monotonously repetitious noises and motions
- anxiously obsessive desire for the maintenance of sameness
- limitation in the variety of spontaneous activity
- different relation to objects
- masturbatory orgasmic gratification
- unusual relation to people
- good cognitive potentialities
- serious-mindedness and tenseness when dealing with people
- physically essentially normal
- come from highly intelligent families

Kanner noted the similarities between these children and schizophrenic patients in their shared obsessiveness, echolalia<sup>90</sup>, stereotypy and extreme aloneness. However, he also emphasised two key differences between the conditions which he believed were enough to warrant a new label. The first was an extreme aloneness that was present from the beginning of life, as opposed to a withdrawal after a normal period of development (as found in schizophrenia). The second was that the children had an excellent and purposeful relationship with objects but not with people. At this point there were no diagnostic tools available to detect autism; instead Kanner relied on descriptions of the children's behaviour, parental reports and observations he made. He later labelled this group of behaviours as 'early infantile autism' (1973: 51). What was particularly unique about his article was that it described cases of similar symptomatology, rather than employing a particular framework or making claims about treatment efficacy (Evans 2017: 112). Ideas of autism as an early stage of thinking and a clinical syndrome related to

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<sup>90</sup> This is repetition of words and phrases that someone else has said.

schizophrenia were not new; however, Kanner's 'ability to capture these ideas in a circumscribed group of child cases' was unique (Evans 2017: 113).

By 1949 Kanner had narrowed the characteristic features down to 'a profound withdrawal from contact with people, an obsessive desire for the preservation of sameness, a skilful and even affectionate relation to objects, the retention of an intelligent and pensive physiognomy, and either mutism or the kind of language which does not seem intended to serve the purpose of interpersonal communication' (1973: 51).<sup>91</sup> He noted that the condition was now 'reasonably well established' and argued for its clear separation from other conditions, grounding it firmly in psychology nosology<sup>92</sup> (Kanner 1973: 52). Despite this Kanner still documented the similarities to schizophrenia, even suggesting that it may be the earliest manifestation of autism, and stated that he did not believe it would ever be fully separated from the schizophrenia group (which it now has been). However, he still argued for a distinct clinical label (Kanner 1973: 55).

### **Post-Kanner**

After Kanner's publication several additional cases were described by other people (Putnam 1948; Rank 1949; Despert 1951; *Bakwin 1954*; Kestenberg 1954; Knowlton 1954 [although described as atypical, the behaviour of the child in question looks to be autistic]; *Chapman 1957*; Maier and Campbell 1957; Polan and Spencer 1959 [one of the cases presented involved twins])<sup>93</sup>, including retrospective analysis (Darr and Worden 1951), helping to generate further support for autism as a separate condition.

By 1954 Kanner's case material had increased to one hundred patients. He adjusted his list of symptoms after noticing that they were present within the first two years of life. He

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<sup>91</sup> He had talked about the role of language in his studies in a previous paper *Irrelevant and Metaphorical Language* (1946).

<sup>92</sup> 'The branch of medical science dealing with the classification of diseases' (Oxford Dictionaries n.d.).

<sup>93</sup> Those in italics are cases of autism within twins.

continued to maintain that the two principle criteria were the desire for aloneness and obsessive insistence on sameness, suggesting that 'all other symptoms can be explained on that basis' (Kanner 1973: 70). Bakwin (1954: 492) provided support for Kanner's principle criteria; however, he placed additional emphasis on the autistic child's 'failure to use language properly' as another core symptom (p. 492). He also emphasised the failure of Kanner to mention 'unusual sensitivity to sensory stimuli' (p. 493), an idea that was later raised by Eisenberg (1956: 611) who found that several autistic children had a preoccupation with sensory impressions, with 'perceptual difficulties at a sensorimotor level'.

Kanner began to explore the idea that there were different behavioural manifestations of autism and suggested that a distinction should be made between primary and secondary symptoms. The primary symptoms were the two principle criteria which he suggested held the group together 'regardless of the number and nature of the secondary manifestations' (Kanner 1973: 82). In a later follow-up study of some of the original cases, Kanner found that the primary features were retained in adolescence<sup>94</sup> but that some of the secondary symptoms had been lost, e.g., echolalia (1973: 88). This further problematised the diagnosis, as the secondary manifestations could potentially distract less experienced clinicians from making a diagnosis with the core symptoms being masked by their presence.

Cases continued to present themselves (Kanner and Eisenberg had 120 cases combined by 1956), which led both Kanner and Eisenberg (1956: 558) to suggest that while the condition had become generally clinically accepted, there were still 'inevitable differences in diagnostic allocation'. This problem was in part due to a lack of set criteria that all clinicians followed, as well as a lack of diagnostic tools. Descriptive diagnoses were aiding clinicians and providing further support for the existence of early infantile autism; however, the actual diagnosis was

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<sup>94</sup> At this time Kanner still maintained that autism was a childhood disorder even though the core symptoms were still present in adolescence. Eisenberg (1956) had similar views to Kanner about it being a childhood disorder even though he found that in 46 of the 63 cases he reviewed, the individuals had poor adjustment in adolescence.

still problematic. The core symptoms could increase or decrease, depending on who was carrying out the diagnosis, and the importance each clinician placed on secondary symptoms could be weighted differently, depending on their personal viewpoint. This meant that there were differences in diagnosis, potentially meaning that the same child could receive different labels depending on who was diagnosing them.

During the 1950s, despite Eisenberg and Kanner promoting the idea of autism as a distinct disorder, there were still some individuals who contested the separation of autism from schizophrenia. Szurek (1956: 522) implied that it was 'unnecessary' to separate the two and instead it should be considered on 'a psychopathological spectrum' with schizophrenia, or as part of the '*gradient of severity of disorder*' [italics in the original]. Bender (1959: 85) raised issues with the selection of the original cases as they were a 'limited group of children from the particular sophisticated, intellectual strata' and therefore could not be considered 'a clinical or etiological entity'.

The drive to create a list of symptoms to aid the diagnostic process continued and in the 1960s a British working group came together to create a 'definitive list of diagnostic points that could be used to identify psychotic children with accuracy' (Evans 2017: 200). They sought to clarify the symptoms and to label children as autistic, schizophrenic or atypical, proposing nine diagnostic points using the 'awkward term' of schizophrenic syndrome in childhood (Evans 2017: 200-201):

1. gross and sustained impairment of emotional relationships with people
2. apparent unawareness of own personal identity
3. a pathological preoccupation with particular objects or certain characteristics of them, without regard to their accepted functions
4. sustained resistance to change in the environment and a striving to maintain or restore sameness
5. abnormal perceptual experience
6. acute, excessive, and seemingly illogical anxiety
7. speech may have been lost or never acquired, or may have failed to develop beyond a level appropriate to an early stage
8. distortion in motility patterns
9. a background of serious retardation

(adapted from The Working Group 1961: 890).

These criteria have similarities to the original criteria except that there is no distinction between primary and secondary symptoms. However, the group stated that they 'were not intended as absolute criteria... nor were they designed for use as a rating scale' (ibid.). This reflects the continued uncertainty and fluidity that surrounded the diagnostic profile of autism at the time. It was further echoed in the fact that the separation of autism from schizophrenia was still being explored, with authors stressing the need for better and more comprehensive diagnostic classification and advocating for the use of mixed diagnostic sources, emphasising the use of 'historical information... in conjunction with the current clinical examination'<sup>95</sup> (Eaton and Menolascino 1966: 63). An additional study provided support for the diagnostic criteria that were beginning to be justified, with the only difference being in finding a high rate of seizures in patients, the authors suggesting that this may be an additional symptom of autism (Schain and Yannet 1960). The authors discussed the overuse of the term as a diagnostic label and the confusion in labelling a condition which has similarities to others. Kanner also demonstrated his frustration in this:

Instead of the many would-be autistic children who are not autistic, we have the ever ready rubber stamp of "the brain-injured child". While this certainly is regrettable, it has at least driven the acrobatic jumpers onto another bandwagon and has left the serious study of autism to those pledged to diagnostic accuracy (1965: 414).

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<sup>95</sup> This is now common practice.

This indicated the increasing popularity of the term as a diagnostic label but also the problems this could entail, potentially leading to misdiagnoses. The lack of suitable checklists or diagnostic tools further confused the issue of diagnosis.

The discussion of the criteria continued into the 1970s, with Ward suggesting, after evaluating literature, that there were four distinguishing criteria: a lack of object relation from birth; lack of speech for communicative purposes; a maintenance of sameness through stereotypical behaviour; and a lack of developmental or neurological dysfunction (1970: 355). The 1970s also saw a shift in the understanding of autism. The blaming of parents (particularly mothers<sup>96</sup>) for 'causing' autism was reducing, with some efforts being made to promote confidence in parents to enable them to become better caregivers (Tanguay 1973; Kessler 1974). Alternative models for diagnosis were being suggested, e.g., the use of a multidisciplinary team to evaluate and manage the autistic child, as well as differential diagnosis (Tanguay 1973). In addition to this, people were beginning to think more holistically about the diagnostic labelling and the impact that it could have (Kessler 1974). Interestingly, Kessler drew attention to the notion that a child could receive different diagnostic labels depending on the clinician, suggesting that the diagnosis is 'as much influenced by the setting<sup>97</sup> and orientation of the diagnostician as it is by the particular characteristics of the child under study' (1974: 138). This approach demonstrated the issues that existed with autism diagnosis at the time emphasised the need for universally accepted diagnostic criteria and tools. Kessler also discussed the political dimension of labelling in the USA and how there was inconsistency in this, with both encouragement and discouragement in the use of diagnostic labels to fulfil different agendas.<sup>98</sup>

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<sup>96</sup> As popularised by Bruno Bettelheim (1967) and discussed in Chapter 1.

<sup>97</sup> The idea of setting is integral to this research, particularly whether alternative settings could reveal more about the behavioural manifestation of the condition.

<sup>98</sup> This tendency is still present: one author spoke to the chief of child psychiatry at the National Institute of Mental Health who reported giving diagnoses that are most helpful in accessing services (e.g., in Maryland, USA, an autism diagnosis ensures easier access to Medicaid and better care than a 'mental retardation' diagnosis) (Grinker 2008: 130).

In addition to the shift in attitudes towards the diagnosis a follow-up study was carried out on Kanner's original children, which enabled people for the first time to see how autistic children developed (Kanner 1973). Kanner found a mixture of outcomes for the children. Donald T. had gone to college, had a job and 'whilst not completely normal, he has taken his place in society very well, so much better than we ever hoped for' (Kanner 1973: 164). In comparison Virginia was in a state hospital and 'does not talk, uses noises and gestures, but seems to understand when related to. She desires to keep to herself rather than associate with other residents' (Kanner 1973: 172). What is interesting about this is that Kanner comments on the different outcomes that have occurred perhaps being due to the settings that the children were raised in (state hospital vs. home setting), arguably although perhaps not knowingly at the time, alluding to the importance of the idea of intervention.

Another shift that was occurring was a striving for more comparability among diagnosticians to help aid the process. Rutter proposed the following components, suggesting that there was a varying set of diagnostic criteria that dealt with a wider variety of conditions, all being labelled as 'autism' (1978: 156):

(1) an onset before the age of 30 months, (2) impaired social development that has a number of special characteristics and is out of keep with the child's intellectual level, (3) delayed and deviant language development that also has certain defined features and is out of keeping with the child's intellectual level, and (4) insistence on sameness, as shown by stereotyped play patterns abnormal preoccupations or resistance to change.
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Linked to the notion of presenting a more holistic and rounded diagnostic process, Rutter suggested that the cases should also be discussed in relation to the child's IQ and neurological/medical status.

In 1979 a seminal study by Wing and Gould was published that changed perspectives on what autism was, introducing the 'triad of impairments' (social interaction, language abilities [communication] and imagination). The study examined children living in Camberwell,

investigating the prevalence of autism and finding a rate of 21.2/10,000 (Wing and Gould 1979: 24). Additionally, they introduced subgroups based on the quality of social interaction (aloof, passive and odd) (Wing and Gould 1979: 14-15). Although this study was not directly related to the diagnosis of autism it was significant in contributing to the understanding of autism (particularly the use of the triad of impairments) and was used by many as a basis to diagnose. Furthermore, the introduction of the triad of impairments was considered to be innovative because the study used the 'new sociological category of 'social impairment' along with the prior classifications for autism and mental handicap' (Evans 2017: 301).

A final significant influence in the history of the diagnosis of autism in this period was the shift in thinking among academics and practitioners towards seeing autism as a distinct clinical entity (DeMyer, Hingtgen and Jackson 1981). This profound change in thinking was symbolised in two ways. Firstly, the leading journal in the field was renamed from *Journal of Autism and Childhood Schizophrenia* to *Journal of Autism and Developmental Disorders* (as it is still known today) in 1979. Rutter stated that 'the title and scope of the journal have been broadened to include a wider range of developmental disorders related to autism. This carefully circumscribed broadening is also intended to clarify the developmental factors that shape the autistic symptom picture' (Rutter in Evans 2017: 285). Secondly, the DSM-III revision of the prominent diagnostic manual listed infantile autism as a separate condition to schizophrenia, placing it in the category of pervasive developmental disorders (PDD). This was a major moment of recognition for autism as a distinct clinical entity and came some thirty-seven years after Kanner studied his initial cases.

### **Inclusion in the Diagnostic Manual and Beyond**

The DSM-III was published in 1980 and had the following as symptoms for infantile autism (APA 1980):

- A. onset before 30 months
- B. pervasive lack of responses to other people
- C. gross deficits in language development
- D. if speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal
- E. bizarre responses to various aspects of the environment: e.g. resistance to change, peculiar interest in or attachments to animate or inanimate objects
- F. absence of delusions, hallucinations, loosening of association, and incoherence, as in schizophrenia

Support was found for this set of criteria, with substantial agreement found between it and the experience of autism specialists (Stone 1987). However, discrepancies were still found in the diagnosis based on the diagnostician's individual discipline, which meant that different disciplines were relying on alternative criteria. The list of symptoms in DSM-III was criticised for the inclusion of the seemingly arbitrary 30-month period and the failure to account for additional factors, e.g., the severity of the syndrome (Volkmar and Cohen 1988). Further difficulties were raised with the lack of any criterion related to wider cognitive impairments (Prior 1984) and with a need to distinguish between abnormalities that *must* be present and behaviours that *might* be characteristic (Bishop 1989).

However, the introduction of the term into the diagnostic manual did lead practitioners to begin discussing problems with the diagnosis of such a condition. Freeman and Ritvo (1982) provided three main criticisms. Firstly, there was a lack of consensus on the full definitions and symptoms required for a diagnosis among professionals. Secondly, there was a lack of general guidelines for obtaining the data and little guidance on how the data should subsequently be interpreted. Finally, there was a lack of people who were specifically trained to recognise autism and make appropriate referrals.<sup>99</sup> In addition to this, Denckla (1986) noted disagreements with an interdisciplinary group about: whether there were deficits in symbolic/imaginative play; what the age of onset was and the subsequent importance of this; and the role of IQ. This

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<sup>99</sup> See Freeman and Ritvo (1982) for a review of definitions and tools up until the 1980s.

demonstrated how there was still much confusion surrounding the term among professionals. They did, however, agree on the core characteristic of social impairment and the presence of repetitive behaviours.

In 1987 a further revision of the DSM, DSM-III-R, was published (adapted from APA 1987: 38-39):

- A. Qualitative impairment in reciprocal social interaction as manifested by the following:
  - (1) marked lack of awareness of the existence or feelings of others
  - (2) no or abnormal seeking of comfort in times of distress
  - (3) no or impaired imitation
  - (4) no or abnormal social play
  - (5) gross impairments in ability to make peer friendships
- B. Qualitative impairments in verbal and non-verbal communication, and in imaginative activity
  - (1) no mode of communication, such as communicative babbling, facial expression gesture, mime, or spoken language
  - (2) markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction
  - (3) absence of imaginative activity
  - (4) marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm and intonation
  - (5) marked abnormalities in the form or content of speech, use of 'you' when 'I' is meant, idiosyncratic use of words or phrases, or frequent irrelevant remarks
  - (6) marked inability to initiate or sustain a conversation with others, despite adequate speech
- C. Markedly restricted repertoire of activities and interests
  - (1) stereotyped body movements
  - (2) persistent preoccupation with parts of objects, or attachment to unusual objects
  - (3) marked distress over changes in trivial aspects of the environment
  - (4) unreasonable insistence on following routines in precise detail
  - (5) markedly restricted range of interests and a preoccupation with one narrow interest
- D. Onset during infancy or childhood. Specify if childhood onset (after 36 months of age)

Diagnosis requires eight of the sixteen items to be present, including two from group A, one from B and one from C. Items are scored as present *only* if they are developmentally appropriate.

The criteria for this were drawn, 'almost word for word, from Wing's definition of the 'triad' (Evans 2017: 348). In comparison to the previous version, the DSM-III-R removed the 'arbitrary' age of onset and condensed the impairments into three key areas, providing more explicit details. Clear guidelines were also included which specified how many symptoms, and from which categories, were required for a diagnosis.

Support was found for these changes, including high specificity<sup>100</sup> and sensitivity<sup>101</sup>, when comparing the DSM-III-R criteria to the diagnoses made by expert clinicians (Spitzer and Sigel 1990). When comparing these criteria to the ICD-10, high overall agreement was found, as well as with two other diagnostic tools<sup>102</sup> (Sponheim 1996), with some suggesting that the DSM-III-R was better than the previous version as it separated the behaviour patterns from other conditions (Waterhouse et al. 1993). However, issues with the DSM-III-R were reported, including whether the behaviours used were developmentally appropriate (Aitken 1991). Such diagnosis could prove problematic for very young children, as well as those who are mute or developmentally delayed.

Moving into the 1990s, there was a growing focus on screening and diagnosing at a younger age (Baron-Cohen, Allen and Gillberg 1992; Lord et al. 1993; Stone and Hogan 1993; DiLavore, Lord and Rutter 1995; Stone et al. 1999), with some suggesting that a diagnosis ideally occur in pre-school (Gillberg, Nordin and Ehlers 1996) and Stone et al. (1999) finding that children could be reliably diagnosed below three years old.<sup>103</sup>

Another key development in the 1990s was the exploration of a distinction between two groups of autistic people (Waterhouse et al. 1996). It was suggested that although there were shared core symptoms, there were distinct differences: the first group had higher verbal and

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<sup>100</sup> This is the 'proportion of individuals with a disorder who have a negative screen result' (Charman and Gotham 2013: 53).

<sup>101</sup> This is the 'proportion of individuals with a disorder who have a positive screen result' (Charman and Gotham 2013: 53).

<sup>102</sup> These were the CARS and ABC which will be discussed in more detail later on.

<sup>103</sup> Although this was criticised later by Reznick et al. (2007) who suggested that it is problematic to diagnose young infants, as presently it is unclear exactly what behaviours could predict an eventual diagnosis. Charman and Baird (2002) have suggested that the diagnosis should be tentative until the age of five. This has been supported by some who highlight the problems with the stability of the diagnosis on very young children and promote waiting for children to be older for a more accurate diagnosis (Matson, Wilkins and González 2008), with others suggesting that screening should start before 18 months and then be repeated later at 24 and 36 months (Landa 2008). However, Eaves and Ho (2004) found that the diagnosis was stable over two time periods and 87.5% of children retained their autism diagnosis (the others moved from autism to atypical autism) (Moore and Goodson 2003). This discussion is ongoing.

nonverbal IQ scores and a presence of perservative interests<sup>104</sup> and impaired prosody; the second group had lower verbal and nonverbal IQ scores, significant impairments in comprehension of language and social imitation, and the presence of sensory abnormalities and motor stereotypes. The distinction between the two groups gained further momentum when Frith translated Asperger's work into English in 1991.<sup>105</sup> This revealed that seemingly unaware of each other's work<sup>106</sup>, Asperger and Kanner had been studying similar types of children.

Asperger presented the case of four male children (1991 [1944]: 38):

The children I will present all have in common a fundamental disturbance which manifests itself in their physical appearance, expressive functions and, indeed, their whole behaviour. The disturbance results in severe and characteristic difficulties of social integration. In many cases the social problems are so profound that they overshadow everything else. In some cases, however, the problems are compensated by a high level of original thought and experience. This can often lead to exceptional achievements in later life.

He described the cases in detail which led him to develop the first diagnostic criteria for the condition which has come to bear his name:

- persistence over time, characteristics are seen throughout the whole life span
- the language used feels unnatural, and is often presented like they are speaking into an empty space rather than to a person
- there is a level of autistic intelligence which cause them to produce original ideas, and they have difficulty with mechanical learning. There is also unusual knowledge in specific areas e.g. poison, and a mature appreciation for art
- the limitation in their social relationships is the central part to the disorder
- stereotypic behaviour
- tend to follow their own interests and impulses
- collectors
- absence of a sense of humour

(adapted from Asperger 1991 [1944]: 67-84).

Asperger's was more readily accepted as a separate clinical entity in comparison to autism: it was included as Asperger's syndrome in the ICD-10 in 1992 and as Asperger's disorder in the

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<sup>104</sup> This refers to highly selective and obsessive behaviours that are often repeated.

<sup>105</sup> Although others had discussed his work previously (Wing 1981a; Gillberg and Gillberg 1989; Szatmari, Bremner and Nagy 1989).

<sup>106</sup> Although this has been challenged in *Neurotribes* by Steve Silberman (2015).

DSM-IV in 1994<sup>107,108</sup>. Its first official recognition as a distinct clinical entity was within the ICD-10, in which it was grouped with several conditions under the umbrella category of PDD. Other conditions in this category included childhood autism, atypical autism and Rett syndrome. Asperger's was presented as being similar to the clinical description of autism<sup>109</sup>, but differed in its lack of 'general delay or retardation in language or cognitive development', and the fact that 'most [affected] individuals are of normal general intelligence' (WHO 1992: 258). However, prior to these publications Gillberg had presented his own diagnostic criteria in 1991. He enumerated six areas of difficulty (the minimum number of symptoms required for a diagnosis are in parentheses): social impairment (2); narrow interest (1); compulsive need for introducing routines and interests (1); speech and language peculiarities (3); nonverbal communication problems (1); and motor clumsiness (in Attwood 2008: 37). Support was found for these criteria, with authors arguing that they were closer to Asperger's definition and included more specific criteria for current behaviour (Leekham et al. 2000).

Prior to the publication of the next revision of the DSM, DSM-IV, a field trial was conducted to address issues with the previous versions (Volkmar et al. 1994). It had been found that the DSM-III-R produced more false-positive cases, as well as there being support for the inclusion of other PDDs, e.g., Asperger's, Rett's and childhood degenerative disorder. The authors of the DSM-IV therefore worked to align conceptually the clinical description in the DSM-IV to that in the ICD-10, allowing more continuity in diagnosis.

In 1994 the DSM-IV was published and changed the label to 'Autistic Disorder', which moved away from the belief that the condition only affects children. Similarly to the ICD-10, the

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<sup>107</sup> The DSM-IV will be discussed later in the chapter.

<sup>108</sup> Volkmar et al. (2000) expressed concern over the validity of Asperger's as a diagnostic concept, suggesting that further differences between this and autism needed to be found.

<sup>109</sup> The ICD-10 description of autism was like that in the DSM-III-R, presenting similar ideas involving the triad of impairments. For a diagnosis of childhood autism, the symptoms needed to be present prior to three years old, in addition to at least six symptoms being displayed across the three core deficit areas (as opposed to the eight needed in the DSM-III-R) (WHO 1992).

diagnosis was placed under the umbrella of PDD, which included Rett's Disorder, Childhood Disintegrative Disorder, Asperger's disorder and (Pervasive Developmental Disorders-Not Otherwise Specified) PDD-NOS. The descriptions of the symptoms were expanded and more clear examples were presented (APA 1994: 70-71):

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
- (1) qualitative impairment in social interaction, manifest by at least two of the following:
    - a) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
    - b) failure to develop peer relationships appropriate to developmental level
    - c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing or pointing out objects of interest)
    - d) lack of social or emotional reciprocity
  - (2) qualitative impairment in communication, as manifest by at least one of the following:
    - a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    - b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - c) stereotyped and repetitive use of language, or idiosyncratic language
    - d) lack of varied, spontaneous make-believe, or social imitative play appropriate to developmental level
  - (3) restrictive repetitive and stereotypic patterns of behaviour, interests, and activities, as manifested by at least one of the following:
    - (a) encompassing preoccupation with one of more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - (b) apparently inflexible adherence to specific, non-functional routines or rituals
    - (c) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
    - (d) persistent preoccupation with parts of objects
- B. delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. the disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

(APA 1994: 70 - 71)

This version maintained the three core deficits and the age of onset. However, the DSM-III-R required at least eight out of sixteen items for a diagnosis, whereas the DSM-IV reduced this to six. The number of items under each heading was reduced to four and the comment on differential diagnosis was incorporated. This version was praised for linking the two diagnostic

manuals (Rutter 1996) and for having a single set of general criteria (Lord et al. 1997). In addition to this, little difference was found between clinically assigned diagnoses and those based on the DSM-IV (Klin et al. 2000) and support was found for all of the diagnostic criteria (except the absence of gestural communication and make-believe play) (Dickerson Mayes and Calhoun 1999). However, some criticised the manual for: not being applicable to young children due to their lack of expressive speech (Charman and Baird 2002); being less stringent than the ICD-10 (Tidmarsh and Volkmar 2003); and having too narrow a definition, with too broad speech delays described (Klin et al. 2005).

An important incorporation into the manual which helped to align it with the ICD was the inclusion of Asperger's, which reflected the growing appreciation and understanding of two distinct conditions, as supported by research (e.g. McLaughlin-Cheng 1998; Prior et al. 1998). Similar core features were shared between Asperger's and autism, with an additional four points (APA 1994: 77):

- The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.
- Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Despite the support the criteria were criticised for failing to match the criteria set forth by Hans Asperger (Gillberg et al. 2001), while those with Asperger's tended to meet the diagnostic criteria for autism (Tidmarsh and Volkmar 2003; Woodbury-Smith, Klin and Volkmar 2005; Tyron et al. 2006). These studies suggested that research needed to concentrate on whether Asperger's could be redefined to enable it to be accurately differentiated from autism. This idea was supported by Freeman, Cronin and Candela (2002) who noted the difficulties in distinguishing between the two conditions due to the overlap of symptomatology. The description of Asperger's in the DSM-IV was further criticised for making the condition appear

not to be severe due to a low numerical requirement of symptoms (Gillberg et al. 2001).

Flaskerud (2010) reflected how, from a clinical perspective the criteria made it difficult to distinguish between Asperger's and high-functioning autism.

In 2000 a revised version of the DSM-IV (DSM-IV-TR) was published. There were no revisions to the diagnostic criteria that affected any of the diagnostic groups in the PDD category; however, it was noted that 80% accuracy in the diagnosis of autism could be achieved with the use of this manual (Starling 2014).

During the 2000s researchers were becoming more aware of the effects that an autism diagnosis has on the subject's family, particularly the parents (Avdi et al. 2000; Glasberg 2000; Boushey 2001; Charman and Baird 2002; Freeman, Cronin and Candela 2002; Nissenbaum et al. 2002; Brogan and Knussen 2003; Mansell and Morris 2004; Osborne and Reed 2008). This was particularly important for the actual diagnostic process. Freeman and Cronin (2002) emphasised the importance of a good rapport with the parents of the child, as this enables a collaborative relationship between parents and professionals – this is key, as parents are often the primary source of information. When receiving a diagnosis, 50% of parents thought that the information on treatment, future outcomes and strategies for their diagnosed child had been explained 'slightly' well or 'not at all' well by professionals (Mansell and Morris 2004: 395). One study found that only a small sample of parents recalled having heard a 'positive prognosis for their child' (Nissenbaum et al. 2002: 35). Another found that 40.1% of parents were not satisfied with the diagnostic process and only 23.5% were extremely satisfied (Goin-Kochel, Mackintosh and Myers 2006). One parent commented on how the diagnosis was given to them, 'I suppose, in one sense, quite cold and calculating, it sort of accounted that this is the problem, that's it, goodbye' (Osborne and Reed 2008: 314). Hodge (2005) suggested that parents might feel blackmailed into getting a diagnosis in order to be able to access services. However, there were some positive experiences reported. One study found that 55% of parents were satisfied

or very satisfied with how the diagnosis was revealed to them (Brogan and Knussen 2003).

Assessing parent's responses to the diagnosis, 75% claimed to have felt relief and had a greater acceptance of their child's behaviour (Mansell and Morris 2004).

The publication of the DSM-5 in 2013 altered the diagnostic criteria again. The conditions were subsumed into the umbrella term of ASD (including Asperger's, childhood disintegrative disorder and PDD-NOS) with these now placed in the section on neurodevelopmental disorders. The diagnostic criteria given are as follows (APA 2013: 50-51):

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:
  1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. Deficits in nonverbal communicative behaviors used for social interaction, ranging for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
  1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g. extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
  3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds of textures, excessive smelling or touching of objects, visual fascination with lights or movements).
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

In addition to the actual diagnosis, a current severity score is required for sections A and B. This is divided into three levels – requiring support, requiring substantial support and requiring very substantial support (APA 2013: 52). This means that not only does an individual receive a diagnostic label, but they are also given a level of severity which can be used to assign the appropriate level of support to them.

The DSM-5 differs from the previous version in that the symptoms have now been divided into a dyad, as opposed to a triad, of impairments, which has been praised by researchers (Harstad et al. 2015). The categories are now: social communication and interaction; and restricted and repetitive behaviours. The arguably arbitrary date of three years was removed and replaced by a suggestion that the symptoms are seen in the ‘early developmental period’ (APA 2013: 50-51). The other differences present are listed below:

1. Symptoms are based on a lifetime occurrence.
2. Examples are illustrative and not exhaustive.
3. Some of the instances of ‘and’ are replaced with ‘or’, so not all symptoms are required.
4. Wording describing some symptoms has been relaxed.
5. The importance of peer relationships is emphasised.
6. A new criterion is introduced that symptoms ‘may be masked by learned strategies later in life’.
7. Several additional examples of symptoms are included.

(adapted from Dickerson Mayes et al. 2014: 69.)

High sensitivity was found, with a slightly higher proportion of adults and females diagnosed in comparison to previous versions (Young and Rodi 2014). Mandy et al. (2014) found that the DSM-5 description fitted well with both Finnish and UK samples, helping to support it cross-culturally. Furthermore, Gensler (2012: 88) praised the DSM-5 for helping to get rid of the ambiguities of diagnosis.

However, issues with the DSM-5 were raised even prior to the publication with Flaskerud (2010: 688) discussing concerns within the scientific world over the removal of the Asperger’s label before sufficient time had been allowed for the biological testing of differences between Asperger’s and classic autism, arguing that any such merging would be premature.

When comparing the DSM-IV-TR and DSM-5 diagnoses, only 55% of the sample achieved a DSM-5 diagnosis (even though they had a DSM-IV-TR diagnosis). While this might increase the accuracy of diagnosis, it may be problematic for specific groups, as those who met the new criteria had greater symptom severity and lower IQ and adaptive behaviours scores (Taheri, Perry and Factor 2014). The DSM-5 has been reported to have issues diagnosing those who had previously received a diagnosis (Matson, Beighley and Turygin 2012; Taheri and Perry 2012; Williams et al. 2014; Smith, Reichow and Volkmar 2015; van Steensel, Bögels and de Bruin 2015) and is particularly problematic for capturing those who had previously been diagnosed with PDD-NOS (Matson, Beighley and Turygin 2012; Dickerson Mayes, Black and Tierney 2013; Dickerson Mayes et al. 2014; Young and Rodi 2014; Smith, Reichow and Volkmar 2015) and with diagnosing females (McCrory 2013; Linton et al. 2014). The issue of under identification appears to have been pre-empted by the DSM-5 authors, as Matson and Jang (2014) drew attention to the fact that the DSM-5 contains a footnote indicating that someone who already had a diagnosis would not lose it, even if they failed to meet the new criteria. Furthermore, issues have been found with the broader autism phenotypes not fitting well with Finnish individuals, this suggesting that cross-cultural variability may be problematic in individuals with milder autism characteristics (Mandy et al. 2014). Evans (2017: 417) has pointed out that the removal of Asperger's and the fusing of the social and communication domains of the triad of impairments has arguably destabilised the categories.

## **Diagnostic Tools**

This section of the chapter will focus on the diagnostic tools that have been developed to help diagnose autism. This exploration will be divided into the eras before and after inclusion of autism in the diagnostic manuals, with the latter divided into screening tools, scales and interviews, and observational measures.

## **Before Inclusion in Diagnostic Manuals**

Before autism was recognised as a clinical entity in the diagnostic manuals (as discussed above), a few checklists were developed to help diagnose individuals. Polan and Spencer (1959) produced a thirty-point list of symptoms divided into five areas (language distortion, social withdrawal, activities lack integration, obsessiveness and nervousness, family characteristics). Initial testing found considerable differences between autistic and schizophrenic children; however, the authors failed to provide a cutoff score which would diagnose an individual as autistic. Rimland (1964) developed the Diagnostic Checklist for Behaviour-Disturbed Children (Form E-2), an eighty-point checklist. This was found to have excellent sensitivity (90%) when diagnosing autistic and intellectually disabled groups (Teal and Wiebe 1986). However, it was criticised for a lack of reliability by Parks (1983), poor validity and reliability by Masters and Miller (1970) and poor sensitivity by Douglas and Sanders (1968). In addition to this, the tool struggled to distinguish between groups, e.g., those with infantile autism, autism with associated symptoms and early infantile autism (Leddet et al. 1986). Further criticism was directed at the fact that it relied on parental reports and not observations (Freeman and Ritvo 1982), with Prior and Bence (1975) pointing out discrepancies in reports completed by parents and teachers. A further screening test was developed involving fourteen items thought to be significant manifestations of the condition (Rendle-Short and Clancy 1968). Support for its use as a screening tool rather than a diagnostic tool was found as it produced a high rate of false-positives (Capute et al. 1974).

In summary, prior to autism being recognised in the diagnostic manuals, there was a problematic lack of diagnostic tools resulting in a reliance on reports from other clinicians often based on observational analysis. Once autism was officially introduced, several tools began to be developed to help systematically diagnose those on the spectrum. This will be explored according to the three types of tool available: screening tools; scales and interviews; and observational tools.

## Screening Tools

A screening tool may be applied to an individual to identify the possible presence of autism and to determine whether further investigation is warranted. The tools are usually in the form of a brief questionnaire or checklist which can be filled out on paper or (more recently) online. They can be answered by parents, teachers, GPs, clinicians or the individuals themselves. Most of the tools focus specifically on diagnosing autism, e.g., Autism Behaviour Checklist (ABC) (Krug, Arick and Almond 1980), Autism Spectrum Quotient (AQ) (Baron-Cohen et al. 2001b), Checklist for Autism in Toddlers (CHAT) (Baron-Cohen, Allen and Gillberg 1992), Modified-Checklist for Autism in Toddlers (M-CHAT) (Robins et al. 2001), Early Screening of Autistic Traits Questionnaire (ESAT) (Swinkels et al. 2006), Gilliam Autism Rating Scale-3 (GARS-3) (Gilliam 2014) and Social Communication Checklist (SCQ) (Rutter, Bailey and Lord 2003). Other tools have been developed for the diagnosis of Asperger's, e.g., the Childhood Asperger Screening Test (CAST) (Scott et al. 2002) or Asperger's and HFA, e.g., the Asperger Syndrome Screening Questionnaire (ASSQ) (Ehlers, Gillberg and Wing 1999). Other tools focus on distinguishing autism from developmental disabilities, e.g., the Screening Tool for Autism in Two-Year-Olds (STAT) (Stone and Ousley 1997) (see Table 1 for a summary).<sup>110</sup>

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<sup>110</sup> These screening tools have been selected as they are more commonly used or have more substantial research conducted on them. There are other tools available.

name and authors	target group	to be completed by	length
Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers, Gillberg and Wing 1999), previously the Asperger Syndrome Screening Questionnaire	7-16-year-olds with normal intelligence or 'mild mental retardation'	lay informants	27 items
Autism Behaviour Checklist (ABC) (Krug, Arick and Almond 1980)	child +	parent, teacher or caregiver, then analysed by a trained professional	57 items
Autism Spectrum Quotient (AQ) (Baron-Cohen et al. 2001b) Autism-Spectrum Quotient – Short Form (AQ-S) (Hoesktra et al. 2011)	originally for adults but adolescent and child versions are now available	mainly used for self-diagnosis	AQ: 50 items AQ-Short: 28 items
Baby and Infant Screen for Children with aUtism Traits (BISCUIT): Parts 1 – 3 (Matson et al. 2009a)	17-37 months	informant based (e.g., parents)	Part 1 (symptoms of ASD) 62 items
Checklist for Autism in Toddlers (CHAT) (Baron-Cohen, Allen and Gillberg 1992); Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al. 2001); Quantitative Checklist for Autism in Toddlers (Q-CHAT) (Allison et al. 2008)	children younger than 3	parents and GP/health visitor  Q-CHAT: parents only	CHAT: 14-point list (nine questions and five points of observation) M-CHAT: 23-point questionnaire. Q-CHAT: 25 items
Childhood Asperger Screening Test (CAST) (Scott et al. 2002)	children aged 5-11 years old	parents	37 item questionnaire
Developmental Behaviour Checklist – Autism Screening Algorithm (DBC-ASA) (Brereton et al. 2002)	children	parents/teachers	29 item scale subset from DBC
Early Screening of Autistic Traits Questionnaire (ESAT) (Swinkels et al. 2006)	young children	parents	14 item scale
Gilliam Autism Rating Scale-3 (GARS-3) (Gilliam 2014)	individuals between 3-22	administered by trained and experienced individuals	48 Likert-type items
Screening Tool for Autism in Two-Year-Olds (STAT) (Stone and Ousley 1997)	24-35 months	professionals	12 items administered in a play-like situation, taking less than 20 minutes
Social Communication Checklist (SCQ) (Rutter, Bailey and Lord 2003) previously ASQ (Autism Screening Questionnaire) adult and adolescent versions were also developed	children over the age of four (providing mental age exceeds two) with two versions, current and lifetime	parents/primary caregivers	40 questions

Table 1: summary of some of the screening tools for highlighting autism

Screening tools have several advantages, including being easy, quick and cheap to administer. There is evidence of their high predictive value which supports their use. The ESAT was found to have high sensitivity (Swinkels et al. 2006), as was the SCQ (Eaves, Wingert and Ho 2006; Allen et al. 2007; Snow and Lecavalier 2008; good sensitivity and specificity reported in Oner, Oner and Munir 2014) and the STAT was found to have excellent sensitivity and very good specificity (Charak and Stella 2001-2002), particularly when the cut-off score was increased (Stone, McMahon and Henderson 2008). High sensitivity and specificity was found for the CAST (Scott et al. 2002; Williams et al. 2005), as was moderate test-retest reliability (Allison et al. 2007). Eaves and Williams Jr. (2006) found the ABC to have high reliability, while the CHAT was found to be a good tool for predicting autism (Baron-Cohen, Allen and Gillberg 1992). The DBC-ASA saw children with autism scoring significantly higher than those without (Deb, Dhaliwal and Roy 2009). The ASQ (the previous version of the SCQ) was found to have high sensitivity and specificity (Auyeung et al. 2008). The BISCUIT had excellent accuracy in its diagnosis rates, could successfully distinguish between autism and PDD-NOS in 88.6% of cases (Matson, Dempsey and Fodstad 2009) and successfully distinguished an autism diagnosis and no-diagnosis in toddlers (Matson et al. 2010a). When compared to other tools (SRS and CCC) the SCQ was found to have the best sensitivity and specificity (Charman et al. 2007), and greater specificity when compared to the DBC-ASA (although marginally lower sensitivity) (Witwer and Lecavalier 2007). The SCQ also performed the best when reviewed against five different scales, with the ASSQ also showing promise (Norris and Lecavalier 2010). When compared to the DSM-Q (a questionnaire formatted from the DSM-IV-TR), there was 89% agreement (Goin-Kochel and Cohen 2008). When the BISCUIT and M-CHAT were compared, the BISCUIT had higher sensitivity and overall classification than the M-CHAT, but comparable specificity (Matson et al. 2009b). When the CAST and SCQ were compared, it was found that the CAST was better at detecting at-risk participants (Scott et al. 2002). Several of the tools have been translated, helping to provide support for their use beyond English-speaking, Western countries. The CHAT

and M-CHAT were translated and adapted into Chinese and high sensitivity and specificity scores were still maintained (Wong et al. 2004). The Japanese version of the CHAT (CHAT-J) (Koyama 2010) and M-CHAT (M-CHAT-JV) were satisfactorily able to identify ASD (Kamio et al. 2014). Support was also found for the use of the tools in Arab countries, with high sensitivity, specificity and predictive value documented (Seif Eldin et al. 2008). A Turkish translation of the M-CHAT found the positive predictive value (PPV) to be 75%, suggesting it is a useful tool (Kara et al. 2014); however, it was found that when parents completed it there were high rates of false positives, these being considerably reduced when healthcare staff administered it. A French-Canadian version of the AQ was produced which matched scores from the original version, although the cut-off score was lower (Lepage et al. 2009) and a Polish version of the AQ was found to have comparable psychometric properties to other language versions (Pisula et al. 2013). In addition to this, the ASSQ has been translated into multiple languages (Finnish [Mattila et al. 2009], Lithuanian [Lesinskiene 2000 in Mattila et al. 2009] and Norwegian [Posserud, Lundervold and Gillberg 2006]). High sensitivity and specificity, negative predictive value (NPV) and good PPV were found for a Mandarin version of the CAST (Sun et al. 2014). A Persian version of the GARS used in Iran found it to be a useful rating scale with similar psychometric properties to the US normative sample (Samadi and McConkey 2014). Overall, the use of screening tools is very popular, with one study indicating that the GARS was the second most widely used measure for school psychologists and the ABC the fifth (Allen, Robins and Decker 2008). The GARS was also found to be the most commonly used instrument in parts of Scotland (Hathorn et al. 2014).

However, disadvantages have been found with some of the screening tools. There have been issues with misdiagnosing, e.g., the ABC had a high rate of false-positives when compared to the CARS<sup>111</sup> (Sponheim 1996) and high false-negative rates when compared to the DSM-IV

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<sup>111</sup> The Childhood Autism Rating Scale – a scale used to contribute to the diagnostic process, as will be discussed in the next section.

(Rellini et al. 2004), as well as not being useful for diagnosing children younger than three (CHAT; Höglund Carlsson et al. 2010). Poor sensitivity rates have been found in the GARS (South et al. 2002) and the SCQ (Eaves, Wingert and Ho 2006; Allen et al. 2007). The CHAT was found to miss many cases (Klinger and Renner 2000; Senior 2000). The choice of questions used within some tools has been questioned e.g., the GARS was criticised for overemphasising stereotyped and repetitive behaviours and not covering or placing enough emphasis on several communicative and social areas (Lecavalier 2005), meaning that those with HFA or Asperger's could be missed. In addition to this, the GARS was found to have poor sensitivity and specificity when compared to the Child Behavior Checklist (CBCL). The PPV for the M-CHAT was very low for low-risk samples (Kleinman et al. 2008; Pandey et al. 2008) and it was found to create potentially unnecessary referrals (Kleinman et al. 2008).

Revisions to the tools have been in order to address some of the issues that have been discussed. For example, the CHAT (now the M-CHAT) was revised in order to reduce the administration time, lower the age to preschool children, consider parental report and allow the tool to be administered to all children and not just those identified as having developmental concerns or autistic-like behaviours (Robins et al. 2001: 133). In addition to this, the authors criticised the CHAT for relying on abnormalities of behaviour rarely seen before three, a lack of standardised measures used, the need for it to be administered by a specialist and the requirement for structured interactions which may not always be possible (ibid.). Following these revisions, high sensitivity, specificity, NPV and PPV were found (Robins et al. 2001), as well as high agreement with an ASD diagnosis (Wiggins, Piazza and Robins 2014). The M-CHAT2 was found to have high (Eaves, Wingert and Ho 2006) and very good sensitivity (Snow and Lecavalier 2008). In addition to this, a revision to the GARS (GARS-2) resulted in the tool being much quicker and simpler to complete with a more flexible format (Montgomery, Newton and Smith 2008).

In conclusion, despite some strengths seen in the screening tools, there are still problems with those available. They do not capture every person who is later diagnosed, nor do they always correctly identify those without autism. This kind of screening process should therefore be considered as the start of an ongoing process and a dialogue between parent (or individual) and professional (Charman 2003a). One should remember that the screening tool is a means to investigate the *potential* of autism, something which is further explored in more detail with diagnostic tools, where a diagnosis may be confirmed. A screening tool should never be used solely for diagnosis but instead as part of a wider programme of information collection. This is highly relevant to the research underlying this thesis as the research explores a diagnostic, rather than a screening, tool. A screening tool could be used as the basis for a recommendation for the fuller diagnostic assessment that would occur within the iA 'pod' based on the ADOS-2, giving a more holistic and complete view of the individual than would be seen within a screening tool.

## **Scales and Interviews**

After an individual has been recognised as being at-risk through the use of screening tools, they are referred for a formal diagnosis. Part of this assessment usually consists of the administration of scales and/or interviews. The interviews tend to be carried out by trained individuals, e.g., clinicians, whereas scales can be completed without trained assistance. Both are completed either by the individual in question, or by someone who knows the person well, e.g., parents. Research has supported the use of parental report as parents are 'highly motivated observers of their infant's behaviour, with most parents engaging in vast amounts of contact' (Reznick et al. 2007: 1692). Some of the tools focus specifically on diagnosing autism, e.g., the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter and Le Couteur 1994), Childhood Autism Rating Scale (CARS) (Schopler et al. 1980) and Social Responsiveness Scale (SRS) (Constantino et al. 2003). Some tools distinguish between a range of conditions (autism, Asperger's syndrome, psychiatric disorders or other developmental disorders), e.g., the

Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing at al. 2002).

Others look to diagnose autism alongside co-morbid conditions, e.g., the Developmental,

Dimensional and Diagnostic Interview (3di) (Skuse et al. 2004) (see Table 2 for a summary).<sup>112</sup>

name and authors	target group	to be completed by	length
<b>SCALES</b>			
Childhood Autism Rating Scale (CARS) (Schopler et al. 1980) CARS-2 (Schopler et al. 2010)	children (at least two years)	clinician, teacher or parent	15 items (5-15 minutes)
Social Responsiveness Scale (SRS) formerly the Social Reciprocity Scale (Constantino et al. 2003) Social Responsiveness Scale-Second Edition (SRS-2) (Constantino and Gruber 2012)	SRS – Children SRS-2 – Preschool Form (2:6-4:6); School-Age Form (original SRS) (4:0-18:0); Adult Form (19-89)	parents and/or teachers (SRS, SRS-2 (preschool and school-age)  parents, spouses, friends, relatives and self-report (SRS-2 Adult)	15-20 minutes
<b>INTERVIEWS</b>			
Developmental, Dimensional and Diagnostic Interview (3di) (Skuse et al. 2004) Shorter version (3di-sv) developed by Santosh et al. (2009)	children	clinician completes on a computer program based on parent/caregiver report	full: 90 minutes (740 items); abbreviated: 45 minutes (53 items)
Autism Diagnostic Interview (ADI) (Le Couteur et al. 1989) and the ADI-R (Lord Rutter and Le Couteur 1994)	ADI – children with a chronological age (CA) of 5+ and MA of two years ADI-R – children with MA of 18 months	trained individual carries out the interview with parent/caregiver	ADI-R – 93 items, 2-3 hours

Table 2: a summary of some of the diagnostic tools (scales and interviews) for autism, taken in part from Vllasaliu et al. (2016)

There are several advantages to these scales and questionnaires. Good agreement rates have been found between diagnostic tools. For example, Reszka et al. (2014) noted that the CARS, SRS and ADOS were reliable and valid measures. Excellent agreement has been reported for these tools compared to the diagnostic manuals, which indicates that they are diagnosing appropriately. The DSM-IV diagnosis and the CARS were found to have complete agreement by

<sup>112</sup> Similarly to the screening tools, only some scales and interviews are discussed. Other ones are available, e.g. the Adult Asperger Assessment (AAA) (Baron-Cohen et al. 2005) and the Asperger Syndrome Diagnostic Interview (ASDI) (Gillberg, Gillberg and Wentz 2001).

Rellini et al. (2004) and high agreement by Perry et al. (2005), Chlebowski et al. (2010) and Dickerson Mayes et al. (2014). Additionally, when compared to clinical judgment, the CARS was reported to have significant agreement (Ventola et al. 2006) and high sensitivity (Wiggins and Robins 2008). Moderate-to-excellent agreement was reported between the DISCO and clinical judgement (Nygren et al. 2009). There is also evidence of high predictive value, providing support for the use of these diagnostic tools. Teal and Wiebe (1986) reported 100% accuracy when using the CARS on autistic children and children with ID. Magyar and Pandolfi (2007) further noted that CARS discriminates between autistic individuals and those without. The CARS was found to be better at identifying cases of 'low-functioning' autism than HFA (Dickerson Mayes et al. 2009). The CARS had high specificity (Perry et al. 2005) and high sensitivity (Volkmar et al. 1988; Perry et al. 2005), the SRS had excellent sensitivity and specificity (Bruni 2014) and high sensitivity (Morgan 1988; DiLalla and Rogers 1994; Stella, Mundy and Tuchman 1999; Charman et al. 2007) and the 3di had both high sensitivity and specificity (Skuse et al. 2004). The DISCO was praised for its reliability (Leekham et al. 2002) and was found to have high inter-rater reliability (Wing et al. 2002). In some cases, minor amendments to tools were found to be useful. For example, the CARS had good sensitivity and specificity when the cut-off score was lowered to help distinguish between PDD-NOS and autistic disorder on one hand and autism and other developmental disorders on the other, as well as an increase in agreement with the DSM-IV and ADOS (Chlebowski et al. 2010). Some of the tools have been found to retain their sensitivity, specificity, validity and reliability in translation and have been tested in other cultures. Nordin, Gillberg and Nydén (1998) found 100% sensitivity and 70% specificity in a Swedish translation of CARS and moderate and high accuracy were found in India (Nair et al. 2014). It was found that the cut-off for autism remained 'basically the same' in a Tokyo version of CARS (30 v. 30.5) (Tachimori et al. 2003).

However, some of the tools have been reported to have disadvantages and issues related to misdiagnosis, e.g., the CARS was found to misdiagnose 38.1% of those without autism and

misclassify nearly 20% of those with autism (Volkmar et al. 1988). The tools also have issues with diagnosing certain groups with conditions like HFA. For example, three of the four most intelligent and 'high-functioning' individuals did not receive a diagnosis on the ADI (Yirmiya, Sigman and Freeman 1994), with the CARS also having difficulties with identifying this group (Charak and Stella 2001-2002), and with distinguishing between those with Asperger's and those with PDD-NOS from those who were autistic (Rellini et al. 2004). One possible reason for these difficulties reported in some of the research may be that the CARS was developed prior to the DSM-III-R and ICD-10 and so is orientated towards different symptoms (Lord 1991; Lord and Risi 1998). Finally, the interview-based diagnostic tools have been criticised for their length, with the ADI-R taking the longest (2-3 hours). This makes them not only time-consuming but also more expensive to administer. Furthermore, the accuracy of the rater can affect diagnosis or severity within the rating scales (Bruni 2014).

There have been revisions to the diagnostic tools to help tackle some of the issues raised. For example, the ADI was revised (it is now the ADI-R) to improve its differentiation of autism from other conditions in young children, reduce its length and increase its efficiency so that it can be used in a clinical, as well as a research, setting (see Lord, Rutter and Le Couteur 1994). Following the revisions, the ADI-R was found to successfully discriminate between autistic, non-autistic children with ID, and children with language impairments (Lord et al. 1993; Lord, Rutter and Le Couteur 1994), including with children as young as 20 months (Cox et al. 1999). Excellent specificity was reported (Matson et al. 2010b), with excellent reliability for inter-examiner agreement (Cicchetti et al. 2008), the revision also attracted praise for being a stable diagnostic tool (Moss et al. 2008) and module 4 having very good sensitivity and specificity (Hus and Lord 2014). Good agreement rates with other tools have also been found which support the amendments, e.g., with CARS (Pilowsky et al. 1998; Saemudsen, Magnússon and Sigurdardóttir 2003), DISCO (Nygren et al. 2009), SRS (Constantino et al. 2003), 3di-sv (Santosh et al. 2009) and professional judgement (Mazefsky and Oswald 2006). Furthermore,

translations have found good validity and reliability in Bulgarian (Hill et al. 2001) and Spanish (Vrancic et al. 2002) versions, with moderate agreement found with a clinical diagnosis in Greece (Papanikolaou et al. 2009). In addition to this, the ADI-R remained a stable diagnostic instrument when conducted on the telephone, with no differences found in the diagnostic algorithm or the diagnosis reached (Ward-King et al. 2010).

However, there are still issues with this revision. Overdiagnosis within certain groups, e.g., the severely mentally handicapped (Lord et al. 1993; Lord 1995) has been observed, and likewise underdiagnosis in others such as 'high-functioning', verbal individuals (Boelt and Poutska 2000) and young children (Lord 1995; Cox et al. 1999). Poor sensitivity rates have been reported (Matson et al. 2010b) and De Giacomo et al. (2009) found that it detected only 39% of verbal and 61% of nonverbal children. This tool has been further criticised for its potential to be influenced by parental bias (Klinger and Renner 2000; Mildenberger et al. 2001) and, although short, it still takes a substantial time to complete (Klinger and Renner 2000). It was also found to have poor-to-fair agreement with other measures including clinical judgement (Wiggins and Robins 2008).

In summary, despite these diagnostic tools showing some robustness and revisions helping to combat some of their weaknesses, there remain some issues with even the most widely used tools. None of the tools consistently and correctly diagnose every person on the spectrum, which further illustrates the difficulties with the diagnostic process. The scales and interviews are open to bias if the individual (or their family) potentially seeks to gain or avoid a diagnosis. This emphasises the need for a combination of these tools with observational measures to help provide more accurate diagnoses. Furthermore, it may be that working in an environment that can support a greater degree of interaction, as will be demonstrated within the iA 'pod', allows for some of these weaknesses to be challenged. This could potentially

remove bias and provide further information on those who the existing tools currently struggle to diagnose, thereby helping aid the diagnostic process.

## Observational Tools

Observational tools constitute another key area in the diagnostic process and involve making observations of the individual. This may be within a naturalistic setting, e.g., at school or home, or in a clinical setting. Some of these tools are autism-specific e.g. the Autism Diagnostic Observation Schedule (ADOS) (Lord et al. 1989), the Autism Observation Schedule for Infants (AOSI) (Bryson et al. 2008) and the Behaviour Function Inventory (BFI) (Adrien et al. 2001). Some are used to distinguish autism from ID and typically developing (TD) children, e.g., the Behavior Observation Scale (BOS) (Freeman et al. 1980) (see Table 3 for a summary).

name and authors	target group	to be completed by	length
<b>OBSERVATIONAL TOOLS</b>			
Autism Diagnostic Observation Schedule (ADOS) (Lord et al. 1989) further revisions include: the Pre-Linguistic Autism Diagnostic Observation Schedule (PL-ADOS) (DiLavore, Lord and Rutter 1995); the Autism Diagnostic Observation Schedule-Generic (ADOS-G) (Lord et al. 2000); Autism Diagnostic Observation Schedule-Toddler (ADOS-T) (Luyster et al. 2009); Autism Diagnostic Observation Schedule-2 (ADOS-2) (Lord et al. 2012)	ADOS: 6-18 years  PL-ADOS: less than 3 years  ADOS-G: young children to adults  ADOS-T: children under 30 months  ADOS-2: 12 months to adults	trained professional	PL-ADOS: 17 ratings ADOS-G: 28-31 ratings depending on module ADOS-T: 41 ratings ADOS-2: 29 to 41 ratings depending on module
Autism Observation Schedule for Infants (AOSI) (Bryson et al. 2000 in Bryson et al 2008)	6-18 months	trained professional	18 items
Behavior Observation Scale (BOS) (Freeman et al. 1980)	children (autistic, ID and TD)	trained professional	67 defined behaviours
Behaviour Function Inventory (BFI) (Adrien et al. 2001)	children	trained professional	longitudinal observation (over two days)

*Table 3: summary of some of the observational tools used for the diagnosis of autism*

Support has been found for observational tools, e.g., the ADOS had the highest sensitivity rate when compared to clinical judgement (Wiggins and Robins 2008) and the AOSI had good to

excellent inter-rater reliability (Bryson et al. 2008). There have been several subsequent revisions of the ADOS, which is often described as one of the 'gold standard' tools. These have helped to tackle a variety of issues, e.g., the PL-ADOS was developed to focus on children younger than six who were not using phrase speech. The activities were made to be shorter, and more flexible and allowed the children to move freely around the room. This was found to have good reliability (DiLavore, Lord and Rutter 1995). The ADOS-G was adapted for use in a clinical setting. The demographic was extended, with four modules used for different language abilities and developmental levels. Very good agreement was found between a team diagnosis and the ADOS-G (Mazefsky and Oswald 2006). The ADOS-G was found to have high sensitivity and specificity for the diagnosis when translated into Greek (Papanikolaou et al. 2009). Excellent inter-rater and test-retest reliability was found for the ADOS-T (ADOS-Toddler) (Luyster et al. 2009). When revisions were made to the ADOS algorithms, similar sensitivity and specificity ratings to the original ADOS were found (Gotham et al. 2007). Oosterling et al. (2010) found that the predictive validity for autism increased, as well as for ASD cases as a whole. However, this was not the case for participants tested using module 1 or with a mental age of less than fifteen months. For non-autism ASD cases, there was less consistent improvement in predictive validity. When looking at developing a severity metric (as introduced in the ADOS-2), it was found that new scores were less influenced by verbal IQ, and a greater comparability of scores across age, module and time were found (Gotham, Pickles and Lord 2009). The ADOS-2 had increased sensitivity and specificity rates in comparison to the original and was praised for its inclusion of the toddler module, to which enhanced the population it could be used on (McCrimmon 2014).

There have been issues raised with the observational tools, including the lengths of time taken to administer them. For example, the fact that the BFI is longitudinal makes it impractical for use as a routine clinical instrument (Adrien et al. 2001). Some of the tools have been criticised for questionable validity and reliability, e.g., the BOS was discovered to only have

validity and reliability in initial studies (Parks 1983). Another issue is the fact that only a snapshot of behaviour is seen (aside from in the BFI), with a failure to incorporate parental interview, something introduced as necessary in DSM-IV (Klinger and Renner 2000). The ADOS has been criticised for its brief administration period, one which is not always adequately long for restricted and repetitive behaviours to be displayed (Allen, Robins and Decker 2008). The use of the ADOS (and ADI-R) was rare in Latino, Spanish-speaking communities, possibly because of its expense, time involved and the extensive training and supervision period required (Williams, Atkins and Soles 2009).

In conclusion, despite some of these diagnostic tools, particularly the ADOS and various revisions, being widely used and producing good results, there are still issues with them, a significant one being that the tools tend to focus on a snapshot of behaviour, and so does not present a complete view of the individual. Ideally the observations should be carried out in multiple settings, not just in the clinical setting used in the ADOS, as this will help capture more accurately the range of behaviours of the individual. The research underlying this thesis involved an alternative environment to the clinical one. As this space is unusual and entirely new for the participants, as well as being responsive, following their lead, it may help to reveal more about the behaviour of the individual than established clinical methods are able to.

The above review of screening and diagnostic tools for autism has shown an ongoing process of their being developed in order to improve the diagnostic process. The continual changing of labels and criteria reflects a growing understanding of the condition but also illustrates that, as yet, there is no single, complete definition of autism, nor a diagnostic tool that can identify it with 100% accuracy. This means that the diagnosis must rely on a range of tools and experienced clinician(s) to give a 'best estimate diagnosis', placing importance on the expertise of the diagnosing team. As has been demonstrated, it is important to use a range of

tools to gain information about the individual for use in the diagnosis. One cannot rely on screening tools for the diagnosis as they tend to have low sensitivity, pointing to the need for further investigation. Relying purely on scales and interviews opens the process up to parental or individual bias and depending solely on an observation tool does not provide a complete, historical account, offering only a snapshot of behaviour. It would therefore be most appropriate and efficient to work with a combination of the three measures, using tools that have robust research support, e.g., the ADOS and ADI-R. It may also be that the alternative models, as discussed in Chapter 1, can not only provide further information about autism beyond that offered by the scientific and medical models, but also help this information filter into the diagnostic process. Providing additional information for diagnosis from participants engagement in the iA 'pod' would not only be useful for the actual diagnostic process, but may help to shift focus to a strength- rather than deficit-based model, this possibly being useful for the individual and their parents.

## **Current UK Diagnostic Practices**

This chapter has thus far explored the history of autism diagnosis, including an examination of the tools available for diagnosis. Its focus will now shift to current diagnostic practices within the UK. The numbers of autistic people being diagnosed has been increasing and in the UK the number of autistic children who have an Education and Health Care Plan has grown considerably from 44,000 in 2012 to 57,211 in 2016 (Evans 2017: 415).

Where individuals live within the country affects which diagnostic manual is used (ICD v. DSM), meaning that the label given to an individual will vary based on location. In an area where the DSM-5 is used, the diagnosis would be ASD, whereas in areas where the ICD-10 is used it is still possible to get a variety of diagnoses, e.g. autism, Asperger's and PDD-NOS. The referral for the diagnosis usually occurs through a GP and patients should be sent to an

individual specialist, although the diagnosis should be carried out by a multidisciplinary team, as outlined in the National Institute for Health and Care Excellence (NICE) guidelines. In Kent the autism pathway for individuals under 18 has four stages: initial concerns (parents/carers should bring these to attention of the professionals they are in contact with); gathering information (e.g., from their educational setting); initial screening/assessment (carried out by professionals using a range of tools); and diagnosis ('the assessment route followed is age dependent and can vary across geographical locations') (Kent County Council 2017: 5). Despite efforts by the NHS to improve the diagnostic process, interviews with NHS staff revealed that they did not feel they had enough time to diagnose properly, with 42% of them reporting use of clinical judgment, rather than any specific criteria, to aid the diagnosis. There was also found to be a variation in the diagnostic terms used, with Asperger's often used to 'soften the impact of diagnosis' (Karim, Cook and O'Reilly 2014: 120).

As mentioned previously, the 'gold-standard' diagnosis is generally considered to be a combination of the ADOS and the ADI-R, this helping to provide 'a greater level of diagnostic clarity' (Le Couteur et al. 2008: 269), with evidence supporting the use of these tools in conjunction with each other (Gray, Tonge and Sweeney 2008). Studies have found good agreement for autism diagnosis between the two measures, with the best agreement being for the non-ASD or 'other' group (Le Couteur et al. 2008). This has been further supported with both the ADOS-G and ADI-R being translated into Greek, satisfactory and moderate levels of agreement being reported (Papanikolaou et al. 2009).

However, issues have been found with the use of these two tools in the differential diagnosis between autism and specific language impairment (Leyfer et al. 2008). Luyster et al. (2009) raised issues with the ADOS which could also be applied to other diagnostic tools, specifically that reaching a cut-off (or failing to) does not necessarily indicate a diagnosis (or missed diagnosis) and that a clinician's judgement is of huge importance. Similar concerns have

been expressed by others, with Prior et al. (1998) suggesting that clinical consensus is the 'gold standard' and differential diagnosis by experience professionals is best (Charman and Baird 2002).

Further issues have been raised with current diagnostic practices, particularly in relation to the diagnosis of females (who are argued to be underdiagnosed) either being misdiagnosed or missing out on a diagnosis completely (NAS 2012). This is partly due to 'masking' or camouflaging behaviours (NAS 2012; Hiller, Young and Weber 2016; Attwood 2017; Dean, Harwood and Kasari 2017; Hull et al. 2017) which can make a female appear to have no, or less, autistic symptoms. A reduction in the appearance or severity of symptoms may cause reluctance to seek help or diagnosis, or for clinicians to be less willing to diagnose a female, particularly if she does not deviate far from the behavioural norms (Attwood 2017). It has been found that, on average, females wait longer to receive a diagnosis (Goin-Kochel et al. 2006; Siklos and Kerns 2007; Beeger et al. 2012). In addition to this, females appear more social (scoring similarly to TD males), which could, to a 'naïve' clinician, mean missing a diagnosis because the females demonstrate social skills that would suggest that they are not on the spectrum (Head, McGillivray and Stokes 2014). This shows the importance of clinicians understanding the more complex needs of autistic females and being able to pick up on the subtle symptoms or spot the camouflaging techniques employed by some. It may be that engaging within the drama environment explored in this research can offer further opportunities for more complex interactions, e.g., with multiple forms of social communication with different people, which could cause the masking behaviours to stop and the autistic traits to emerge, allowing a more accurate representation of the individual's behaviour to be demonstrated.

## **Conclusion**

As has been demonstrated in this chapter there is a continual evolution in the understanding of autism which, although becoming more refined, still has areas of incompleteness. The fact that there is currently no single known cause (and that one is unlikely to be found in the near future) means that diagnosis has to rely on behavioural measures which, as has been demonstrated, can be problematic. As discussed in Chapter 1, the dominant construction of autism is within the medical and scientific fields, which is where most of the diagnostic tools have been developed. While these have been essential in securing diagnoses for people thus far, it may be that engagement with the alternative constructions of autism (e.g., those issuing from the arts) could prove helpful for the diagnosis. The research underlying this thesis used engagement within a drama-based environment to help support one of the 'gold standard' tools, the ADOS-2, at the same time seeking to expose any alternative behaviours that are not currently captured by this tool or the diagnosis more widely.

## CHAPTER 3: METHODOLOGY

The previous two chapters considered autism both through a historical analysis of the condition and as part of a variety of models. These are both important to how autism is currently perceived and help to contextualise the thesis research. The present chapter will introduce in more detail the research that was conducted for this thesis, which, while drawing on established diagnostic practices, offers an alternative way to assess autism. The chapter will be presented in a format which is more familiar to psychology researchers, although it will refer back to the drama-based practices discussed in the Introduction where relevant.

This chapter starts with a presentation and brief discussion of the research questions that underpinned the project. The research design and settings are introduced, with the setup and content of the iA environment discussed in more detail, including a consideration of how the practitioners are trained. The chapter then moves on to the recruitment procedures and a discussion of the participants. The measures that were used for the research are presented: the ADOS-2; the diagnostic performance tool (a novel<sup>113</sup> coding tool); and the practitioner form. Part of this discussion will include a review of how the diagnostic performance tool was developed, as well as a presentation of the testing data. The production of this was influenced by the ADOS-2 and the DSM-5, allowing it to align with current diagnostic criteria, as well as taking inspiration from an established tool used within the creative practice 'Sounds of Intent'<sup>114</sup>. The procedure used in the research is then presented. the ethics discussed, and analysis of the

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<sup>113</sup> This refers to a tool that has been developed for the purpose of this research, which although influenced by diagnostic criteria and the established tools, is an original construction.

<sup>114</sup> This is a tool which assesses musical development in children and young people with learning disabilities, including autism (see <http://soundsofintent.org/>). It is used to evaluate behaviour based on work within a creative medium, as supported by research (Welch et al. 2009; Welch and Ockelford 2010; Vogiatzoglou et al. 2011). The tool has three levels of interaction which assess the response in increasing levels (reactive, interactive and proactive). Within each of these, there are further numerical classifications (1-6), which evaluate the level that the individual reaches within the level of interaction. For example, a P3 assessment would mean that the individual has a proactive response and 'makes simple patterns in sound intentionally through repetition or regularity' (from the *Sounds of Intent* booklet).

project conclude the chapter.

## Questions

The research has four questions that it sets out to explore:

1. Can engagement in the play- and drama-based environment iA enhance the profile of strengths, difficulties and differences that are found within children on the autistic spectrum in comparison to the ADOS-2?
2. Can the ADOS-2 coding be completed in a different environment to the clinical one?
3. Is there agreement between the ADOS-2 scores in the clinical and drama-based settings?
4. Does engagement with iA provide information about the individual, based on their interactions, that is not demonstrated in the current diagnostic setting?

The main research question (question 1) will compare behaviour demonstrated in this environment to the behaviour manifested as part of the clinical diagnosis using the ADOS-2. Previous research into iA has demonstrated potential benefits for autistic children, e.g., in social communication, interaction and emotion recognition (Beadle-Brown et al. 2017). Furthermore, evidence has emerged which contrasts with the perceived deficits of, and difficulties for, people on the autistic spectrum, particularly when compared to diagnostic criteria, e.g., creativity and imagination (Trimingham and Shaughnessy 2016; Trimingham in press; Shaughnessy 2016a) and joint attention (Trimingham and Shaughnessy 2016), as well as showing these to be potentially useful means to aid communication with autistic people and help with certain skills (Trimingham and Shaughnessy 2016). While the participants in the AHRC iA project all displayed autistic behaviour, it may be that engagement within the drama environment elicits examples of different behaviours that would demonstrate strengths and skills not evident in current diagnostic situations.

The secondary questions (questions 2, 3 and 4) are also important as they can contribute to the diagnostic process by exploring how different diagnostic environments can affect diagnostic scoring. This allows for the exploration of additional information about the individual in question which would enable a more holistic profile and thus potentially have positive implications for diagnostic practices. Furthermore, it may provide additional support for the use of the ADOS-2 while extending its use outside of a clinical environment.

## **Design**

This research is an exploratory study using a repeated measures design<sup>115</sup> based on observational methods. The behaviours of the participants were compared across two different environments through data collection from the ADOS-2. The clinical ADOS-2 was conducted by an NHS professional externally to the research. The data thus detailed was compared to the ADOS-2 scores after participants engaged in the iA drama-based environment measured by the thesis author. Further qualitative data was obtained from the diagnostic performance tool to provide supplementary information about the participants.

## **Settings**

The research occurred at the University of Kent in Canterbury within the iA pod (see the Introduction for a discussion of this). The behaviour demonstrated by participants was compared to the information obtained by diagnostic reports carried out by NHS professionals within the East Kent Hospitals University NHS Foundation Trust as part of standard diagnostic procedures. The clinical environment was unaffected by the research and the author did not

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<sup>115</sup> This is where 'each participant experiences all levels of the independent variable' (Coolican 2009: 79).

influence how these were conducted – only the diagnostic letters and, where possible the ADOS-2 algorithms (described later in the chapter) were retrieved.

The iA environment was contained in a structure known as ‘the pod’ (see the Introduction for a description of it). The particular environment that was selected for this



*Figure 2: The exterior of the pod.  
Photo courtesy of Matt Wilson at the University of Kent.*

research was the Arctic. This environment was the only one of the five used within iA that was white; whereas the others used black material to cover the structure. The metal structure of the pod was covered in white material with a white tarpaulin floor (see Figure 2). Inside the pod LED lights were set up on T-stands at two corners and were

controlled within the space, meaning that the participants could alter the lights should they wish. When the participants entered the environment the lights were set to a blue/green wash. Additional lighting states occurred during the sessions, including flashing from light to a blackout as part of a stimulated storm and a warm wash (pink/orange) to indicate the end of the session. A sound system was also set up within the pod with two speakers which, again could be operated by the participants through an easy-to-use programme, Q-CART, running on a Mac laptop. In addition to this there was a microphone which was often hidden under some material for participants to find. This had a slight reverb on it so that the voices were mildly distorted. A projector was set up on one of the pod walls. When the participants entered the pod this was projecting an animated snowfall, which could be switched to a live-feed projection of the pod during the session. To record the sessions there were four static cameras (including the live-feed one) which were attached near the four corners of the space to capture the whole area within the pod. In addition to this, a small hand-held camera was operated by a practitioner who could document interactions close-up as well as any action that occurred outside of the pod.

In addition to the technical elements the pod was decorated with scenery and props to complement the environment (see Figure 3). White camouflage netting hung from the roof to create a 'cave' which was filled with soft material (e.g., blankets), hats and toy penguins. A 'pond' was set up on one side (made from a reflective silver material that is sometimes worn after endurance sports events). Several cardboard fish painted with



*Figure 3: The interior of the pod.  
Photo courtesy of Matt Wilson at the University of Kent.*

fluorescent colours were placed in the pond. There was also a tunnel and smaller tubes covered in white material. In addition to this, there was a plethora of shredded and torn paper and some soft snowballs strewn around the space. The environment also contained an assortment of characters (discussed below) which worked alongside the participants using different modes of communication, both verbal and nonverbal to suit the communication style of the participants.

The pod was set up inside a larger studio space at the University of Kent with enough room so that the participants could easily move around the pod's exterior, and a clear entrance and exit from the pod. Three studio spaces were used (one space was used only once) dependent on availability. In the two main studio spaces the insides of the pod were laid out as mirror images of each other to ensure access to a fire exit. Ideally the participants would have experienced the same studio space twice but this was only possible for one participant (Harriet<sup>116</sup>).<sup>117</sup>

The Arctic environment was selected for this research for several reasons. This environment was the lightest one available. Anticipating that some participants might experience anxiety about entering unfamiliar spaces (not only the pod, but also the University

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<sup>116</sup> All participants' names have been changed.

<sup>117</sup> Retrospectively, this did not appear to have caused issues for the participants, with one participant commenting on the change of space and pointing out the differences, to which the practitioner responded that the storm had caused them to have to move things around.

campus) and working with strangers, it was decided that a lighter environment might help alleviate any potential issues.<sup>118</sup> In addition to this, the most established slapstick character (the Snowman) who had been popular in the AHRC iA project for his comic value, was present. The presence of this character may have helped to encourage engagement because of the enjoyable nature of slapstick, as witnessed in participants in the AHRC iA project and noted in research. The Arctic environment also included characters with different levels of communication to support the variety of communication levels present in the participants.

A crucial aspect of the environment was the role of the practitioners. A pool of practitioners was recruited via an applied theatre lecture and workshop given at the University by the author, or through having expressing interest in iA. The practitioners were current or recently graduated drama students from the University who had experience in applied theatre contexts, some with experience of working with autistic children. An adapted version of some of the training from the AHRC iA project<sup>119</sup> was used and taught either by the author or by external practitioners with expertise in that area.<sup>120</sup> The training sessions that were offered to practitioners for this research were an introduction to autism, puppetry, clowning and working in an ensemble. The training sessions helped to support the techniques that were used in the iA environment as discussed in the Introduction (e.g., play, turn-taking, liveness [or presence,] etc). As the practitioners were drama students from the University, they already had a particular way of working which gave them some of the basic skills required for this practice (e.g., devising and ensemble work). Some of the practitioners had been involved in the rehearsal sessions offered

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<sup>118</sup> It should be noted that within the AHRC iA project anxiety about entering the space due to its darkness was not an issue. However, as this research environment was going to be unfamiliar in comparison to the pod being set up in the participants' school hall with their peers, it was felt that this environment might be preferable.

<sup>119</sup> The training for the AHRC iA project was based on *Elements of Performance Art* (Howell and Templeton 1977) by The Ting: Theatre of Mistakes. For a discussion of the training used in the AHRC iA project, see Trimmingham in press, Shaughnessy 2016a and 2016b.

<sup>120</sup> The puppetry session was conducted by Peter Morton, a puppet specialist <http://www.peter-morton.co.uk/>, and the ensemble session by Judi Vivas a physical theatre artist <https://www.judita-vivas.com/>.

to members of the public. There was a pool of seven practitioners, although only two or three were required for each session. The practitioners were unpaid and mostly students, which affected their availability for the research (see Table 4).<sup>121</sup>

participant	session 1							session 2						
	practitioner initial							practitioner initial						
	AH	CN	JB	RW	SC	TH	VJ	AH	CN	JB	RW	SC	TH	VJ
1 - David	X		X				X	X						X
2 - Harriet	X					X				X	X			X
3 - Annabelle						X	X			X				X
4 - Ed	X					X				X				X
5 - Amy						X	X			X				X
6 - William	X						X	X						X
7 - Megan	X						X	X						X
8 - Emma		X					X		X			X		X

Table 4: the practitioners present in each session

The practitioners performed as various characters: the Dog; Inuit; Penguin; and Snowman (see Table 5). These characters all had full-body costumes, some having masks: the Dog had a mask that sat on top of the head and the Snowman had an orange nose, not dissimilar to a clown's red nose. The Inuit was verbal and offered more developed narrative and higher levels of verbal communication. The Penguin, Snowman and Dog communicated without language, instead using sounds and physical communication.

<sup>121</sup> Ideally, the participants would have worked with the same practitioners.

participant	session 1				session 2			
	D	I	S	P	D	I	S	P
1 - David	X	X	X		X	X		
2 - Harriet		X	X			X	X	X
3 - Annabelle		X	X			X	X	
4 - Ed		X	X			X	X	
5 - Amy		X	X			X	X	
6 - William		X		X		X		X
7 - Megan		X		X		X		X
8 - Emma			X	X		X	X	X

Table 5: the characters who were present in each session: D = Dog, I = Inuit, S = Snowman and P = Penguin

In addition to the practitioners there was also a technician (a drama student) and a camera operator (a psychology student). Both had experience of working with people with special needs and as they were interacting in a different way to the practitioners (to be discussed in Chapter 5), they did not participate in the training sessions (see Table 6).

session one					
participant	number of practitioners	author present	camera operator present	technician present	total adults present
1 - David	3	Y	N	N	4
2 - Harriet	2	Y	N	N	3
3 - Annabelle	2	Y	Y	Y	5
4 - Ed	2	Y	N	N	3
5 - Amy	2	Y	Y	Y	5
6 - William	2	Y	Y	Y	5
7 - Megan	2	Y	Y	Y	5
8 - Emma	2	Y	Y	N	4

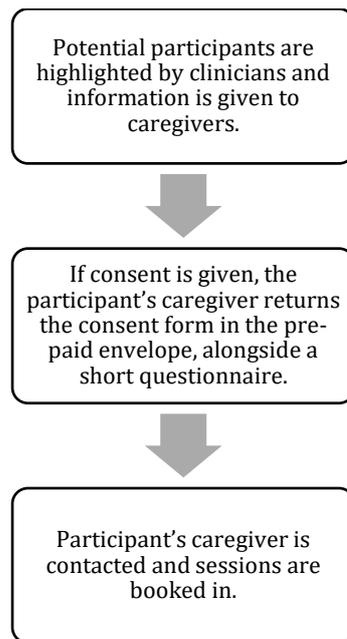
session two					
participant	number of practitioners	author present	camera operator present	technician present	total adults present
1 – David	2	Y	N	Y	4
2 – Harriet	3	Y	N	N	4
3 – Annabelle	2	Y	N	N	3
4 – Ed	2	Y	N	N	3
5 – Amy	2	Y	N	N	3
6 – William	2	Y	Y	Y	5
7 – Megan	2	Y	Y	Y	5
8 – Emma	3	Y	N	N	4

*Table 6: the number of adults (and who they were) present for each session*

The techniques that were used within the environment were those discussed in the Introduction: play; turn-taking; liveness (or presence); open space; physicality; improvisation; working as an ensemble; and puppetry.

## **Recruitment**

Staff within the NHS who were involved with the diagnostic process initially recruited the participants. They identified potential participants based on the inclusion criteria (to be discussed below) and distributed information packs (see Appendix 1) and consent forms to them. These were either given to the accompanying adult of the potential participant during standard meetings as part of the clinical diagnosis, or were sent to their home address. If they chose to participate the consent form was returned in a pre-paid envelope with a short questionnaire about the participant. The author then responded to them answering any questions they had and, if they were happy to proceed, booked them into the research sessions.



*Figure 4: recruitment process for the research*

## **Participants**

There were eight participants, aged between three and eleven years old (mean age = 7.5, age range = 3:11-11: 8).<sup>122</sup> There were three male participants (37.5% [mean age = 5:4, age range = 3:11-6:5]) and five female participants (62.5% [mean age = 8:7; age range 7:2 -11:8]). All had been through the diagnostic process for autism within East Kent NHS services. To take part in the research they needed to have been assessed for autism within the last twelve months. However, due to the participants availability to attend the drama sessions, for some the participation in the research occurred slightly over this period. The only exclusion criteria were if participants had a severe visual impairment (as the pod is not currently configured for this) or if they had no or poor understanding of English (as participants needed to be able to understand practitioners' instructions). As the participants were under the age of twelve, informed consent was sought from their parents/guardians. The participants were all recruited by NHS staff and of the twelve who returned consent forms, eight (66.7%) completed the sessions. Of the four

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<sup>122</sup> More information about the participants is presented in Chapter 4.

who did not, one participant chose to drop out because the environment was too juvenile for him, one person returned the form once the practical sessions had finished and two did not return contact after various attempts from the author.

## **Measures**

There were three measures that were used within this research, all observational tools for collecting data: the ADOS-2; the diagnostic performance tool; and the practitioner form. The first two were the main tools for collecting data with the practitioner tool being used to provide supplementary information to support these.

### **ADOS-2**

The ADOS-2 (Lord et al. 2012) is a standardised, semi-structured observational tool that is designed for use in the context of 'natural' social interactions. This tool is used as part of the diagnostic process for autistic individuals frequently used in the UK and is commonly referred to as the 'gold-standard' of diagnostic tools (see Figure 5 for a flowchart of the ADOS-2 process). The assessment usually occurs in a one-on-one interaction between the examiner (a trained individual) and the examinee (the individual who is going through the assessment), although for module 1 a caregiver is also present. There are four modules available, based primarily on the individual's expressive language level and secondarily on their chronological age (Pre-Verbal/Single words; Phrase Speech; Fluent Speech Child/Adolescent; Fluent Speech Adult), for use in children aged thirty-one months to adults, and an additional toddler module for younger children (twelve to thirty months). Each assessment has a module booklet comprising three sections. The first section is a series of semi-structured observation tasks or 'presses' through which the examiner guides the individual. These presses are designed to give the individual the greatest possible opportunity to demonstrate their skills. There is a mixture of structured and less structured 'presses'. The second part is the coding section, in which ratings are assigned to

the individual immediately after the assessment and are based on the observations made during the interaction. The individual's behaviour is standardly scored from 0 (not abnormal) to 2 or 3 (very abnormal). There are other scores used (4, 7, 8 and 9) for some of the codes which denote either specific language abilities, an item which is problematic to code for several reasons or the presence of atypical behaviours that are not specified (McCrimmon 2014). For example, in code A5 in module 1 'stereotyped/idiosyncratic use of words or phrases', an individual can be scored with an 8 if their language is too limited to judge. The third section of the ADOS-2 is the algorithm section wherein the item codes are converted into algorithm scores. These algorithm scores are divided into two areas, social affect and restricted and repetitive behaviours, these giving two individual totals that, when added together, create the overall total used to arrive at the ADOS-2 classification (non-spectrum, autism spectrum and autism). In addition to this, a comparison score is made, based on the age of the individual, which gives a level of autism spectrum-related symptoms (minimal-to-no evidence, low, moderate and high). The ADOS-2 assessment results in the subject being given a classification and a severity level.

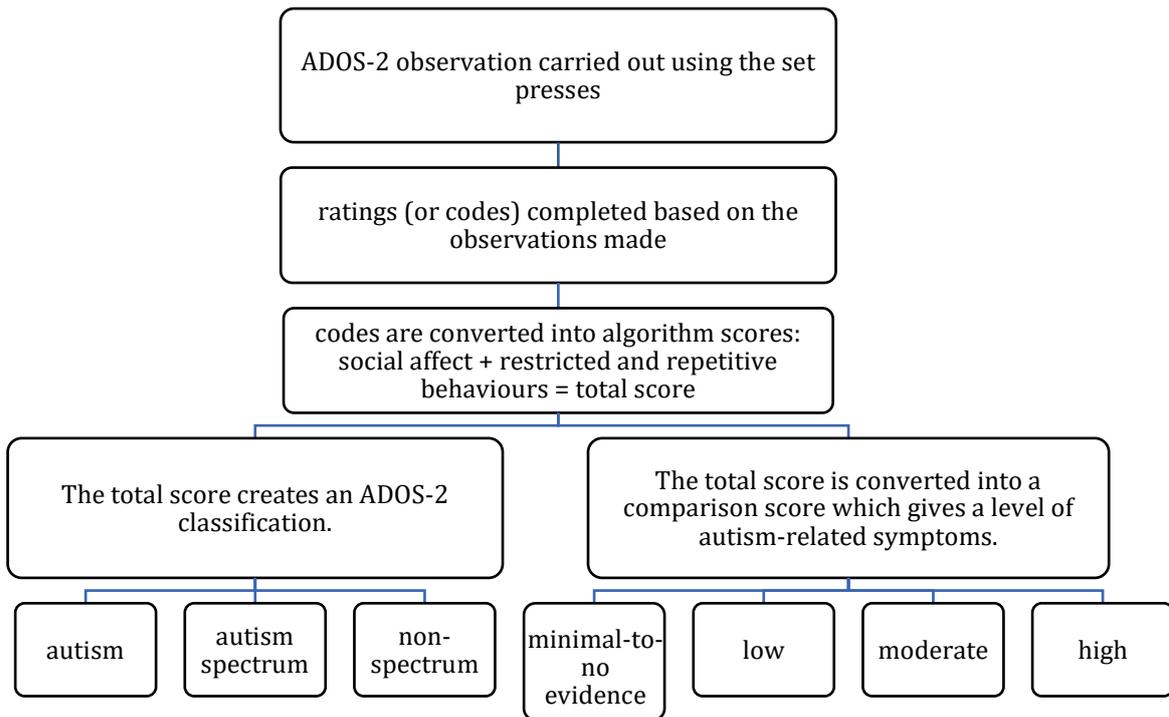


Figure 5: flowchart showing the process of scoring on the ADOS-2

## Diagnostic Performance Tool

This tool was developed specifically for the needs of the project as there was not a suitable one readily available that would encompass all the behaviours participants might demonstrate based on observations in the AHRC iA project. However, the ADOS-2 and the DSM-5 were analysed and used to provide a foundation for the new tool. This meant that the behaviours that would be captured by it could be used for the diagnosis, as they were grounded within current diagnostic practices and tools, allowing the new tool to be meaningfully compared to the clinical ADOS-2 and the subsequent diagnosis.

Prior to the initial development of the tool, live observations of clinical ADOS-2 assessments were carried out by the author at Kent and Canterbury Hospital (also where the participants for the research were recruited). The clinician observed was part of the diagnostic

team that was likely to carry out the clinical ADOS-2 for some of the participants recruited.<sup>123</sup> Four ADOS-2 assessments were observed, as well as the subsequent clinicians' discussions about diagnostic outcomes (as other members of the diagnostic team had used different diagnostic methods) and the conversations with the parents/guardians revealing the outcomes. This provided first-hand experience of how the ADOS-2 is completed and of its role in the wider diagnostic process within the NHS. In addition to this, videos of the research ADOS<sup>124</sup> assessments that were carried out as part of the AHRC iA project were viewed. This provided experience of viewing the ADOS as part of a research setting as opposed to the clinical one, as well as providing the opportunity to see how different people conduct the ADOS. This was particularly important as it was highly likely that the participants would be diagnosed by different clinicians. Furthermore, the author had a working knowledge of the behaviours demonstrated by participants in the iA environment, having worked on the AHRC iA project as a technician/facilitator in the third school, Helen Allison.

### ***Development of the tool***

The initial development began with an analysis of the DSM-5 and the ADOS-2, using a combination of both to help provide a framework to analyse behaviours and to ensure that the tool would match diagnostic criteria. The ADOS-2 was selected as it is an observational tool that is facilitated through a play-based interaction, which has some basic similarities to the iA environment approach. In addition to this, another framework, Sounds of Intent, an established tool that evaluates creative work, was used as a further scaffold to support the creative medium in which the observations for this research were occurring.<sup>125</sup> This tool was selected as it is one of few readily available that has been used to create a structured evaluation of a creative environment. The diagnostic performance tool went through seven revisions (a summary of the

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<sup>123</sup> This clinician carried out the clinical ADOS-2 assessment for four (50%) of the participants.

<sup>124</sup> The AHRC iA project used the ADOS as opposed to the ADOS-2, as the latter had not yet been published.

<sup>125</sup> This tool will be discussed later in Chapter 5, to provide a scaffolding for analysing the qualitative data.

original version and subsequent revisions are contained in Table 7), with testing completed between each revision using footage of the AHRC iA project. The footage used for the testing was from the final school, as this was when the techniques of the project had been most fully realised, as well as the footage being of the highest quality.

coding version iteration	key revisions made to the diagnostic performance tool
1	<ul style="list-style-type: none"> <li>- <i>Sounds of Intent</i> headings used</li> <li>- 'X' marked the range of behaviours seen</li> </ul>
2	<ul style="list-style-type: none"> <li>- <i>Sounds of Intent</i> headings removed and replaced with a numerical score based on the amount of behaviours demonstrated</li> <li>- more detailed descriptions provided of behaviours</li> </ul>
3	<ul style="list-style-type: none"> <li>- <i>Sounds of Intent</i> headings incorporated and combined with a numerical score</li> <li>- some divisions to certain behaviours to record differences between response to another child and a practitioner</li> <li>- divided into 'criteria according to DSM-5' and 'additional areas of interest'</li> </ul>
4	<ul style="list-style-type: none"> <li>- two documents created for 'diagnostic criteria' and 'additional material'</li> <li>- further division in relevant categories to record different responses to a practitioner as 'practitioner as themselves and not character/puppet'</li> <li>- incorporation of coding for ability to adapt to changing environment under RRB</li> <li>- incorporation of interaction with other (e.g. character, puppet and media) in relevant categories</li> <li>- the 'stereotyped or repetitive movements' condensed into one category not viewing it through interaction with another</li> <li>- removal of 'ritualised behaviour'</li> <li>- embody of characters divided into another person, character and puppets</li> </ul>
5	<ul style="list-style-type: none"> <li>- In additional material, notes on behaviour that demonstrated 'empathy' and 'humour' were incorporated.</li> </ul>
6	<ul style="list-style-type: none"> <li>- some shift in ordering</li> <li>- some minor adjustments to language</li> <li>- additional material divided into communication and interaction and creativity and imagination</li> </ul>
7	<ul style="list-style-type: none"> <li>- data collection amended so that no numerical data was collected, instead focusing on collecting qualitative data</li> <li>- removal of <i>Sounds of Intent</i> headings, instead focusing on 'presence' or 'absence' of behaviours</li> <li>- adjustment of headings in diagnostic criteria to match DSM-5</li> <li>- more positive language used</li> <li>- in additional information profile, headings were reworked and an additional section incorporated</li> </ul>

Table 7: the key revisions of the diagnostic performance tool

For the first version (see Appendix 3) a list of behaviours which feature in the ADOS-2

and diagnostic criteria was compiled. A list of other behaviours was also devised comprising those that had been present within the AHRC iA project but not found in the current ADOS-2 diagnostic process. This would ensure that the diagnostic assessment could be completed within the iA environment, as well as providing further information that would potentially aid the diagnostic process. In addition to this, the levels that are employed within the Sounds of Intent framework (reactive, interactive and proactive – see Appendix 2) were used to help evaluate the levels of interaction that participants showed. Although Sounds of Intent was designed for auditory engagement, part of the process of developing the tool included testing the viability of its use in another creative environment that was not exclusively auditory.<sup>126</sup> This framework evaluates responses to a creative stimulus through behavioural observation. In the original version the creative stimulus was music, but the same framework can be mapped onto behavioural responses to the drama environment, relying on similar behavioural cues that would likely be demonstrated to show the varying engagement levels of an individual. This would enable behaviours to be teased apart, allowing a deeper evaluation of any given action through the levels than is currently possible within the ADOS-2. The initial coding marked when a behaviour was seen and subsequently analysed in the table by using an 'X', meaning that a child could be marked as displaying examples of interactive and proactive behaviour for a single behaviour code.

The testing demonstrated that although the headings for behaviours were useful, there were issues with the lack of ability to ascertain how many examples of each level of behaviour were shown. For example, a child may have demonstrated just one example of proactive behaviour, but many of interactive. When using this coding framework and focusing on the highest level of attainment, it can therefore appear that the child has greater capabilities than they actually do as they have displayed both proactive and interactive behaviours, despite the

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<sup>126</sup> Astrid Breel (2017) has also used this framework as a model for assessing levels of agency in participatory performance.

fact that the majority of their engagement was at the interactive level. As it is plausible that a single example of behaviour can be coincidental, it was important to be able to rate the amount of behaviour demonstrated to enable a more accurate and effective assessment. In addition to this, to relate the tool more closely to the ADOS-2 a numerical value was attached to behaviours using a similar numerical scale to that of the ADOS-2 (0, 1 and 2), allowing a direct comparison between the two environments (clinical and iA). However, the numerical value was arrived at in a way that emphasised positive marking (within two of the three sections) so that skills received higher marks, rather than there being a focus on scoring abnormal behaviour, as seen in the ADOS.<sup>127</sup> Furthermore, more detailed descriptions were included in the headings of the behaviours to enable them to be identified more readily (see Appendix 4, for version 2).

After testing version 2 it was noted that the amount of behaviours demonstrated was not necessarily a useful measure, particularly within such a complex environment. It was therefore more beneficial to return to placing emphasis on the levels of interaction used within the Sounds of Intent framework as this would place emphasis on the quality rather than the quantity of the interactions. Further amendments included attaching a numerical score to the levels of interaction, so 'no behaviour displayed' was rated as 0, reactive as 1, interactive as 2 and proactive as 3. In addition to this, some of the headings were separated to explore the uniqueness of the creative environment and to attempt to isolate and analyse these behaviours more effectively, e.g., 'insistence on sameness' was divided into 'ritualised behaviour' and 'an inability to adapt to a changing environment'. Likewise, 'restricted interests' was divided into fixed interests related to the environment and fixed interests that were unrelated. The coding was clearly differentiated into two areas (criteria according to the DSM-5 and additional areas of interest) (see Appendix 5).

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<sup>127</sup> Although the scoring system employed matches that of the ADOS-2, inspiration was taken from the positive marking employed in the Sounds of Intent framework.

In version 4 (see Appendix 6) the coding was divided up more explicitly into two areas, allowing for a clearer distinction between the behaviours used for clinical diagnosis and the behaviours that were not. Further distinctions clarified the various roles that a practitioner could have within the environment. When referring to direct engagement with practitioners this was recorded as 'practitioner as themselves and not character/puppet', as the engagement with a practitioner out of role was akin to the clinician within the diagnostic setting, whereas the use of a character or puppet was supplementary, unique to this particular environment and explored in more detail within the 'additional information' category. Information about how stereotyped or repetitive movements were linked to interaction with others was found to be irrelevant so stereotyped or repetitive movements were viewed in terms of the participant's overall engagement with the environment. The 'ritualised behaviour' category was removed as superfluous since this behaviour could be identified through other codes. The 'embodying characters' were divided into additional sections (another person, character or puppet) to reflect the different ways in which participants could engage with practitioners and how the latter could embody characters in a variety of ways. This could also be used to record whether there was a preference shown by the child which could provide helpful information for future intervention.

In the fifth version (see Appendix 7), the only amendments were the incorporation of two new areas within the 'additional material' section: empathy and humour. These behaviours had been demonstrated by participants in the AHRC iA project (for a discussion of empathy see Trimmingham and Shaughnessy 2016b; for a discussion of humour see Trimmingham and Shaughnessy 2016a) and as they are perceived to be areas of deficit for autistic people<sup>128</sup>, their

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<sup>128</sup> e.g., the mindblindness theory (discussed in Chapter 1) and Asperger's recording a lack of humour in his initial patients

appearance in the drama environment challenges current understanding, particularly in ToM. These behaviours are also not fully explored within the ADOS-2.

In the penultimate version (see Appendix 8) there was a shift in the ordering of the codes and the 'additional material' section was divided into 'communication and interaction' and 'creativity and imagination'. This helped to make the framework clearer and easier to compare to the ADOS-2. Some minor adjustments to language were also made.

The final version (see Table 8 and Appendix 9) shifted the way in which the feedback was collected as it was clear that attaching a numerical value was redundant and that collecting qualitative data which could then be coded using the ADOS-2 codes, would prove to be more useful and allow the behaviours demonstrated within the creative environment to be explored in more detail. This is similar to the way that the ADOS-2 is completed. Additional revisions included the removal of the Sounds of Intent headings – while being useful in developing the tool, these were no longer productive to use as it was difficult to accurately assign a category for some of the behaviours. Instead, the presence or absence of behaviours was noted. The diagnostic criteria section was divided into the 'absence of normal developmental features (social communication and social interaction)' and the 'presence of abnormal developmental features (restricted, repetitive patterns of behaviour, interests or activities)'. This aligned closer to the DSM-5, incorporating some of the language that is used therein. However, the phrasing within the diagnostic section was specifically chosen to encourage a more positive view of the behaviours displayed so that there was a reduced focus on what the individual could *not* do. The 'additional information' profile saw amendments made to its headings and space incorporated for information on peer interactions, unusual skills, and attention and focus, as well as an additional section on abnormal responses which was based on the 'other abnormal behaviours' section within the ADOS-2.

<b>absence of normal developmental features</b>	
social communication and social interaction	social and emotional reciprocity
	non-verbal communication used for social interaction
	developing, maintaining and understanding relationships
<b>presence of abnormal developmental features</b>	
restricted, repetitive patterns of behaviour, interests or activities	stereotyped or repetitive motor movements, use of objects, or speech
	insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or nonverbal behaviour
	highly restricted, fixated interests that are abnormal in intensity of focus
	hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment
<b>additional information for profile</b>	
other observations of behaviours and skills	peer interactions
	interaction with other
	verbal communication
	functional play/use of objects
	imagination
	unusual skills
	humour
	empathy
other abnormal responses	attention and focus
	hyperactivity
	aggressive/destructive
any additional notes	anxiety

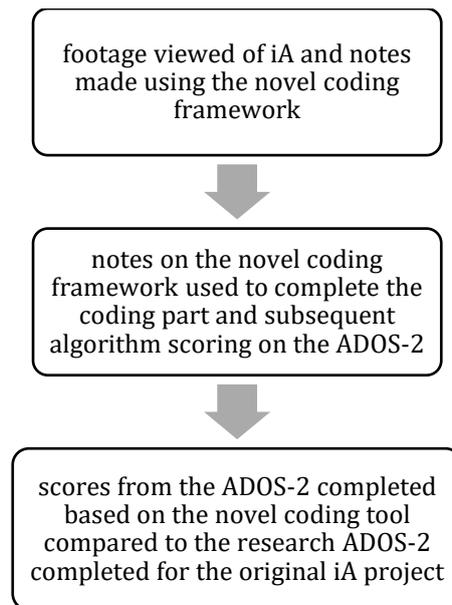
Table 8: the final version of the diagnostic performance tool (for full version see Appendix 9)

The testing of this tool focused on a specific week's interaction that the AHRC iA participants took part in, 'Arctic week one', as this would most closely align with the experience that the participants for the thesis research would have (see Figure 6).<sup>129</sup> This testing was completed on six participants, their ADOS-2 scores computed from the qualitative data. The ADOS-2 scores from the iA environment were then compared to the scores research ADOS<sup>130</sup> completed for the AHRC iA project.<sup>131</sup>

<sup>129</sup> The Arctic was the environment that was chosen for the participants in the thesis research for reasons previously discussed. It was decided that data from the first time that the AHRC iA participants had experienced this environment would be most relevant to the experience of the participants for the thesis research.

<sup>130</sup> The original ADOS from the AHRC iA project had to be converted into the ADOS-2.

<sup>131</sup> The clinical ADOS results for these participants were not collected for the AHRC iA project and therefore could not be used for direct comparison.



*Figure 6: the sequence of testing for the final revision of the diagnostic performance tool*

### ***Initial Testing***

Testing of the final version of the tool was completed alongside one supervisor<sup>132</sup> to assess whether it was possible to complete an ADOS-2 from the information obtained via the tool and without the usual testing methods of the ADOS-2. The tool was found to be sufficient – the ADOS-2 could be completed successfully with some minor adjustments to the environment. These involved behaviours that were likely to occur naturally within the creative environment, but which would be brought to the attention of the practitioners as being a requirement for the completion of the ADOS-2, meaning that a practitioner may have to consciously include it, e.g., seeing if a participant followed a point or calling the participant’s name.

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<sup>132</sup> Julie Beadle-Brown, who has extensive knowledge and practical experience of using the ADOS, both for clinical and research use.

The ADOS that was completed as part of the research methodology (and converted into the ADOS-2)<sup>133</sup> for the AHRC iA project (research ADOS-2<sup>134</sup>) was compared to the ADOS-2 scores for 'Arctic week one' completed by the author (iA ADOS-2).<sup>135</sup> The iA ADOS-2 scores were completed prior to the research ADOS-2 scores being revealed to the author. The analysis was completed for ADOS-2 classification, severity level and comparison scores, using intraclass correlation<sup>136</sup> (at a 95% confidence interval), calculating agreement between the two ADOS-2 scores on SPSS. Absolute<sup>137</sup> and consistency<sup>138</sup> intraclass correlation were measured and are presented in the text below. The evaluation of these was based on the agreement scoring proposed by Cicchetti (2001): 0.90-1.00 = excellent; 0.80-0.89 = good; 0.70-0.79 = fair; and < 0.70 = poor.

#### *Comparing Overall ADOS-2 Classification*

For the overall ADOS-2 diagnostic classification (non-diagnosis, autism spectrum and autism), agreement between the two ADOS-2 scores was calculated as 'fair' (consistency = .762 and absolute = .762) (see Table 9). Five of the participants had an exact match with their diagnosis and one participant scored in the autism range in the research ADOS-2 and the autism spectrum in the iA environment.

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<sup>133</sup> Up to three ADOS's were completed for the AHRC iA project: at baseline, post-intervention and then as a follow-up. The first research ADOS was used for this comparison. The use of the ADOS in the AHRC iA research was predominantly for outcome measures, although it was partly used to double check diagnosis.

<sup>134</sup> The ADOS completed for the AHRC iA project was the older version of the ADOS, as ADOS-2 had not yet been published. Julie Beadle-Brown completed the conversion of these scores from the research videos and notes, to the ADOS-2 scores (she had not completed the ADOS assessments for the research originally).

<sup>135</sup> Although the author worked on the AHRC iA project with the children, she was unaware of the ADOS scores but did know that the participants were diagnosed (as this was a requirement of the AHRC iA research participation).

<sup>136</sup> This measures the reliability of groups of data. The ICC is used to measure a range of numerical data taken from groups or clusters and is used here to assess the 'reproducibility of numerical measures made by different people measuring the same thing' (Andale 2017).

<sup>137</sup> This type is when 'systematic differences between raters are irrelevant' (MedCalc 2017).

<sup>138</sup> This type is when 'systematic differences between raters are relevant' (MedCalc 2017).

participant number	research ADOS-2 diagnosis	iA ADOS-2 diagnosis
1	autism	autism
2	autism	autism
3	autism	autism
4	autism	autism spectrum
5	autism spectrum	autism spectrum
6	autism	autism

Table 9: the two ADOS-2 classifications for each participant in the initial testing, n=6

#### Comparing ADOS-2 Severity Level

The severity level had lower agreement, being classed as ‘poor’ (consistency .585 and absolute .615) (see Table 10). Severity ratings (on both the moderate and high levels of severity) matched for three participants. One participant was originally scored in the high severity level but scored in the moderate level for the iA ADOS-2. Another participant originally scored within the moderate severity level in the research ADOS-2 and then in the low severity level for the iA ADOS-2. The final participant scored in the low severity level in the research ADOS-2 but was then scored in the moderate level for the iA ADOS-2.

participant number	research ADOS-2 severity level	iA ADOS-2 severity level
1	high	moderate
2	moderate	moderate
3	moderate	moderate
4	moderate	low
5	low	moderate
6	high	high

Table 10: the two ADOS-2 severity level ratings for each participant in the initial testing, n = 6

#### Comparing ADOS-2 Comparison Scores

The comparison scores (ranging from 1-10) had ‘fair’ agreement (consistency .723 and absolute .727) (see Table 11). Three of the participants were rated as lower in the iA ADOS-2 compared to the research ADOS-2 (range -1 to -3 [mean = -2]). Two participants matched exactly on their scores. One participant demonstrated a score two points higher in the iA environment.

participant id	research ADOS-2 comparison score	iA ADOS-2 comparison score	difference
1	8	6	-2
2	6	6	0
3	7	6	-1
4	7	4	-3
5	3	5	+2
6	9	9	0

Table 11: the ADOS-2 severity scores for the two environments in the initial testing, n = 6

The small number of participants ( $n=6$ ) may have affected the results and could have made the reliability appear lower; so considering this, the results are relatively good.

As the participants were split across ADOS-2 modules, the number of participants within each module was too low to run tests to produce meaningful data (see Table 12).

ADOS-2 module number	participant number
module 1 (few to no words)	2
module 1 (some words)	1
module 2	2
module 3	1

Table 12: the number of the participants in each module of the research ADOS-2, n = 6.

In addition to the testing discussed above which assessed the use of the diagnostic performance tool and the ADOS-2 from video footage of the AHRC iA project, rehearsal sessions were undertaken by the author and some of the trained practitioners. This enabled further testing of the diagnostic performance tool based on live and recorded observations of practical sessions from participants who were not involved in the AHRC iA project. Additionally, this enabled the practitioners who had been trained in some of the relevant methods (discussed earlier in the chapter) to experience working in the pod prior to the research. Members of the public were invited to a free drama workshop in the iA environment via the mailing list of a local charity, the Kent Autistic Trust. Practice sessions were offered in February and June 2015, the participants consisting of eight children who were diagnosed on the autistic spectrum (7:1 male to female ratio) and one neurotypical female sibling. This allowed for practical elements of the environment to be tested, including the questionnaire given to parents to ascertain basic information about their child and the participant information sheets (see Appendix 10) given

prior to participating in the research. It also tested the viability of having autistic children come to an unfamiliar location and interact with strangers inside the pod. The practice sessions were successful, with participants (regardless of capabilities) being willing and able to participate with no, or very limited, anxiety. In addition to this, successful completion of the diagnostic performance tool and the subsequent completion of the ADOS-2 coding and algorithm were found, proving that the tools were successful to capture observational data in this environment.

### **Practitioner Form**

A short form (see Appendix 11) was provided to the practitioners immediately after the practical sessions, to assess the participants they had interacted with. This was to collect information about the interactive behaviour of each participant that may be missed on the footage, e.g., eye contact, as well as to give an indication of the feeling of the interaction from the practitioner's perspective e.g., the ease of it. This information was used to complement the information provided via the diagnostic performance tool.

### **Procedure<sup>139</sup>**

The original proposed procedure which included two counterbalancing conditions of pre- and post-assessment exposure had to be abandoned due to issues with recruitment and the timings of participant consent being granted (see Appendix 12). The procedure was therefore amended so that there were no counterbalancing groups, instead all participants experienced the iA environment post-diagnosis. Ideally there would be more than one participant per session to assess peer interaction; however, when this was not possible a family member or friend was invited to participate who was not diagnosed.

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<sup>139</sup> See Figure 7 for a flowchart of the research procedure.

Once participants had been recruited and contact had been made by the author to arrange the sessions, an electronic participant information sheet was provided to the adult who had given consent. These were sent in both Microsoft Word and PDF formats to enable the adults to make any appropriate amendments.

When the participant and their accompanying adult(s) arrived at the University, they were greeted by the author who was not in costume and who answered any additional questions that the adult(s) had. Once the session was ready to start, the author introduced the participant(s) to the practitioners outside the studio space. The practitioners were at most partially in costume so that the participant(s) could see who they were. The author introduced each practitioner and who they would be performing as, e.g., “This is Vicki and she is going to be the Penguin today”. All of the practitioners (including the author) returned to the pod and took up their starting positions (usually hidden under some material or in the ‘cave’ within the pod, pretending to be asleep) and the cameras that were fixed around the pod were switched on. The author collected the participants(s), usually with the Inuit, and this was filmed with the hand-held camera, either by the author or the camera operator (depending on availability). They entered the studio space together and were guided into the pod.

Within the pod, the techniques that were discussed in the Introduction were employed to help with the engagement of the participants. This was supported by a loose narrative that was used to guide the interaction, based on the AHRC iA project model. For this research there were narrative points, but room was left to allow participants the opportunity to be their own authors of the narrative and to provide opportunities for demonstrating agency.<sup>140</sup> The pod was framed as the Inuit’s home which was inhabited by a variety of creatures, e.g., the Snowman and the Penguin. When they entered the pod, the participant(s) was given the opportunity to have a

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<sup>140</sup> Shaughnessy (2017b: 68) discusses this when exploring how imaginative cognition is found with creative processes, emphasising the benefits of the arts: ‘the role of the arts is associated with agency and authorship, a means of moving between and beyond the different aspects of lived experience, harnessing creative resources to bring the cognitive affective into dialogue’.

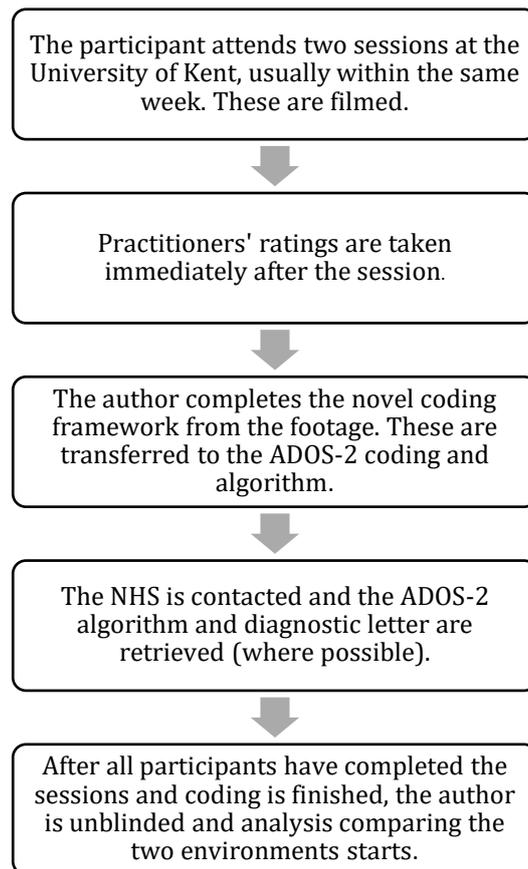
look around to see if they would discover the sleeping practitioners (e.g., the Snowman and the Penguin). Ideally this was initiated by the participant(s) although the practitioners would guide them in this direction if it was not. The opening action would then usually involve finding a way to wake the characters up, testing the participant's problem-solving skills. At some point during the session, usually about halfway through, a simulated storm would occur which involved lights flashing and loud sound effects generated by the equipment setup within the pod. This was done to see how each participant would respond to a sudden change in the environment and offer them a clear opportunity to 'perform' and play within the environment. The characters would respond accordingly, moving around the space as if they were being blown around by large gusts of wind and/or throwing snow to generate the effect of a snowstorm. This usually prompted the participant(s) and practitioners to seek cover in the cave. During the session, usually after the storm, one of the characters would become upset. This was to see if: (1) the participant(s) would notice this and (2) to test their response to this and thereby explore empathy. As the session came to an end, the lights would change colour to indicate a significant change to the environment, i.e., that the sun was rising and so the characters needed to return to the cave to prevent themselves from getting too hot, and were also tired after playing with the participant(s). In addition to the loose narrative there were games that the practitioners could use to help engage participants in the environment, e.g., fishing, snowball fights or hide-and-seek. The aim of the session was to allow the participants to lead with the practitioners following their cues; however, these games provided a mode of engagement for participants who were not confident or comfortable to do this. At the end of the session the participant left the pod with the author (and the camera operator when relevant) and met the adult(s) outside the studio space. The hand-held camera was then stopped. The sessions lasted for thirty minutes.

After the session whoever had escorted the participant to the studio space was invited to view the pod.<sup>141</sup> Once all of the participants had left, the fixed cameras were stopped and the practitioners were asked to fill out a short form based on their experiences of the participants they had interacted with in the sessions. There was a similar format for the second session.

After each session the footage was viewed and the diagnostic performance tool was completed by the author. Subsequently, ADOS-2 scores were assigned based on this data. The appropriate NHS service was contacted and the diagnostic letters sent to families and the ADOS-2 algorithms were retrieved (where possible). When received, these were not viewed by the author, but instead immediately locked away. Only once all of the participants had completed the sessions and ADOS-2 scores were filled out for all of them was the author unblinded to the information from the NHS and thus able to begin the analysis.

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<sup>141</sup> Everyone took up this opportunity and often the participants would show them around, pointing out different elements.



*Figure 7: a summary of the research process*

## **Ethics**

Ethical approval was granted by the NHS Research Ethics Council (REC) and East Kent Hospitals University NHS Foundation Trust (EKHUFT) Research and Development office. Due to initial issues with recruitment, the criteria were expanded and the opportunity was introduced for participation of children who were not participants in the research, e.g., family members to help provide peer interaction when no other participant was available. In addition to this a supplementary research site was added, Sussex Partnership NHS Foundation Trust (SPFT), with additional approval sought through REC and the SPFT Research and Development office.

The potential risks for the participants were minimal but the main risk areas will be discussed briefly in turn: anxiety and distress; breach of confidentiality; and minor inconvenience.

### **Anxiety and Distress**

Participants may potentially have experienced this as they were encountering a new environment and strangers. In order to reduce this information sheets were sent prior to their session, written at an appropriate language level. When participants arrived at the sessions, steps were taken to ease the transition from the reception area to the studio space, and then to the pod. Procedures were put in place (although never needed) to remove participants from the session if they experienced any distress. The participant's accompanying adult(s) also remained in the reception area during the session in case they were required.

### **Breach of Confidentiality**

There was a minimal risk of this but to reduce the chance the only physical documents that contained identity information, the consent forms and contact information/questionnaires, were kept locked up at the University of Kent. When information was received from the NHS this was anonymised and kept locked up at the University of Kent when not in use, in a different location to the identity-revealing documents. All anonymised data was numerically coded. Electronic data (e.g., videos) were stored on two external hard drives which, when not in use were stored in secure locations at the University of Kent. These were accessed via either University computers or the author's personal laptop, both of which were password protected. Once the videos had been transferred from the SD memory card to the hard drives, the files were deleted from the former. Any documents that contained information were numerically coded and password protected (where possible).

## **Inconvenience**

There was a mild inconvenience to participants and their families as they had to come to the University for the session. They did not receive payment or travel reimbursements for this; however, parking permits were provided when needed. In lieu of payment, a data CD containing video clips of the participant's sessions (and stills, where relevant) was sent to each family, along with a short report on their experience in the environment, which focused on their strengths and experiences demonstrated during the session.

## **Analysis**

Analysis was conducted using the IBM SPSS Statistic 24 software package. Intraclass correlation coefficient (at a 95% confidence interval) average measures were used to calculate the agreement in scores between the clinical ADOS-2 scores and the ADOS-2 scores compiled from the participants' engagement in the iA environment. Both absolute and consistency statistics were assessed and these were evaluated using the scoring proposed by Cicchetti (2001), as used in the initial testing and discussed on page 145. For some of the data the range, mean and standard deviation were also calculated.

In conclusion, this chapter has presented the methodology of the research, discussing the research questions, the design, the settings, the recruitment procedures and participants, the tools used (including the development and testing of a new coding framework), the procedure, ethics and method of analysis. The following three chapters will present the results of the practical research.

## CHAPTER 4: QUANTITATIVE ANALYSIS

This chapter will present the quantitative data obtained from this research. The data were collected through analysis of video footage of iA sessions. Extensive descriptions of behaviour were noted in the diagnostic performance tool, which was supplemented by feedback from practitioners provided in a short form completed directly after they had finished each session. Both sets of information were used to complete the coding and subsequent algorithm sections within the ADOS-2. Requests for the clinical ADOS-2 and diagnostic letter were made to the NHS after each participant had completed their two iA sessions. The author did not view the medical data obtained from the clinical diagnosis and the ADOS-2 until all participants had completed both practical sessions and the video and additional coding had been completed. The data from the two ADOS-2's (clinical and iA) were subsequently compared.

This chapter will analyse the information obtained from the clinical and iA ADOS-2's in two parts. The first part will compare the ADOS-2's on five levels, asking the following five questions (see Table 13):

1. How does the clinical diagnosis (based on the ADOS-2 and additional measures) compare to the ADOS-2 completed from the iA environment, in regard to diagnosis or non-diagnosis?
2. How do the clinical and iA ADOS-2 compare in their classifications, rated as either non-spectrum, autism spectrum or autism?
3. How do the ADOS-2 severity levels (minimal-to-no evidence, low, moderate or high) compare for the two environments?
4. How similar are the clinical and iA ADOS-2 comparison scores (in the range 1-10 and use to assign the severity level)?

5. How do the scores that contribute to the ADOS-2 algorithm compare between the clinical and iA ADOS-2? These scores are broken down into three areas: the overall total; social affect; and restricted and repetitive behaviours.

analysis level	comparison measures between the two environments	
	clinical environment	iA environment
1	diagnosis (based on ADOS-2 and other diagnostic measures <sup>142</sup> ) <i>diagnosis or non-diagnosis</i>	ADOS-2 classification <i>diagnosis or non-diagnosis</i>
2	ADOS-2 classification <i>non-spectrum, autism spectrum or autism</i>	ADOS-2 classification <i>non-spectrum, autism spectrum or autism</i>
3	ADOS-2 severity level <i>minimal-to-no evidence, low, moderate and high</i>	ADOS-2 severity level <i>Minimal-to-no evidence, low, moderate and high</i>
4	ADOS-2 comparison score	ADOS-2 comparison score
5	ADOS-2 algorithm scores (SA + RRB = OT)	ADOS-2 algorithm scores (SA + RRB = OT)

Table 13: list of comparison measures made between the clinical and iA environment

The second part of this chapter will focus on the possibility of completing the ADOS-2 within the iA environment and, if there were any issues with completion, how this affected the results (and, where relevant, how additional information was sought or how the environment was altered to incorporate the testing of certain behaviours). As discussed in previous chapters, the ADOS-2 assessment is completed by a trained examiner who observes behaviour and uses this to create several different scores. Initially, qualitative data is compiled based on the individual's response to a series of 'presses'. These notes are then used to create coding scores divided across five areas. Several of the codes are then transferred or converted into the algorithm which produces a total score, this then being used to calculate the ADOS-2 classification, comparison score and level of autism-related symptoms.

<sup>142</sup> These diagnostic measures involve retrospective information about the participant's developmental history which is not obtained within the ADOS-2. The research for this thesis focused solely on current observable behaviour and not developmental history, which would need to be included as part of a full, clinical diagnosis.

## **Participants**

Eight participants (see Table 12) completed the iA drama sessions and the ADOS-2 was filled out by the author based on the information obtained from video footage of each of these sessions, further complemented by additional data obtained from the practitioners. The male-to-female ratio of the participants was 3:5. The mean age was 7 years and 5 months (range 3:11-11:8) at time of participation. The mean time between clinical diagnosis and participation was 10 months (range 4-16 months).

Below is a brief introduction to each participant, bringing together information provided by the parents, diagnostic information provided by the NHS via diagnostic letters, and relevant comments from the author related to their participation.

### **Participant 1**

David was the youngest participant and demonstrated limited verbal capabilities. There was a fourteen-month gap between his clinical diagnosis and participation in the research. He was accompanied by his mother to the sessions and his cousin participated in the sessions but was not included as a participant. He brought a Thomas the Tank Engine toy into the first session and a Thomas the Tank Engine book into the second (his mother had tried to get him to leave the book outside before entering the pod). He also had a dummy that he chewed on. The diagnostic letter indicated that he had previously been seen at the hospital due to developmental concerns and had had grommets inserted a few months earlier. The clinical ADOS-2 for this participant was not forwarded from the NHS and therefore his inclusion in the analysis is only at the first level, comparing his clinical diagnosis to the iA ADOS-2.

## Participant 2

Harriet had fluent speech but initially came across as shy during the sessions. There had been a six-month gap between her clinical diagnosis and her involvement in this research. Neither her parent nor the diagnostic letter declared any additional diagnoses, although she did wear glasses. In the first session she was accompanied by her mother and younger brother (although he did not participate), and in the second session by just her mother. To the second session she spontaneously brought along a 'snow tiger' toy called Stripe. She had been referred by the SENCO at her primary school after it was noted that she had difficulties with socialising, although her mother had gone to her GP two years earlier due to concerns with her social interaction. A 3di<sup>143</sup> interview was conducted and the summary returned with the diagnostic letter. This was completed with her mother and she scored in the ASD range on all domains.

## Participant 3

Annabelle had fluent speech and on the parental questionnaire her mother declared an ADHD diagnosis prior to the sessions. The gap between her clinical diagnosis and the research was thirteen months. She came along to the first session with her mother and mother's partner, and to the second with them and her two siblings. She had moved to Kent from another location and was re-referred to a hospital following the move. A developmental review using various aspects of the Griffiths Scale<sup>144</sup> was reviewed and the information from this was included in the diagnostic letter. The diagnostic letter also indicated that an SCQ<sup>145</sup> was given to her parents and the SRS<sup>146</sup> to her school, although the results of both measures were not included in the letter.

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<sup>143</sup> A diagnostic interview conducted on a computer and completed based on report from parents/caregivers (Skuse et al. 2004).

<sup>144</sup> A developmental measure.

<sup>145</sup> Social Communication Questionnaire, a checklist used to highlight autism and completed by parents/primary caregivers (Rutter, Bailey and Lord 2003).

<sup>146</sup> Social Responsiveness Scale, a diagnostic scale for autism and completed by parents and teachers (Constantino et al. 2003b).

#### **Participant 4**

Ed had limited speech and his father's partner claimed that a regression in language had occurred after the clinical diagnosis, something she attributed to a reduction in the one-to-one support offered to him in his educational setting. The gap between his clinical diagnosis and the research project was sixteen months, the longest such period of any of the participants. He was accompanied to both sessions by his father and his father's partner. In the first session he brought in a small stretchy toy, but quickly handed this over to a practitioner. At the second session his father commented that he had eagerly come straight to the building's entrance, which he took to be a sign that Ed had enjoyed the previous session and wanted to come again. Despite efforts taken to remain blind to diagnosis, the diagnosis of this participant was revealed by his father's partner prior to his involvement in the session. He had been assessed at a hospital seven months prior to diagnosis after concerns were raised about his lack of language and social interaction and a developmental general delay. Global developmental delay was reported in the clinical diagnostic letter. Due to an issue with the ADOS-2 details supplied by the NHS for this participant a complete analysis of his data could not be completed. However, the ADOS-2 diagnosis and severity level were included within his diagnostic letter, meaning that his data could be analysed for levels one to three.

#### **Participant 5**

Amy had fluent speech. The time period between her clinical diagnosis and the research project was the shortest of the participants, at four months. No other diagnoses were declared, although she did wear glasses and the clinical letter reported a lazy eye. She was accompanied to the sessions by her mother, and her younger sibling and mother's partner also attended the second one. She had been referred by her primary school after they had noticed some difficulties. The SRS was scored at the highest level for all issues related to possible ASD and the SCQ completed by her mother, scored 21, which is in the moderate to high range. These results were only noted in the diagnostic letter and full reports were not included. At the clinical

appointment a DISCO<sup>147</sup> was conducted, this reporting significant areas of concern in social communication and interaction, and a limited development of imagination. However, major issues with rigidity and routine were not reported in the DISCO. A comprehensive report of the DISCO findings was included within the diagnostic letter.

### **Participant 6**

William had fluent speech and attended the sessions with his sister who was also a participant (Megan). He was accompanied to both sessions by his mother. There was a six-month gap between his clinical diagnosis and his participation in the research. In the clinical diagnostic letter, an additional issue was noted with a chromosome imbalance (arr15q.11.2q13.1 duplication), for which further investigation was needed into his biological parents. The diagnostic letter also noted that he had previously been referred by an inclusion manager at his school due to concerns in relation to his progress in learning. The SCQ was completed by his parent producing a score of 20 (significant impairment in social communication). The SRS questionnaire was completed by his school, producing a 'T' score of 87, indicating severe difficulties in social communication. During the diagnostic assessment a 3di interview was conducted with his mother, the results of which fulfilled diagnostic criteria for ASD and a report was included in the diagnostic letter.

### **Participant 7**

Megan was the oldest participant and had fluent speech. She attended the sessions with her brother who was also a participant (William). She was accompanied to both sessions by her mother. There was an eight-month gap between her clinical diagnosis and her research participation. No other diagnoses were reported by her mother. Due to issues with the

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<sup>147</sup> The Diagnostic Interview for Social and Communication Disorders is an interview which is intended to differentiate between a range of social and communication disorders, e.g., autism and Asperger's syndrome (Wing et al. 2002).

information received from the NHS and retrieval of the ADOS-2, Megan could only be included in the analysis at level one.

### **Participant 8**

Emma had fluent speech and was accompanied to both sessions by her mother. In the first session her cousin accompanied her in the environment, although she was not a participant. There was an eleven-month gap between her clinical assessment and her participation in the research. In her diagnostic letter it was noted that she had been previously seen by the paediatrician three times at the hospital in view of concerns for a possible social communication disorder. During the clinical appointment a 3di had been conducted with her mother and grandmother. This showed impairments in social communication, reciprocity and restricted and repetitive behaviours, and overall indicated an ASD diagnosis. A report of the 3di was included in the diagnostic letter. No other diagnoses were declared, although Emma was known to be on medication (6mg of Circadin, half an hour before bed).

ID	sex	age at research	age at clinical diagnosis	research ADOS-2 module	clinical ADOS-2 module	additional diagnostic measures used at clinical diagnosis	additional diagnoses	referral information
David	M	3:11	2:9	1	unknown	unknown		originally seen at 18 months with motor and general delay
Harriet	F	8:3	7:9	3	3	3di		SENCO from primary school referred, noting difficulties in social skills mother had concerns for previous 2 years
Annabelle	F	7:2	6:1	3	3	Griffiths Scale, SCQ (parent), SRS (school)	ADHD	referred at previous location and re-referred following move to Kent
Ed	M	5:8	4:4	1	unknown	unknown	global developmental delay	seen seven months prior due to concerns about lack of language, social interaction and general developmental delay
Amy	F	7:3	6:11	3	3	SCQ (parent), SRS (school), DISCO by clinician		mother and grandmother had concerns for some time school raised concerns
William	M	6:5	5:11	3	3	SCQ (parent), SRS (school), 3di by clinician	chromosome imbalance	seen five months prior after school raised concerns about progress in learning
Megan	F	11:8	11:0	3	unknown	unknown		unknown
Emma	F	8:9	7:10	3	3	3di		seen previously on three occasions

Table 14: overview of participant information

## **Results of Diagnostic Comparison Between the Two Environments**

The results of the comparison between the two environments will be presented, working through the levels in order as indicated in Table 13.

### **Participants' Overall Diagnoses**

All of the participants ( $n=8$ ) received a clinical diagnosis of ASD. The ADOS-2 and other diagnostic measures were used to reach these diagnoses. In the iA environment all of the participants were found to score within the autism or autism spectrum range of the ADOS-2<sup>148</sup>, giving a 100% matching rate between the clinical diagnosis and the iA ADOS-2. As the ADOS-2 could be completed in a non-clinical environment and still produced a consistent result to the clinical diagnosis, this provides support for its completion in a non-clinical environment and demonstrates how it can be completed successfully even when the presses from the ADOS-2 are not explicitly used.

### **Participants' ADOS-2 Diagnoses**

The clinical ADOS-2's were obtained from the NHS for six of the participants. Two of the participants' information was not retrieved. In the first case (David) this was unavailable due to difficulties in retrieving the data from the NHS archives, and in the second (Megan) it required additional parental consent, with the parent failing to respond to further contact from the author. Ed's ADOS-2 was returned; however, the information was incomplete and it was unclear which module 1 the clinician had used ('few-to-no words' or 'some words'), meaning that this participant's data could only be used for analysis at levels two and three. Therefore only six participants' data could be used for the quantitative analysis (Harriet, Annabelle, Ed, Amy, William and Emma) with Ed's data not being used for levels four and five of the analysis. The

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<sup>148</sup> As mentioned earlier the iA ADOS-2 would not be sufficient for a full diagnostic assessment and additional measures of developmental history would be required. However, it is a positive indicator that the iA ADOS-2 matches the clinical outcome for all the participants.

mean age of the participants ( $n=6$ ) at research involvement was 7:3 (age range 5:8-8:9) and the mean age of the participants at time of clinical diagnosis was 6:6 (age range 4:4-7:10). The male-to-female ratio was 2:4. Five of the participants were assessed using module 3 of the ADOS-2 and one (Ed) was assessed using module 1. This was in both the clinical and the iA ADOS-2. Of the participants ( $n=2$ ) excluded from the quantitative research the mean age, at time of participation in the research was 7:11 (age range 3:11-11:8) and mean age at time of clinical diagnosis was 6:11 (age range 2:9-11:0)<sup>149</sup>, with a gender ratio of 1:1. One participant was assessed on module 1 (David) and the other (Megan) on module 3 of the iA ADOS-2. It is likely that they would have been assessed on the same module for clinical assessment; however, without access to the clinical ADOS-2 it is not possible to confirm this.

The analysis was carried out in the same way as for the initial testing (see Chapter 3). For the analysis of ADOS-2 classification, severity level and comparison scores, intraclass correlation coefficient (at a 95% confidence interval) average<sup>150</sup> measures were used to calculate the levels of agreement in SPSS between the ADOS-2 scores in the clinical and iA environment. Both absolute and consistency statistics were assessed. For the evaluation of these the agreement scoring proposed by Cicchetti (2001) will be used: 0.90-1.00 = excellent; 0.80-0.89 = good; 0.70-0.79 = fair; and < 0.70 = poor.

### ***Comparing Overall ADOS-2 Classification***

For the overall ADOS-2 classification (non-diagnosis, autism spectrum and autism) agreement across the two environments was calculated as 'fair' with consistency = .727 and absolute = .762 (see Table 15). Four of the participants had an exact match on their diagnosis between the two environments. One participant was classified as having autism on the clinical ADOS-2 and on the iA ADOS-2 was classified as autism spectrum. The participant (Amy) who

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<sup>149</sup> These participants were the youngest and oldest.

<sup>150</sup> This is where the 'reliability of different raters [is] averaged together' (MedCalc 2017).

had not met the criteria for autism in the clinical ADOS-2 was still given an overall clinical diagnosis based on other assessed measures.<sup>151</sup> The cut-off score for the ADOS-2 on module 3 is six and she had scored five in the clinical ADOS-2 and six in the iA ADOS-2.

participant name	clinical ADOS-2 diagnosis	iA ADOS-2 diagnosis
Harriet	autism	autism spectrum
Annabelle	autism spectrum	autism spectrum
Ed	autism	autism
Amy	non-diagnosis	autism spectrum
William	autism	autism
Emma	autism spectrum	autism spectrum

Table 15: the ADOS-2 classifications for each participant in the two environments, n = 6

### **Comparing ADOS-2 Severity Levels**

The severity level (minimal-to-no evidence, low, moderate and high) had better agreement across the two environments, classified as 'good' with consistency = .850 and absolute = .872 (see Table 16). Four participants had exact matches on their severity scores between the two environments. Among these four participants were seen three of the levels of severity scores (low-high) which is a positive indicator that the matching between the two environments across different severity levels can occur with good agreement. One participant was rated in the high severity range in the clinical environment and the moderate severity range in the iA environment. Another participant was rated in the low severity rating in the clinical environment and in the moderate severity range in the iA environment.

participant name	clinical ADOS-2 severity level	iA ADOS-2 severity level
Harriet	high	moderate
Annabelle	moderate	moderate
Ed	high	high
Amy	low	low
William	High	high
Emma	Low	moderate

Table 16: the ADOS-2 severity levels for each participant in the two environments, n = 6.

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<sup>151</sup> This was clarified with the clinician who carried out the ADOS-2 for her clinical assessment.

### **Comparing ADOS-2 Comparison Scores**

The comparison scores (which can range from 1-10) had ‘good’ agreement with consistency = .863 and absolute = .840 (see Table 17). Three of the participants were rated as having lower scores in the iA environment when compared to the clinical environment. One participant had an exact match on their score, and another participant had a one-point difference in scores between the two environments with a higher severity score recorded in the iA environment.

participant name	Clinical ADOS-2 Comparison Score	iA ADOS-2 Comparison Score	Difference Between Two Scores
Harriet	8	5	-3
Annabelle	5	5	0
Amy	4	3	-1
William	10	8	-2
Emma	4	5	+1

Table 17: the ADOS-2 comparison scores for each participant in the two environments, n = 5

### **Module 3 scores<sup>152</sup>**

The scores for module 3 can be broken down into overall total, social affect and restricted and repetitive behaviour scores (see Table 18). The agreement of scores between the two environments was ‘poor’ (consistency = .597 and absolute .594 [overall total]; consistency = .532 and absolute =.518 [social affect]; consistency = .422 and absolute =.400 [restricted and repetitive]). This was likely due to the small sample size and the range of scores that could occur.

participant name	clinical ADOS-2 module 3 scores			iA ADOS-2 module 3 scores		
	SA score	RRB score	OT score	SA score	RRB score	OT score
Harriet	12	2	14	8	0	8
Annabelle	5	2	8	5	3	8
Amy	5	1	6	6	1	7
William	20	0	20	11	3	14
Emma	7	0	7	8	0	8

Table 18: the ADOS-2 module 3 scores for each participant in the two environments, n = 5 (SA = social affect; RRB = Restricted and repetitive behaviours; OT = overall total)

<sup>152</sup> Coincidentally this was the module that all the usable participants data (n=5) was from.

When the score ranges are compared between the two environments (see Table 19), the social affect and the overall total ranges are smaller, and the restricted and repetitive behaviours score range is slightly larger in the iA environment. This pattern is also replicated in the means and standard deviations. The lower social affect scores in the iA environment were anticipated due to the presence of multiple practitioners actively seeking engagement and the presence of a peer, which were thought likely to increase the demonstration of social skills. The higher restricted and repetitive scores were also anticipated in the iA environment due to the participants being able to move around the space, rather than being encouraged to remain seated (as in the clinical ADOS-2), as well as the potential need for them to display this type of behaviour when dealing with the highly stimulating environment found within the pod.

scores	clinical ADOS-2 module 3 scores			iA ADOS-2 module 3 scores		
	range	mean	standard deviation	range	mean	standard deviation
SA	5 – 20	9.8	6.380	5 – 11	7.6	2.302
RRB	0 – 2	1	1.000	0 – 3	1.4	1.517
OT	6 – 14	11	5.916	7 – 14	9	2.828

Table 19: the range, mean and standard deviation for ADOS-2 module 3 scores for the two environments, n = 5 (SA = social affect; RRB = restricted and repetitive behaviours; OT = overall total)

## Analysis of Completion of ADOS-2 in the iA Environment

This section will focus on the analysis of the data collected from the iA environment and subsequent completion of the ADOS-2 booklet based on these observations. The discussion will centre on the analysis of aspects of the ADOS-2 that can be completed within the iA environment and draw attention to any areas that are not covered by the behaviour demonstrated in the iA environment but that would be covered in the clinical ADOS-2. This will be done through the exploration of two of the ADOS-2 modules (1 and 3) as these were the two that were used to analyse the research participants in the iA environment. Two participants were assessed on module 1 and six on module 3. In module 1 (phrase speech) there are ten tasks (see Appendix 13) with thirty-four codes. The codes are divided into five sections:

language and communication; reciprocal social interaction; play; stereotyped behaviours and restricted interests; and abnormal behaviours (see Appendix 14). When these codes are converted into the algorithm scores, there are two columns, 'few to no words' and 'some words', to discriminate between levels of verbal ability (see Appendix 15). Fourteen codes are converted to algorithm scores in each column. These algorithm scores are divided into social affect and restricted and repetitive behaviours scores, which, when added together, generate the overall total. In module 3 (fluent speech – child and adolescent) there are fourteen tasks (or presses) (see Appendix 16) which contribute towards twenty-nine scores in the coding section (see Appendix 17). These sections are labelled similarly to those in module 1 except that 'play' is labelled as 'imagination'. Fourteen of these codes are then converted into algorithm scores (see Appendix 18) which, as discussed above, are divided into social affect and restricted and repetitive behaviour scores. These scores are then added together to create the overall total. In both modules, in addition to the diagnosis, a level of autism-spectrum related symptom is assigned (as discussed above).

Initial testing of the viability of completing an ADOS-2 within the iA environment found it to be possible, even when deviating from the format in which the ADOS-2 is intended to be completed, i.e., without using the presses or working with the props that are supplied to complete the assessment (as discussed in Chapter 3 and earlier in this chapter). The codes and algorithms across modules could be completed in the ADOS-2 based on behavioural observation of individuals within the iA environment. The ADOS-2 will be discussed in relation to the three different areas in which scores are given (observation, coding, and algorithm scores) in modules 1 and 3, exploring how it can be completed in the iA environment.

## Observation (tasks)

In module 1 there are ten tasks (or presses) and fourteen are used in module 3. In the iA environment, the presses were not always the same as used in the ADOS-2; however, matches were made if a similar behaviour could be demonstrated that would fulfil the criteria of the press, even without carrying out the exact task.

### Module 1

Of the ten presses observed in the ADOS-2, the iA environment easily elicited behaviours for eight of them (80%) (see Table 20). The two presses that were problematic were '5. Anticipation of a routine with objects' and '7. Anticipation of a social routine' (see Appendix 13 for descriptions of these). Both of these focus on a child's anticipation of a familiar or semi-familiar routine which was not tested for within the environment or likely to be displayed spontaneously. However, the nonverbal behaviours that are relevant to these could be expressed in other behaviours that would occur within the iA environment, although these would not be based on the anticipation of something.

MODULE 1			
ADOS-2 coding no.	ADOS-2 coding	summary of the focus of the ADOS-2 coding	how these fit in the iA environment
1.	free play	How do they spontaneously seek engagement with parent/caregiver? Does the child direct affect to others?  Does the child explore materials, symbolically/functionally? Do they stay with activities, flit from object to object or engage in repetitive actions?	The environment naturally matches requirements as the environment is play-based. Parent/caregiver is not present but similar behaviours can be noted with a range of adults, and peers.
2.	response to name	Hierarchy of Presses used to get attention.  What sounds/actions must be made to get their attention, examiner and parent/caregiver?  Does the child make eye contact? Look at faces or in their general direction? Vocalise?	This environment is likely to naturally have name-calling occur; however, practitioners were explicitly told at some point to test this. Parent/caregiver is not present but similar behaviours can be noted with a range of adults and peers.

3.	response to joint attention	Does the child follow a shift in gaze or require a point?  Focus on the behaviour when playing with toys (eye contact, vocalisation, requesting, shared enjoyment, initiations of joint attention and pretend play)?	This environment is likely to naturally have pointing occur; however, practitioners were explicitly told to test this at some point. The other behaviours could also be naturally assessed.
4.	bubble play	Observe child's affect, initiation of joint attention, shared enjoyment, requesting, and motor behaviour while bubbles are present. Are any unusual behaviours or movements displayed?	While bubbles were not used in this environment, other play materials could be used to observe these behaviours.
6.	responsive social smile	Evaluate response to the examiner and parent/caregiver smiling, the parent/caregiver smiling and making a familiar noise, or calling in a way that implies physical contact or being touched.	While the exact task is not completed, this behaviour is likely to occur naturally within the environment. Parent/caregiver not present but similar behaviours can be noted with a range of adults and peers.
8.	functional and symbolic imitation	Hierarchy of presses used for teaching/imitation trials.  How do they use miniature objects and a placeholder in imitation of familiar actions?  Are they carried out with social awareness and shared enjoyment?	While the identical tasks are not used for imitation, this behaviour could occur naturally within the play-based environment.
9.	birthday party	Evaluate interest and ability to join in the "script". Is doll treated as a representation of an animate being? Does spontaneous contribution occur?  Focus on shared enjoyment, overtures and reciprocity.	While the identical task does not occur, there are several 'scripts' offered to the participants, e.g., joining in with storm and playing hide-and-seek. The puppet would also function in a similar way to the doll.
10.	snack	How are preferences and requests made for food? How is gaze, gesture, reaching, facial expression and vocalisation used to communicate? Does the child show the snack to parent/caregiver or try to feed/share with adults?	Food is not used within the environment; however, there are many props which are likely to engage the participants, enabling a testing of nonverbal behaviours and vocalisations to be evaluated. Parent/caregiver is not present but similar behaviours can be noted with a range of adults and peers.

Table 20: analysis of the presses completed with ease in the ADOS-2 within the iA environment in module 1 (adapted from module 1 of the ADOS-2 [WPS 2012a: 2-8]) (see Appendix 13 for full descriptions).

### Module 3

This module has fourteen presses and the iA environment elicited behaviours for ten of them (71.4%) (see Table 21). The four presses that were problematic were: '1. Construction

task'; '10. Social difficulties and annoyance'; '12. Friends, relationships, and marriage'; and '13. Loneliness' (see Appendix 16 for a description of these). The construction task is based on helping to piece together a puzzle with one (or more) of the pieces being out of reach for the examinee to see if/how they request this from the examiner. Puzzles were not used in the iA environment, making it problematic to explicitly replicate the experience, although it was possible that the participant might at some point within the session need to indicate that they wanted something spontaneously. The other three presses (10, 12 and 13) require interview questions which probe the participant's understanding of social relationships. It was not appropriate to interview participants within the environment; however, they were able to practically demonstrate their understanding of social relationships as they navigated their own relationships with the practitioners and the other participant(s). In addition to this, there were opportunities for them to comment on and affect the practitioners' relationships with each other.

MODULE 3			
ADOS-2 coding no.	ADOS-2 coding	summary of the focus of the ADOS-2 coding	how these fit in the iA environment
2.	make-believe play	To what extent does the child produce imaginative sequences of actions involving materials beyond their most obvious intention? Are the dolls and action figures cast as animate beings with the participant pretending they are interacting with each other? How? Are repetitive or sensory interests in the materials displayed? Observe social overtures, spontaneous language, facial expressions, gestures and how the participant responds to examiner.	The environment naturally matches requirements as it is play-based, and the practitioners are actively seeking out interaction. The puppet and the array of penguin toys operate in a similar manner to the doll and action figures.
3.	joint interactive play	Observe reciprocity and shared enjoyment shown in interactive play. Is participant able to suggest ideas? Can they follow or join in with the examiner's ideas?	The environment naturally matches requirements as it is play-based.

4.	demonstration task	Do they represent familiar actions/gesture? How? Is their body used to represent an object or is mime used to demonstrate the object?	Although demonstration is not explicitly probed for, this was likely to occur naturally due to the environment being play-based, and the variety of props available.
5.	description of a picture	Obtain a sample of spontaneous language and communication, and a sense of what captures their interest.	Although a description of a picture is not explicitly probed for, the information about their language and communication, and what captures their interest, can be assessed within the overall context of the environment.
6.	telling a story from a book	Obtain a sample of spontaneous language and communication, and a sense of what captures their interest.  Response to conventional humour, their spontaneous comments about how the characters are feeling and the degree to which continuity can be presented.	Although telling a story from a book is not explicitly probed for, the information about their language and communication, and what captures their interest, can be assessed within the overall context of the environment.  The characters (e.g. the Snowman) offer a lived experience of humour and allow an assessment of the participant's response to it. Emotion is tested for, with the inclusion of a character demonstrating sadness.
7.	cartoons	Observe use of gesture and coordination with speech, and response to humour. Obtain a language sample and sense of flexibility in adapting narrative. Note any comments on emotions and relationships.	Although cartoons are not used within the environment, information about integrated verbal and nonverbal communication can be obtained naturally via interaction within the environment. The characters (e.g. the Snowman) offer a lived experience of humour and allow an assessment of the participant's response. Emotion is tested for, with the inclusion of a character demonstrating sadness.  Comments on relationships can be elicited via the relationships offered between the practitioners when they are in role and the ongoing narrative which occurs.

8.	conversation and reporting	To what extent are the examiner's statements built on? To what extent do they elaborate on their own statements to provide a lead for you and take a role in back-and-forth conversation? How do they report routine and nonroutine events and describe relationships and emotions? Observe communication, including gaze, facial expression, intonation and gesture.	The environment naturally matches requirements for conversation as the practitioners are actively seeking out interaction. The reporting is more problematic in regard to how the environment was adapted.
9.	emotions	Interview questions asked.  Identify events/objects that elicit different emotions and whether or not these are social. How does the participant describe their emotions?  Are facial expressions or creative uses of language used when describing emotions? Is insight into typical social relationships linked to these emotions, displayed?	Interview questions are not asked; however, the opportunity for demonstration of awareness and understanding of emotions is tested for through one of the characters explicitly showing sadness. The loose narrative of the environment also allows for opportunities for emotions to be displayed by participants. Facial expressions and creative uses of language naturally occur within the environment.
11.	break	How do they occupy themselves during free time and respond to the examiner's withdrawal from, and return to, the interaction?  Do they initiate and participate in unstructured conversation or interaction?	The environment naturally matches requirements as it is based on social interaction, with practitioners actively seeking out interaction and also stepping back from it. As the environment is play-based this encourages, at times, unstructured conversation and interaction.
14.	creating a story	Observe and evaluate creative use of objects in telling a novel story or creating a newscast or commercial.	Although creating a story is not explicitly used within the environment, there are frequent opportunities for imaginative engagement that would test for this.

Table 21: analysis of the presses completed with ease in the ADOS-2 within the iA environment in module 3 (adapted from module 3 of the ADOS-2 [WPS 2012b: 2-10]) (see Appendix 16 for full descriptions).

## Coding

Module 1 has thirty-four codes and module 3 has twenty-nine, both split across five sections. These codes are produced based on the information obtained through the presses discussed above and subsequent observation of behaviour.

## **Module 1**

When exploring the codes in the ADOS-2 that could be completed within the iA environment (see Tables 22 and 24) it was found that for section 'A. Language and Communication' all eight codes could be filled out. In section 'B. Reciprocal Social Interaction', thirteen out of seventeen codes (76.5%) could be scored based on behaviour witnessed within the iA environment. The four codes that were problematic were 'B7. Requesting', 'B8. Giving', 'B9. Showing' and 'B13b. Amount of Social Overtures/Maintenance of Attention: Parent/Caregiver'. B7, B8 and B9 were not explicitly sought in the iA environment, as discussed in regard to the presses above, although it is possible for these to occur naturally when working in such an environment – they just were not probed for in the same way as is done in the ADOS-2. B13b was also unable to be completed as the parent/caregiver was not present in the iA environment. At the time of development of this research the inclusion of a parent/caregiver in the environment was deemed to be inappropriate as their presence might alter the behaviours demonstrated by the participant. However, 'B13a. Amount of Social Overtures/Maintenance of Attention: EXAMINER' could be completed, as information could be gathered on how the participant dealt with strangers through their relationship with the practitioners. The interaction with the practitioners in the pod could be perceived as being similar to how the participant might interact with the examiner during the clinical ADOS-2, as both are strangers. Both codes associated with section 'C. Play' were completed with ease. All of section 'D. Stereotyped Behaviors and Restricted Interests' and 'E. Other Abnormal Behaviors' could be completed, as these codes rely on overall behaviour displayed in an interaction which is not necessarily exclusive to the ADOS-2 environment, rather than being elicited through a specific press.

MODULE 1	
ADOS-2 coding	completion in iA environment (Y/N)
A. Language and Communication	
A1. Overall Level of Non-Echoed Spoken Language	Y
A2. Frequency of Spontaneous Vocalization Directed to Others	Y
A3. Intonation of Vocalizations or Verbalizations	Y
A4. Immediate Echolalia	Y
A5. Stereotyped/Idiosyncratic Use of Words or Phrases	Y
A6. Use of Another's Body	Y
A7. Pointing	Y
A8. Gestures	Y
B. Reciprocal Social Interaction	
B1. Unusual Eye Contact	Y
B2. Responsive Social Smile	Y
B3. Facial Expressions Directed to Others	Y
B4. Integration of Gaze and Other Behaviors During Social Overtures	Y
B5. Shared Enjoyment in Interaction	Y
B6. Response to Name	Y
B7. Requesting	N
B8. Giving	N
B9. Showing	N
B10. Spontaneous Initiation of Joint Attention	Y
B11. Response to Joint Attention	Y
B12. Quality of Social Overtures	Y
B13a. Amount of Social Overtures/Maintenance of Attention: EXAMINER	Y
B13b Amount of Social Overtures/Maintenance of Attention: PARENT/CAREGIVER	N
B14. Quality of Social Response	Y
B15. Level of Engagement	Y
B16. Overall Quality of Rapport	Y
Play	
C1. Functional Play With Objects	Y
C2. Imagination/Creativity	Y
D. Stereotyped Behaviors and Restricted Interests	
D1. Unusual Sensory Interest in Play Material/Person	Y
D2. Hand and Finger and Other Complex Mannerisms	Y
D3. Self-Injurious Behavior	Y
D4. Excessive Interest in or References to Unusual or Highly Specific Topics of Objects or Repetitive Behaviors	Y
E. Other Abnormal Behaviors	
E1. Overactivity	Y
E2. Tantrums, Aggression, Negative or Disruptive Behavior	Y
E3. Anxiety	Y

Table 22: analysis of the completion of the ADOS-2 codes within the iA environment in module 1 (adapted from Module 1 of the ADOS-2 [WPS 2012a: 9-22]) (see Appendix 14 for full descriptions).

### Module 3

When exploring the codes in the ADOS-2 that can be completed within the iA environment (see Tables 23 and 24), for section 'A. Language and Communication', eight out of the nine codes (88.9%) could be successfully completed. The one code that was problematic was

'A7. Reporting of Events' as this was not specifically tested within the iA environment. During the time that the practical sessions were running this issue was raised and discussed with Julie Beadle-Brown who suggested that a question in the second iA session about what happened in the first one could be used to provide information for this press. Unfortunately, due to the timings of the sessions, this was only conducted in Emma's session and was not fully explored by the practitioner asking, who failed to give sufficient time to this before moving on. In section 'B. Reciprocal Social Interaction', ten out of eleven codes could be completed (90.9%). The one problematic code was 'B6. Insight Into Typical Social Situations and Relationships'. This code would have been completed based on the information supplied by interview presses; however, as these were not conducted, this caused an issue, as discussed in the previous section. It is possible that some analysis of this could occur through observing the participant's interaction with others without the use of verbal questioning. The one code associated with section 'C. Imagination' could be coded for with ease. Similarly to module 1, both sections 'D. Stereotyped Behaviors and Restricted Interests' and 'E. Abnormal Behaviors' could also be completed with ease.

MODULE THREE	
ADOS-2 coding	completion in iA environment (Y/N)
A. Language and Communication	
A1. Overall Level of Non-Echoed Spoken Language	Y
A2. Speech Abnormalities Associated With Autism (Intonation/Volume/Rhythm/Rate)	Y
A3. Immediate Echolalia	Y
A4. Stereotyped/Idiosyncratic Use of Words or Phrases	Y
A5. Offers Information	Y
A6. Asks for Information	Y
A7. Reporting of Events	N
A8. Conversation	Y
A9. Descriptive, Conventional, Instrumental, or Informational Gestures	Y
B. Reciprocal Social Interaction	
B1. Unusual Eye Contact	Y
B2. Facial Expressions Directed to Examiner	Y
B3. Language Production and Linked Nonverbal Communication	Y
B4. Shared Enjoyment in Interaction	Y
B5. Comments on Others' Emotions/Empathy	Y
B6. Insight Into Typical Social Situations and Relationships	N
B7. Quality of Social Overtures	Y

B8. Amount of Social Overtures/Maintenance of Attention	Y
B9. Quality of Social Response	Y
B10. Amount of Reciprocal Social Communication	Y
B11. Overall Quality of Rapport	Y
C. Imagination	
C1. Imagination/Creativity	Y
D. Stereotyped Behaviors and Restricted Interests	
D1. Unusual Sensory Interest in Play Material/Person	Y
D2. Hand and Finger and Other Complex Mannerisms	Y
D3. Self-Injurious Behavior	Y
D4. Excessive Interest in or References to Unusual or Highly Specific Topics of Objects or Repetitive Behaviors	Y
D5. Compulsions or Rituals	Y
E. Other Abnormal Behaviors	
E1. Overactivity/Agitation	Y
E2. Tantrums, Aggression, Negative or Disruptive Behavior	Y
E3. Anxiety	Y

Table 23 Analysis of the completion of the ADOS-2 codes within the iA environment in Module 3 (adapted from module 3 of the ADOS-2 [WPS 2012b: 11-22]) (see Appendix 17 for full descriptions).

coding sections	MODULE 1			MODULE 3		
	total no. of possible codes in clinical ADOS-2	total no. of codes completed in the iA environment	percentage of completion	total no. of possible codes in clinical ADOS-2	total no. of codes completed in the iA environment	percentage of completion
language and communication	8	8	100%	8	9	88.9%
reciprocal social interaction	17	13	76.5%	11	10	90.9%
play	2	2	100%			
imagination				1	1	100%
stereotyped behaviours and restricted interests	4	4	100%	5	5	100%
other abnormal behaviours	3	3	100%	3	3	100%

Table 24: comparison of the number of ADOS-2 codes and how many were completed in the iA environment for both modules 1 and 3

## Algorithm Scores

Some of the codes are converted into algorithm scores which generate the overall total. The two sections that make up the overall total consist of the 'social affect' and 'restricted and repetitive behaviour' scores. For both modules 1 and 3 this involves ten algorithm scores in the social affect section and four in the restricted and repetitive behaviours section.

**Module 1**

In module 1 there are two algorithm columns, corresponding to scores achieved from the code 'A1. Overall Level of Non-Echoed Spoken Language'. If the participant scores a 3 or 4 they are assigned to the 'few to no words' column, whereas if they score 0, 1 or 2 they are assigned to the 'some words' column. As can be seen from Table 25, nine out of ten of the algorithm scores for social affect and all of the algorithm scores for the restricted and repetitive behaviour totals can be completed from the iA environment. The only algorithm score that was problematic was 'B9. Showing' as this was not specifically probed for within the iA environment as it is in the ADOS-2 assessment. However, it is possible for this behaviour to occur naturally within the iA environment. Future research would need to ensure that this particular press/code was incorporated within the environment.

MODULE 1		
ADOS-2 algorithm scores	completion of algorithm scores possible in iA environment (Y/N)	
	few to no words	some words
social affect		
A2.	Y	Y
A7.		Y
A8.	Y	Y
B1.	Y	Y
B3.	Y	Y
B4.	Y	Y
B5.	Y	Y
B9.	N	N
B10.	Y	Y
B11.	Y	
B.12	Y	Y
restricted and repetitive behavior		
A3.	Y	
A5.		Y
D1.	Y	Y
D2.	Y	Y
D4.	Y	Y

Table 25: analysis of the completion of the ADOS-2 algorithm scores in the iA environment for module 1

### Module 3

In module 3 there is only one algorithm column. This has ten algorithm scores that contribute to the social affect total and four algorithm scores for the restricted and repetitive behaviours total. As shown in Table 26, nine out of ten of the algorithm scores for social affect and all of the algorithm scores for restricted and repetitive behaviour totals could be completed in the iA environment. The only score that was problematic was 'A7. Reporting' which was not specifically probed for within the iA environment. However, as discussed above, this omission was noted during the period of practical sessions and appropriate amendments to the techniques were attempted (although not fully realised) to incorporate this. Again, this code/press would need to be included in future research.

MODULE 3	
ADOS-2 algorithm scores	completion of algorithm scores possible in iA environment (Y/N)
social affect	
A7.	N
A8.	Y
A9.	Y
B1.	Y
B2.	Y
B4.	Y
B7.	Y
B9.	Y
B10.	Y
B11.	Y
restricted and repetitive behavior	
A4.	Y
D1.	Y
D2.	Y
D4.	Y

Table 26: analysis of the completion of the ADOS-2 algorithm scores in the iA environment for module 3

### Conclusion

The quantitative analysis that has been presented in this chapter provides support for further investigation into the possibility of using alternative environments to complete the ADOS-2. Despite the iA environment not using the presses that are currently used within the

ADOS-2 or the array of props supplied to support the assessment, sufficient information was obtained to complete the assessment in this non-clinical environment.

Returning to the questions posed at the start of the chapter, it was demonstrated that there was a 100% match between the clinical diagnosis (based on the ADOS-2 and additional measures) and the iA ADOS-2 in identifying those with a diagnosis of autism. The second question concerned the ADOS-2 classifications in the clinical and iA environments, and these were found to have fair agreement. The agreement was found to be good for both the ADOS-2 severity levels and comparison scores between the clinical and iA environments. The final question, addressing the algorithm scores in module 3, found poor agreement between the two environments. Overall, these results were reasonably good considering the small number of participants ( $n=6$  for levels 1, 2 and 3;  $n=5$  for levels 4 and 5), as this can have an adverse effect on the intraclass correlation coefficient scores, potentially distorting them.

In the second part of the chapter, modules 1 and 3 were explored in more detail, specifically in reference to how they could be completed within the iA environment. It was found that 80% of the module 1 and 71.4% of the module 3 presses could be completed easily, with only minor amendments needed. When completing the coding for these modules, 100% of the codes could be filled out for four of the sections in module 1 and in the fifth, reciprocal social interaction, 76.5% codes could be completed. Module 3 had a 100% completion rate for three of the sections, 90.9% for the reciprocal social interaction and 88.9% for the language and communication sections. The most important part of this analysis was examining how successfully the algorithm scores could be completed, as these generate the score for diagnostic rating. For both modules 1 and 3, 90% of the social affect and 100% of the restricted and repetitive behaviour sections could be completed. Within each of the modules the one code that could not be completed *could* occur spontaneously, although future research would need to ensure that it was incorporated. This suggests that the completion of the ADOS-2 in an

alternative environment is possible and that it matches reasonably well the clinical ADOS-2 scores and overall clinical diagnosis. The data also matched similarly between modules 1 and 3, suggesting that the iA environment could be applied across different communication levels relatively successfully when using it as a diagnostic assessment setting.

## **CHAPTER 5: QUALITATIVE ANALYSIS – SOCIAL INTERACTION**

The focus of the analysis will now shift to an examination of the qualitative data that was obtained from the research. This chapter will explore the behaviours that were demonstrated by the participants in the category of social interaction. Although these were (quantitatively) explored within the ADOS-2, this chapter will focus on the specific social interactions that were possible within the iA environment. Some of these can be akin to those that the participant would have experienced in the clinical ADOS-2, e.g., the relationship with practitioners being similar to that with the examiner in the sense that they are strangers; whereas others are not practically explored within the ADOS-2, e.g., peer social interaction. Looking at these behaviours therefore allows us to address the question of what alternative information can be provided about the individual through interacting in the iA environment when compared to the clinical one.

The data discussed in both this and the following chapter were retrieved through the transcription of video footage from the practical sessions, this providing detailed descriptions of the participants' behaviours. These descriptions were analysed and divided into themes that emerged from the data. The themes are reflective of elements that are either not covered at all or only partially covered within the ADOS-2 and may well be particular to engagement within the iA environment or indeed other drama-based practices. Although the themes were selected after the qualitative data was analysed, behavioural information that had been obtained from the AHRC iA project influenced some of these categories, as some of the behaviours demonstrated by the participants was found to challenge current understanding surrounding autism from the AHRC iA project e.g. a strength in social interaction seen with puppets or an ability to successfully interact with peers. The behaviours described within the themes are classed as alternative behaviours, as they provide supplementary information about an

individual, leading to more holistic view of them. This contrasts with the medical and scientific constructions of autism as a series of deficits and difficulties (as discussed in Chapter 1). Instead, these behaviours illustrate strengths (although some difficulties are still present) and provide validation for an alternative construction of autism that is facilitated by the arts (as discussed in Chapter 1) and which challenges some of the current theories held about the condition. These behavioural themes provide further information on the individual which supplements the ADOS-2 information already obtained (and discussed in the preceding chapter), as well as having the potential to provide material for use outside the diagnostic setting, e.g., possible interventions.

This chapter is the first of two which qualitatively explore two separate groups of behaviours. These chapters cover, respectively, themes that are partially assessed in the ADOS-2 but which the iA environment gives the participants the possibility to explore further, and themes that are likely to be unique to a drama-based environment. In this chapter, one theme is explored with additional subthemes that are indicated in parentheses: social interaction (with practitioners, with peer and with puppet). The following chapter will consider what has been termed by the author as 'performance intent' – this will be defined and discussed in the introduction to Chapter 6. Within each chapter the themes are introduced and discussed in direct relation to examples demonstrated by participants in this research, reflecting how these extend and contrast with clinical diagnostic reports, where possible, and current understanding of autism. Behavioural examples from this research which support the themes are included within the main body of text and supplemented by photographs and video clips where appropriate. The examples are elaborated on in considerable detail in the appendices. Where relevant, comments from the practitioners' feedback forms have been incorporated to support the observational analysis.

As part of the qualitative analysis in both chapters, pre-existing frameworks have been referenced to help support this investigation and attempt to combat the issues of analysing the complex environments that are often found within creative settings. The framework that is used within this chapter is that of Sounds of Intent, as was introduced in Chapter 3. This framework has been adapted and used in other professional contexts by the thesis author, e.g., for use in assessing responses to music played underwater for adolescents with PMLDs.<sup>153</sup> It has been further adapted for use as a framework for understanding and presenting the analysis in this chapter. The framework was initially used as a measuring tool for recording observations of the participants' behaviour (as discussed in Chapter 3); however, while being useful in the development of the diagnostic performance tool, in the end a different mode of analysis was used, with this framework instead proving to be useful for the analysis in this chapter.

While the social interaction theme which is central to this chapter is assessed within the ADOS-2, the iA environment gave the participants more opportunity to demonstrate and explore these behaviours due to the presence of peers and multiple adults, and the responsive nature of the environment, which provided a greater flexibility for action in comparison to the ADOS-2. In the iA environment three types of social behaviour were observed: with practitioners; with peers; and with puppets. In addition to these behaviours supplying further diagnostic information, they also constitute a challenge to current understanding of autism, which views the condition in terms of deficits in social behaviour. The behaviours discussed also point to behavioural strengths in the participants, which could help in the move towards a more holistic view of autistic individuals, not focusing solely on their deficits. Of course difficulties with social interaction were still demonstrated by participants, as will be described in the following discussion (where relevant, some links will be made to current research); however this will be more fully explored in Chapter 7.

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<sup>153</sup> see <https://www.liquidvibrations.org.uk/research>

## **Social Interaction**

Difficulties with social interaction are among the core deficits in autism and are part of the diagnostic criteria in both the DSM-5 and ICD-10. Within the ADOS-2 there is some testing of this, the individual being assessed on their one-to-one interaction with the examiner in the clinical setting. In addition to this, in module 1 a parent/caregiver is present and their interaction is observed, and in module 3 several interview questions are asked to assess the individual's understanding of relationships and social interaction. Moreover, this is further examined in other assessment tools that are required to be used in conjunction with the ADOS-2 to reach a clinical diagnosis, e.g., the ADI-R, a developmental history interview which is conducted with someone who knows the individual well (Lord et al. 1994).

In comparison to the traditional ADOS-2 setting, in the iA environment there are several other people present, both practitioners and other participants (where possible). This creates a more socially engaging environment and allows the participants more opportunities to demonstrate their skills in social interaction than does the clinical ADOS-2. The interaction with practitioners, peers and one of the puppets<sup>154</sup> (who was operated by a practitioner), will be explored in turn.

## **Practitioners**

The practitioners in the environment were drama students who had undergone specific training in the methods used for this research, as discussed on page 129. They actively sought out social interaction with each participant to encourage their engagement within the environment. The participants could interact with the practitioners as either a character or as a

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<sup>154</sup> Despite the puppet being an inanimate object, this section will discuss it as if it were 'alive', hereafter in referring to it as 'Purdy' or by the masculine pronoun 'he'. This is because he was operated by a practitioner in a responsive manner to the environment, enabling social interaction to occur with the animated object, which, as will be discussed, was an appropriate mode of social interaction for some of the participants.

facilitator. When in character, the practitioner was dressed in a full-body costume and performed as that role. The characters that were available were the Dog (although this character was only present for one participant, David), the Penguin, the Snowman and the Inuit. As previously mentioned, the characters employed varying levels of verbal communication that allowed for more flexibility in social interaction compared to the clinical ADOS-2, which relies on interaction between the person being tested and the clinician (and in some cases a caregiver). The characters were performed by different practitioners from session to session, depending on their availability. The practitioners' aim was to aid engagement within the environment which predominantly meant that social interaction was encouraged, and therefore more likely to occur in comparison to social interaction with peers.

The Sounds of Intent framework has been chosen for the analysis of this research. It assesses engagement with music at three levels: reactive; interactive; and proactive. Within each level there are sublevels which assess how the individual responds to the music. This is illustrated by the diagram in Appendix 2, with the levels of the rated ability increasing from the centre of the circle. The framework has been adapted here to encompass the range of behaviours demonstrated, employing four categories (an additional one was added): non-responsive; minimal; interactive; and proactive response (see Table 27).

analysis category	category description
non-responsive	This behaviour refers to when a participant declined a clear social interaction that was offered to them by the practitioner(s).
minimal	This behaviour refers to when a participant showed some response to social interaction offered to them by the practitioner(s), but this was minimal.
interactive	This behaviour refers to when a participant did interact with a practitioner, responding to social advances, but did not extend these further or actively seek out interaction.
proactive	This behaviour refers to when participants actively sought out interaction with practitioners or extended it beyond its original form.

*Table 27: the analysis categories for social intent in the iA environment and the descriptions of these*

The following discussion will explore the social interaction demonstrated by participants with practitioners through these four categories.

### ***Non-responsive***

The non-responsive behaviours discussed in this section are discussed as they were exhibited by participants who were otherwise competent in offering and responding to social interaction. These rejections are emphasised here to demonstrate that deficits are still seen in some of the participants who otherwise display social interaction skills.

William generally responded well to instances of social interaction offered by practitioners and would often seek these out. However, on three occasions in the second session he declined the opportunities offered to him by the practitioner performing as the Penguin. Two of the approaches involved offers of objects: a bear hat and a microphone. In the first instance he stood up and walked away and in the second he walked past the Penguin. The final example involved physical contact, the Penguin tapping William on the chest as he walked past – he continued walking and ignored her. In all three examples he failed to support his rejection verbally, for example, providing a reason for it, as might be done in typical social interactions to avoid being perceived as rude. These social advances from the Penguin may have failed to interest William or perhaps he simply did not want to interact at that time. However, as this was not vocally supported, it appears to demonstrate a lack of awareness about how social rejection may be perceived and the effect that this might have had on the Penguin. Despite this being a relatively low occurrence within the session, these instances are still noteworthy as they contrasted with William's usual engagement.

Annabelle and Amy were also active in their offering of, and responding to, social interaction. However, in the second session the Inuit requested the help of these two participants to get the Snowman out of the tube in which he had got 'stuck'. Despite the Inuit displaying distress in her vocal intonation and what she was saying, both participants ignored this. Typically, it would be expected that if someone was requesting help and sounded concerned, an offer to help would come willingly. However, this did not occur despite both

participants previously displaying concern towards a character who was distressed (the Snowman during the storm). At the time, the participants were outside the pod<sup>155</sup> and it may be that they were engrossed in their own action and therefore did not see the importance of helping the Snowman out of his predicament. Again, while a demonstration of a single non-response to social interaction may seem to be of little importance, it is significant because both participants had strong skills in this area.

These few instances appeared to be conscious decisions to ignore offers of social interaction by practitioners, which contrasted with the relevant participants' skills as seen in social interaction throughout the sessions discussed later in the chapter. This appeared to be regardless of how it would be perceived by others and demonstrated a lack of awareness of the negative implications that might consequently be experienced by practitioners, thereby demonstrating some issues with Theory of Mind (ToM) as supported by research (e.g., Baron-Cohen et al. 1985; Baron-Cohen 2008). Furthermore, difficulties with ToM were suggested in Amy's diagnostic letter ('she rarely shows sympathy to others') and this may be why she did not come to help initially.

As the iA environment is flexible with multiple and varied possibilities for social interaction to be displayed, it extends beyond the ADOS-2 and allows for difficulties to be seen in those who are more capable of social interaction than perhaps might be demonstrated in the clinical setting.

### ***Minimal***<sup>156</sup>

Neither David or Ed interacted much with the characters but when they did the interaction was evaluated as being minimal. It is interesting to note that both participants were

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<sup>155</sup> As the pod was in a larger studio space there was room for the participants to move around the outside of it. Participants were also free to come and go from the pod.

<sup>156</sup> see Appendix 19 for detailed descriptions

assessed on the ADOS-2 module 1 and that the lack of verbal abilities that this indicates might have been a factor in how they engaged in social interactions.

Throughout both sessions David had minimal interaction with the 'live' characters, instead preferring to interact with the glove puppet bird, Purdy (discussed later in this chapter). There was one clear example of interaction with a practitioner that would be regarded as being minimally responsive. He spent most of the first session outside the pod but entered when the *Thomas the Tank Engine* theme tune was played.<sup>157</sup> He stood next to the practitioner performing as the Inuit and leant into her, smiling. It is likely that this response to social interaction occurred because of the practitioners' engagement with the *Thomas the Tank Engine* theme tune (this was a special interest of his, and they were singing and humming along and swaying from side to side): it facilitated social interaction through shared attention. Due to the flexible nature of the environment, a deviation from the setting was possible and enabled some basic skills in social interaction to be demonstrated by David, which otherwise would not have been seen. This kind of deviation may not be possible in the ADOS-2 due to the more structured approach taken to maintain accuracy of application.

Ed engaged in restricted social interaction with characters and would offer minimal responses if the character was doing something that he enjoyed, e.g., suggesting that they were going to tickle him, to which he responded positively with eye contact and a smile, or if they had something that he wanted, e.g. the bubble toy which he went up to the Inuit and took from her with no eye contact. This suggests that, similarly to David, the social interaction occurred based on what he was interested in and that without this incentive, he appeared to be uninterested in engaging with others.

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<sup>157</sup> This was suggested by one of the practitioners after they had been struggling to engage with him inside the pod.

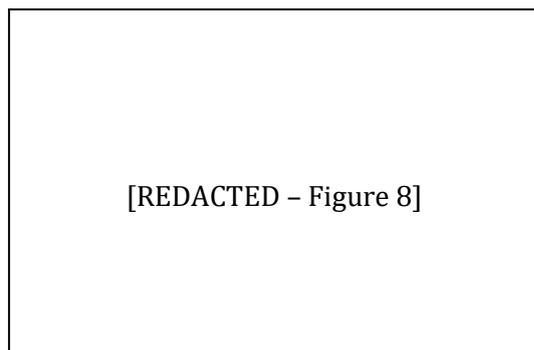
Additional comments about both David and Ed were provided by the practitioners in the feedback forms. It was noted that David had poor eye contact: 'he seemed to avoid eye contact and he was focused on his Thomas the tank engine toy mostly' and 'the most interaction was the very occasional eye contact... [he] made eye contact once or twice during the session'. These issues with eye contact were further noted in his diagnostic letter: 'use of eye contact was inconsistent'. However, the practitioners observed an increase in eye contact in the second session: 'much better than last time, lots of strong eye contact' and 'had strong eye contact with me when dancing to [the] *Thomas* song and when out of the environment'. His focus on the Thomas the Tank Engine toy and practitioners' comments about the increase in eye contact when the theme tune was played, support the behaviour witnessed and the role of this participant's interest in Thomas the Tank Engine supporting social interaction – this may not have been possible to the same extent within the clinical ADOS-2 assessment. Similar comments were made regarding Ed's eye contact: 'he didn't give me much eye contact at all. I got tiny bits of it when he was interested in the bubble wand and occasionally when he looked over... whilst he was running up and down outside of the space with Purdy and [the] Snowman'. One comment of interest regarding Ed was 'he was not able to interact that strongly but he was present and seemed to be enjoying the work we were doing with him/around him as much as I could tell'. The use of 'present' here refers to being 'present' in the performance – demonstrating attention and engagement – as opposed to being just physically present in the space. This is a very important point as despite difficulties in social interaction, the participant was still engaging with, and responding to, the space. The role of the immersive space may be key to this as it strongly contrasts with the ADOS-2 which often occurs in a clinical environment. As the iA environment could gain his attention and engage him, he may have been able to participate in more varied social interactions, even if these were only limited.

Both examples demonstrate the difficulties in social interaction that are present for individuals on the autistic spectrum, supporting the inclusion of deficits in this area in the

diagnostic criteria (APA 2013). In the diagnostic letter provided for David it was noted that he ‘took little enjoyment in interaction with the therapist’, which accords with the behaviour seen within the iA environment. However, due to the flexible nature of the environment used in this research, the use of responsive technology and an array of props, multiple means of social interaction could be offered to the participants beyond the possibilities presented in the clinical ADOS-2. This enables a greater opportunity to discover what may attract a child’s attention, thereby increasing the possibility of social interaction.

### ***Interactive Response***<sup>158</sup>

The focus of this section will be on Harriet whose social behaviour with the practitioners has been evaluated as being interactive, as she often required support either through being invited into interactions or guided through them. When invited into opportunities for social



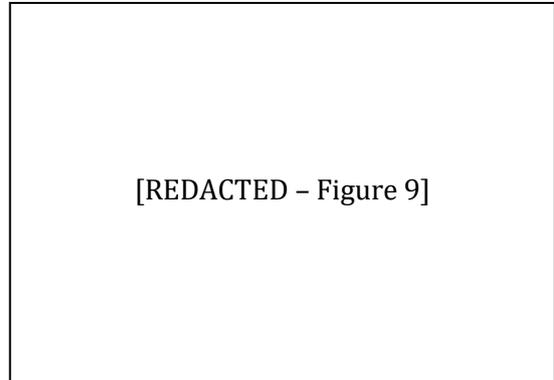
interaction she would gladly join in, e.g., throwing snowballs at the Snowman or waving at him once he had waved at her. She tended to favour being an observer watching the action unfold and interacting only when invited. For example, she enjoyed

watching the Penguin and the Snowman fight over who was going to retrieve the ball that Purdy had thrown and which had subsequently got stuck in the camouflage netting (see Video 1 and Figure 8). She was then invited into the action by the Inuit who asked her to choose between the Penguin and the Snowman as to who was the tallest, and therefore able to collect the snowball, which she did. This kind of supported social interaction was favoured by Harriet who spent most of the time within the sessions near to the Inuit. The Inuit appeared to be a key supportive element for her to engage with the environment, although as the sessions went on she became more autonomous. This was noted by the practitioner who performed as the Inuit, who stated

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<sup>158</sup> see Appendix 20 for detailed descriptions

that Harriet was 'very tentative to do her own thing, she mostly copied and followed me'. This was further supported by observation from the second session: 'she was very shy to begin with; I had to initiate most of the tasks to get her to join in'. Another practitioner commented that she interacted 'tentatively' with them and that 'she didn't seek me out but interacted readily when prompted by the Inuit'. Further evidence was documented in the diagnostic letter: 'she needed support and prompting to generate even the simplest of action and pretence'. The difficulties that Harriet displayed with social interaction align with of the current diagnostic criteria. The Inuit was clearly prominent in enabling her to engage with the environment, offering her someone to model her behaviour on who she could monitor. This may also have been used as a masking technique because she was unsure of how to work with strangers; or, by waiting until she was invited into an activity allowed her to witness the behaviour that she was 'meant' to display. This is typical behaviour seen in autistic females (e.g. Attwood 2017). It may be interpreted (particularly with Harriet) as shyness and could contribute to her autistic symptoms being 'hidden'. By engaging in an environment with several adults, difficulties with social interaction may become more apparent than when dealing with a one-to-one situation as occurs with the clinical ADOS-2. Multiple-person social interaction is more complex and so masking techniques, such as imitation seen among females, may become more apparent thus giving a more accurate view on an individual's skills and potential difficulties in social interaction.

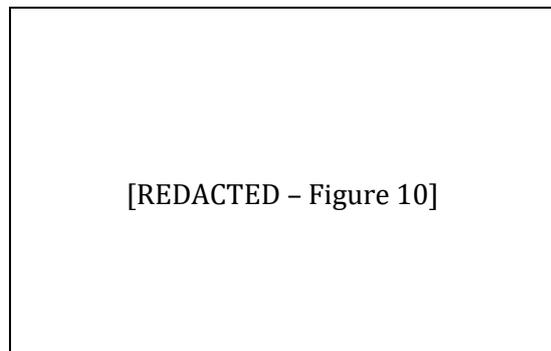


Most of the other participants (excluding David and Ed) presented some examples of interactive behaviour, e.g., through invitation into activities such as fishing by the characters, or responding to questions and requests from characters. However, most of the behaviour that they displayed was analysed at being at the next level, proactive.

### ***Proactive Response***<sup>159</sup>

Within this category of interactive behaviour there were a few subcategories that captured the range of proactive social interaction observed: conversation; shared attention; looking after and helping (empathy); and playful engagement. These are discussed as they are used by the participants to seek out interaction with others. These will be discussed in turn, with tables summarising the description where appropriate.

Conversational skills were demonstrated by all of the participants who were assessed on module 3 (Harriet, Annabelle, Amy, William, Megan and Emma). They asked and responded to questions, e.g., Annabelle continuing conversation with the Inuit and Purdy, who were trying to guess the relationship between her and a toy Penguin, or with Megan, who was telling the



Inuit about the toy penguins in the cave, responding to questions and actively continuing the conversation (see Figure 10). This was also used when the participants were asked for solutions to problems, e.g., how to wake the

Snowman up (Annabelle and Amy). In addition to this, there were moments of spontaneous verbal engagement where a participant would state something to a character about the environment, demonstrating a proactive seeking of social interaction, e.g., Amy describing to the Inuit the differences in the environment between the first and second sessions. Another example of this was when William spontaneously commented that 'it's actually really cold today', even though the session occurred on a warm, summer's day. Although this was momentary and the participant did not continue any performance of it (e.g. shivering or asking for a blanket), it showed an awareness of the pretence framework of the environment and a deeper level of engagement with the imaginary aspect, as well as a desire to share this

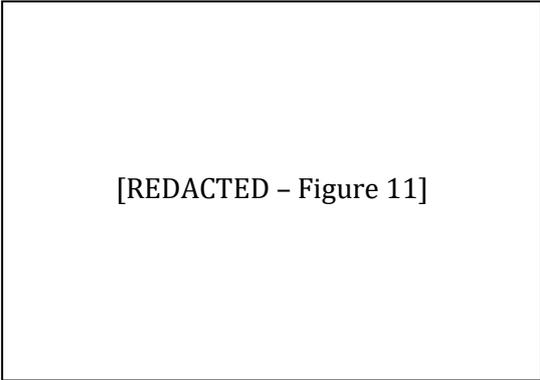
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<sup>159</sup> see Appendix 21 for detailed descriptions

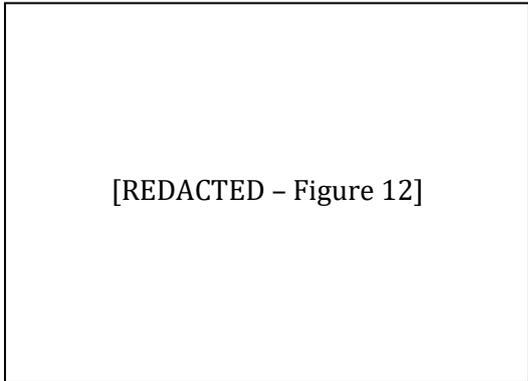
imagination socially. Some of the participants (Annabelle, Amy and Megan) extended their conversation skills imaginatively by communicating with the characters who did not use language (the Penguin and the Snowman). For example, Annabelle and Amy translated what the Snowman said to the Inuit and Amy then responded back in gibberish (see Video 2). Another example was when Megan spoke on the microphone to the Penguin, communicating in a similar manner to how the Penguin communicated. She later animated the penguin toys, accompanied by sounds indicating different accents for each of the toys (discussed on page 239).

The presence of these skills in social interaction and the desire to communicate challenge notions surrounding the relationship between autism and social interaction, as seen in the DSM-5 (APA 2013), particularly the examples demonstrating spontaneous and imaginative communication. Although the ADOS-2 does provide opportunity for conversation, this is extended in the iA environment, particularly with the possibility for imaginative communication. The environment is grounded in imagination and allows participants to demonstrate their understanding of social interaction through conversations with characters who do not use typical language. The fact that three participants understood and communicated in sounds reflects a more complex understanding of appropriate conversational skills and the ability to accommodate the needs of the person they are conversing with. It is unlikely that there is any such opportunity to display these skills in the ADOS-2, particularly as much of the information obtained about the participants' understanding of social relationships is through interview questions rather than a practical demonstration, although the one-to-one interaction with the examiner is assessed. In Amy's diagnostic assessment the letter states that 'a lot of the language that she uses [sic] was not used for communication', which contrasts with her behaviour in the pod where she was able to effectively and creatively alter her language to facilitate communication.

Some of the participants used shared attention to further social interaction with the characters (see Table 28 for a summary). This section will focus on participants who drew attention to an activity they were engaged in or sought someone's help to complete an activity in order to aid social interaction. Megan said to the Inuit 'listen to this' as she pretended to make a tune on the icicles that were hanging down from the pod roof. In the following session she dangled a fish in front of the Penguin's face to get her attention. Amy was given one of the Snowman's black buttons and went to hide it. She drew attention to herself by announcing 'Right. He has another button missing. Can you find it?',



attempting to draw the rest of the characters into her game (see Video 3). Annabelle shared finding the microphone with the Inuit and drew her attention to it, then worked with her while looking at herself in the live feed (see Video 4 and Figure 11). In the second session she shared her discovery of the microphone with the Inuit, commenting that it was 'like last time'. She also shared her discovery of a bear hat with the Snowman, asking him what it was and then getting him to help her into another hat (see Video 5). Another example of attempting to draw attention



involved Emma (see Video 6). She and the other session participant (her cousin) had spent a lot of time outside of the pod and it was felt that Emma was doing this to copy the behaviour of her cousin. The practitioners attempted to sabotage<sup>160</sup> this, with the Penguin, Snowman and facilitator starting

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<sup>160</sup> A technique employed by iA: 'derived from Ting [theatre] and also used in speech therapy, [it] involves setting up situations so that a child is more likely to communicate. Contrary to its sinister sounding name, sabotage in this context refers to ways of intervening creatively when we felt we were stuck or in a stasis' (Shaughnessy 2016a: 207).

to fish inside the pod. She tried to draw their attention towards herself (see Figure 12) and picked up the microphone to say 'hello'. Her cousin then said 'I'm here' through it, which Emma then copied. She then independently entered the pod after realising that this was not going to alter the practitioners' behaviour and worked with them around the pond. There were also a couple of occasions where participants used point (Annabelle and William), facial expressions or eye direction (Annabelle) to guide a character's attention to something that they found interesting.

participant name	examples of shared attention (expanded in text)	supporting media
Megan	'Listen to this.' dangled a fish in front of Penguin's face	
Amy	Announcing they were searching for the button. used point	Video 3
Annabelle	microphone work shared bear hat used point facial expression and eye direction	Video 4/Figure 11 Video 5
Emma	microphone work	Video 6/Figure 12

*Table 28: examples of shared attention behaviour that was shown by participants in the iA environment*

These examples demonstrate autistic children's ability to initiate shared attention through various means: verbal, nonverbal and a combination of the two. These behaviours contrast with research which suggests deficits in these areas, with difficulties in nonverbal communication noted in the diagnostic criteria (APA 2013) as well as in studies (e.g. Morgan, Maybery and Durkin 2003). It may have been that the immersive nature of the pod and the responsive manner that the practitioners worked in, encouraged more opportunities for shared attention, and perhaps a greater desire to further engagement in the environment.

There were multiple examples of the participants looking after and helping the characters (with several demonstrating empathy), which showed a desire for social interaction (see Table 29 for a summary). Several participants offered fish to the characters (Annabelle,

Amy, Megan and Emma); Emma spontaneously offered and then provided help to the Penguin when her home had collapsed (see Video 7); Annabelle and Amy tried to find the Snowman's nose with, Annabelle offering a fish as a replacement nose and Amy apologising when she could not find it. Some participants offered concern to the characters when they displayed signs of being upset, e.g., Annabelle drew the characters' attention to the crying Snowman and then Amy suggested that she could control the storm to stop him feeling sad. In addition to this, some participants offered physical compassion, e.g., Megan rubbed the Penguin's head when she feared the storm in the first session and then rubbed her back in the second one, and Emma patted the Penguin's back when she was crying. Opportunities for displaying empathy were intentionally produced in the environment, as at one point during the session one of the characters (typically the Snowman or the Penguin) would become upset to see: (1) if the participant noticed; and (2) if/how they responded to this. This usually occurred after the storm which caused one of the characters to become scared/upset. This opportunity was given to all of the participants apart from David, as the decision was made not to create a storm due to the lack of time that David had spent in the pod. Annabelle, Amy, Megan and Emma all responded with some empathy towards the characters. In the first session, Annabelle and Amy noticed that the Snowman was upset almost immediately and without prompting from the practitioners (see Videos 8 and 9). Annabelle initially drew Amy's attention to the situation but they both went up to him and attempted to find out what was wrong, offering separate solutions for this. In the second session they sent the Snowman to bed, who then began to cry. In speculating on what was wrong with the Snowman Annabelle found a fish and Amy then suggested that he might be hungry, and both then gave him a fish. Amy then said on the microphone 'make the Snowman not sad'. When they spoke to the Snowman together with the Inuit to find out what was wrong – it was revealed that he would like some friends – Annabelle offered herself as one and they all played hide-and-seek (see Video 10). The storm occurred in both sessions for Megan, which prompted two instances of the Penguin crying, with Megan offering support via physical

comfort through back rubbing (see Video 11). Emma showed empathy towards the Penguin who had become upset after an interaction with the Snowman. She went up to the Penguin, patted her on the shoulder and then, when the Inuit suggested that she should hug her, did so (see Video 12). Later in the session a ‘fight’ occurred between the Snowman and the Penguin to which the Inuit drew Emma’s attention. Emma went and separated the two characters and then hugged the Snowman as the Penguin had been hitting her with a fish (see Video 13). The examples of empathy discussed above were supported by comments from practitioners. One noted ‘she [Annabelle] was especially concerned that the Snowman was upset and asked me why he was crying off her own accord, unprompted’. In the second session the practitioner performing as the Snowman commented ‘they [Annabelle and Amy] knew when he [the Snowman] was upset and also invited him to play hide-and-seek’. With Megan, the practitioner who was performing as the Penguin said that she ‘was especially sensitive towards me when I was upset/scared of the storm’. One practitioner noted that Emma was ‘empathetic towards my character when I was sad’.

participant name	examples of empathy (expanded in text)	supporting media
Annabelle	offered fish looked for snowman’s nose and offered a replacement drew attention to crying snowman and offered solutions helped snowman when he was sad in second session	Video 8
Amy	offered fish looked for snowman’s nose and then apologised offered solution to snowman’s sadness helped snowman when he was sad in second session	Video 9 and 10
Megan	offered fish offered physical comfort	Video 11
Emma	offered fish helped penguin after her home had collapsed offered physical comfort	Video 7 Video 12 and 13

*Table 29: examples of behaviour demonstrating empathy shown by the participants in the iA environment*

The examples discussed above demonstrate how some of the participants could display empathy and offer solutions towards the characters to improve their mood. These participants showed concern and demonstrated caring qualities. The offers of empathy varied among the

participants, with some suggesting solutions to the problems, and others offering physical comfort to relieve the character. This demonstration of empathy by people on the autistic spectrum contrasts with perceived deficits in those with autism (e.g., see Baron-Cohen and Wheelwright 2004), predicated on difficulties with ToM.

Difficulties in some of the participants' ability to display empathy were noted in their diagnostic letters: it was noted that Annabelle 'does not comfort her siblings if they are hurt or upset'; for Amy, comments included that she 'showed little awareness of other people's feelings and sometimes would laugh at others' distress', and that 'she finds it quite difficult to answer questions about people's inner states, thoughts and feelings'. These descriptions of behaviour from the diagnostic process contrast with some of the behaviour demonstrated by these participants in the iA environment, where they showed empathy and compassion for others.

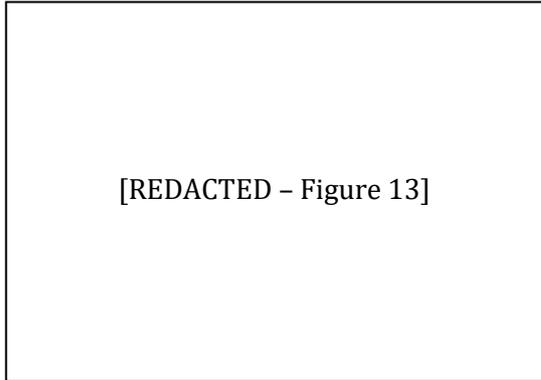
Nevertheless, there were still examples demonstrated of participants not appropriately responding to the simulated opportunities to show empathy. Despite Harriet hearing the Snowman sobbing she initially looked at the Inuit, presumably to see if she was going to respond (see Video 14). As the Inuit did not respond, Harriet continued to watch the interaction that was occurring between the Inuit and the Penguin. As the Snowman continued to sob, the Inuit began directing Harriet's attention towards him. The Penguin then mocked the Snowman, which Harriet smiled at, and the Inuit told him off. During this interaction Harriet did not talk or seemingly react in a way which would be anticipated in typical displays of empathy. William also missed the opportunity to show empathy when the Penguin was crying (see Video 15). While the Penguin was already being comforted by Megan, William looked at her but did not offer comfort, instead walking away. This was observed by a practitioner who noted that William 'showed little concern/empathy when I was upset about the storm'. The lack of empathy shown by Harriet was supported in her diagnostic letter: 'I think [Harriet] is struggling

in her understanding of others, which includes taking their perspectives and demonstrating empathy’.

It is interesting to note that all participants who displayed empathy were female which accords with research on gender differences between empathising and systemising (see Baron-Cohen 2002). The girls displayed more examples of empathy in comparison to their male counterparts – there was only one female (Harriet) who did not when prompted. Although the sample size was small, the empathic behaviour displayed by these participants also matched the patterns seen in social interaction within the group, which suggests a possible link between empathy and social interaction. Those who had a greater desire for, and skills in, social interaction were more likely to demonstrate empathic behaviour (although one needs to be careful about generalising based on this sample). This behaviour showing consideration for others’ feelings reveals skills in ToM. Again, this contrasts with perceived deficits in ToM. The possibility of eliciting empathic responses is greater within this environment than with the clinical ADOS-2, as the characters are responsive and can simulate sadness (or indeed other emotions) to see how participants respond. With the ADOS-2 this is not possible to the same degree, although clinicians may employ performed social behaviours to test the individuals’ responses. In module 3, testing of empathy is done through questioning – a very different experience to being directly confronted by a display of sadness which practically tests these skills rather than theoretically exploring them. This key difference between the ADOS-2 and the iA environment was also central in the earlier exploration of social interaction and understanding of relationships.

The final part of this section will look at how the participants used games and play to facilitate proactive interaction with the characters, behaviour that was demonstrated by several of the participants (Harriet, Annabelle, Amy, William, Megan and Emma) (see Table 30). Some of the participants spontaneously threw snow at the characters (Harriet, Megan and Emma) and one spontaneously threw fish at them (William). The spontaneity is important here as it

demonstrates proactive interaction – the participants tried to play with the characters through engaging in this behaviour. All of the module 3 participants became involved in a game of snow throwing. Several of the participants joined in with a fish game (Harriet, Annabelle, Amy



and Megan) and some (Harriet, Annabelle and Amy) joined in with the game of tasting the fish and describing what it tasted like (discussed on page 239). Emma joined in with a game, in which the characters threw a snowball at her and she batted it back with a tube (see Figure 13). Two participants (Amy and Megan) dressed up as a bear and attempted to play with a character through scaring them (discussed on page 234-235). In addition to this, there were several instances of participants seeking out established games or play that included the characters: Annabelle suggested playing hide-and-seek (Amy and Emma also participated in games of hide-and-seek although did not suggest it); Annabelle and Amy suggested doing the hokey cokey; William tried to get the characters to chase him around the pod and even established his own game in which he actively encouraged the characters to participate (discussed on page 245).

participant name	examples of play and games (expanded in text)
Harriet	spontaneously threw snow played fishing game play fish tasting game
Annabelle	threw snow played fishing game played fish tasting game played hide-and-seek hokey cokey
Amy	threw snow played fishing game played fish tasting game dressed up as a bear played hide-and-seek hokey cokey
Megan	spontaneously threw snow played fishing game dressed up as a bear

Emma	spontaneously threw snow batting game (see Figure 13) played hide-and-seek
William	spontaneously threw fish threw snow chase created his own game

*Table 30: examples of behaviour demonstrating play and games shown by the participants in the iA environment*

These behaviours demonstrate how participants used play to help engage in proactive social interaction. Play skills have been noted to be problematic for autistic people (Hammes and Langdell 1981; Baron-Cohen 1985; Rutherford and Rogers 2003; Lam and Yeung 2012) and this can have a detrimental effect on their social skills. However, skills were shown by participants in the initiation and continuing of games. Although several of the activities discussed above were instigated by the characters and therefore the behaviour displayed by the participants could be seen as imitation, it shows a willingness to continue the social interaction. Because the iA environment is play-based and responsive to participants it offers more opportunity for play and games compared to the ADOS-2. Although the ADOS-2 does explore play, this is done mainly through toys which have limited responsiveness. In the iA environment, these toys are replaced by characters who can offer a much wider range of responses, allowing more flexible play and games than would generally be possible in the more structured environment of the ADOS-2. This allows proactive social interaction to be demonstrated more readily.

In conclusion, the examples discussed demonstrate a range of abilities in social interaction across four levels (non-responsive, minimal, interactive, and proactive), as modelled on the Sounds of Intent framework (see Table 31). The range of abilities in the research participants showed deficits which accord with research surrounding autism, as has been discussed. However, there were multiple examples which showed an active desire for, and skills in, achieving more complex levels of social interaction. Not only do these behaviours challenge

conventional thinking surrounding skills in autism, they also demonstrate flaws within the ADOS-2, which fails to allow for a fuller exploration of social interaction. The iA environment, in contrast, is flexible, imagination-based and involves responsive reactions from the practitioners performing in role, which helps to facilitate greater opportunity for social interaction than is currently possible within the clinical ADOS-2. The ADOS-2 offers single-person (or, in the case of younger children, two-person), rather than multiple-person interaction. The latter allow skills to be demonstrated in more complex forms of social interaction, as well as revealing more subtle differences that become apparent when engaging in social interaction beyond a one-to-one situation. The safe nature of the space may also have encouraged social interaction and allowed for mistakes to be made without ramifications, as well as providing the opportunity to model behaviour from a range of adults.

participant name	social interaction level displayed in the iA environment.			
	non-responsive <sup>161</sup>	minimal	interactive <sup>162</sup>	proactive
David		X		
Harriet			X	X
Annabelle	X			X
Ed		X		
Amy	X			X
William	X			X
Megan				X
Emma				X

*Table 31: a summary of the different levels of social interaction that were displayed by participants in the iA environment as discussed above*

In addition to the behaviour noted through analysis of the videos, practitioner feedback documented participants' exploration of social interactions. Some of the practitioners commented on the positive social interaction they encountered. One noted that Amy 'was really confident and wanted to play a lot. She was very open to interaction.' When discussing Megan, a practitioner said that she interacted 'really well... she seemed to interact with me the most of the practitioners. She copied me and used similar sounds and movements to me when she was a

<sup>161</sup> These non-responses were deemed to be significant as the rest of these participants' interaction was at a higher level. David and Ed also displayed several examples of this.

<sup>162</sup> The other participants in the proactive category did display some of these behaviours although they predominantly interacted at a proactive level.

penguin.' Of Annabelle, one practitioner observed that she interacted 'very confidently and kept coming back to interact. Very pleasant and friendly.'

However, some difficulties were still observed. In the second session a different practitioner commented that Annabelle 'didn't seem interested in me unless we were playing hide-and-seek. When I did give her direction or things to do she seemed unkeen [sic] to follow them.' This was similar for Amy: having been very open to interaction in the first session, a practitioner noted that her interaction was 'good, but she wasn't that interested in me.' One practitioner observed that William's interaction was 'very up and down, at times he was really with me and interacting with me and then he would go off on his own.' These comments were backed up by the footage and demonstrate that although some participants were capable of more complex social interaction, that they still had issues with it. These might be expressed through avoiding it, e.g., spending time outside of the pod or away from the characters, or by ignoring an offer of interaction from a character, e.g., when William ignored several attempts at interaction initiated by the Penguin. It is difficult to know why the participants did this. It may be a result of deficits in social interaction abilities. It could also be that the participants lacked interest in the pod the second time around because it was very similar to how they had experienced it during the first session (as may be seen with Annabelle and Amy), or that they needed time out to process the environment, e.g., there were a couple of occasions where during the first session where William removed himself from the action and sat down popping bubble wrap. This was assumed to be 'stimming'<sup>163</sup> behaviour and once he had spent a couple of minutes doing this, he returned to engaging with the environment. They may also lack the desire to 'please' people and so if they do not want to engage they simply indicate this rather than pretending to play along.

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<sup>163</sup> Self-stimulatory behaviour: 'repetitive body movements or repetitive movement of objects' (Edelson 2016).

One final thing to note is that across all levels of interaction a pattern was seen in which the increase of capabilities of social interaction generally matched the increase in the ADOS-2 module number used and the decrease in scores (the lower the score the less affected the individual is). This suggests that participants with lower verbal abilities tended to engage in less social interaction with the practitioners than those who had higher verbal capabilities. This was despite some of the characters being nonverbal (Penguin and Snowman) and interacting differently to the verbal characters. This raises questions as social interactions are predominantly modelled on verbal capabilities and it may be that those who are nonverbal (or less verbal) *do* engage in social interaction, but in a different sort of way which is not well captured by existing analytic frameworks (e.g., the ADOS-2 and diagnostic performance tool used for this research) or understood by society generally. This notion has been discussed by Blackman (in Savarese and Zunshine 2014: 23),

It may be that the social deficits which are the cornerstone of an autism spectrum diagnosis tell us far more about the person who made them markers for such a diagnosis than about the child whom she observes... That is, the whole testing procedure is somehow actually constructed on whether the tester observed the person to socialize in a way that the tester understood to be socialization... We often use the term "communication" when really we mean that we have observed in another human being a behavior from which we derive meaning.

Therefore it may well be that environments such as the iA one allow for more nonverbal modes of social interaction to be explored but that current evaluation tools do not capture these as successfully as social interactions based on verbal capabilities.

## **Facilitator**

Alongside the practitioners who performed in role as characters there were practitioners who did not and instead had roles as facilitators, aiding the action in non-performance-based roles. There were three types: the camera operator; technician; and the facilitator-practitioner. The camera operator and technician had practical tasks within the

environment filming and operating the technology. Minimal interaction between these practitioners and the participants occurred as they only tended to interact if the participant initiated this. The author was a facilitator-practitioner and took a role that was partially within the pretence framework, operating through facilitation of the action, whether this was through performing in role, acting as an outside eye to guide the interaction or facilitating other roles when practitioner availability was low, e.g., as camera operator or technician. The facilitator-practitioner was therefore more likely to interact with the participants spontaneously to aid the participants' interaction with the environment. Overall there were a few examples of participants interacting with these individuals (see Table 32). This may have been because of the ambiguous nature of their roles – participants were unclear whether they *should* interact with them. It may also have been that these practitioners were less forthcoming in their social interaction with participants and less interesting in comparison to the practitioners performing as characters. Although there were only a few examples of social interaction with them, these will still be mapped onto the adapted Sounds of Intent framework and their significance discussed.

### ***Camera Operator***

Some non-responsive behaviour was shown by William towards a camera operator with whom he had previously established a relationship (see Figure 14). When she said to him 'you haven't found the penguin yet. Do you want to find him?', he responded 'no' and continued with his activity. Ed also ignored a suggestion from the camera operator to find another snowball.

There were a few examples of proactive behaviour demonstrated. When Emma was playing hide-and-seek she turned and directed both gestures and speech towards the camera operator (see Figure 36). After Emma had found the Snowman she said to the camera operator

[REDACTED – Figure 14]

that she would go and find the Penguin. William interacted with the camera operator on several occasions in this way. He spoke to her directly and said 'hello', then introduced himself as Thomas (he was wearing a Thomas the Tank Engine T-shirt). He asked her some questions and offered responses to

hers. He was then happy to follow her direction to go to the pond and help with fishing, which the other characters and Megan were doing. When the camera operator was trying to film him and he was running around the pod, he turned to her and said 'you can't catch me'. When the Penguin was trying to sabotage him running around the pod, he turned to the camera operator and said that he thought that the Penguin did not want him to go that way. He also threw a snowball at the Penguin after the camera operator suggested this. In the second session, when inside the cave he invited her in, saying 'come one' and then 'come inside' to her. Amy also took an interest in the camera operator and asked to take control of the hand-held camera, she then interacted briefly with the environment through its lens (see Video 16).

### ***Technician***

There was minimal direct interaction with the technician, who was not always present in the sessions. The only direct interaction came from William who approached her on two occasions. Near the beginning of the first session he picked up some snow and threw it over her, after seeing the other characters and Megan throwing snow. In the second session he sat next to the technician and watched as she altered the sound effects. He leant on her and looked at the laptop while he pressed some buttons (see Video 17). Amy was aware of her as she would look

towards the technician when she called for the storm in the first session, and commented on the technician's absence in the second session.

### ***Facilitator-Practitioner***

There were a couple of examples of the participants interacting briefly with the facilitator-practitioner across three of the adapted framework levels. Emma showed some non-responsive behaviour when the facilitator-practitioner offered her the option to try one of the fish that the characters had caught (pre-empting the fish-tasting game discussed on page 239): walked away instead and called her cousin on the microphone. Interactive behaviour was demonstrated by Emma when she showed enjoyment through laughter when the facilitator-practitioner was dropping snow on her. Later in the session, when she was working around the pond and the facilitator-practitioner asked which of the fish she thought that the Penguin and Snowman should catch, she pointed to one and said 'the big yellow one'. Proactive behaviour was demonstrated by Amy who drew the facilitator-practitioner into the action, saying that the fish Amy had hidden was near to her. William also picked up a tube and spoke down it to her.

In conclusion, although the social interactions that were engaged in with these individuals were not as extensive as those engaged in with the characters, it is still noteworthy that interactions occurred. The participants were much more forthcoming towards the characters, engaging in multiple examples of social interaction at different levels. This may have been because the facilitators were not as forthcoming with their social interaction, or because the participants were aware of the pretence framework and the ambiguous roles that the facilitators played within it. The latter possibly would demonstrate an understanding of more complex social roles within such an environment.

It is notable that William demonstrated several instances of spontaneous and proactive engagement with these practitioners which was surprising considering the small amount of interaction that he had with the characters. It might be that he preferred to interact with

‘people’ or that he was not aware of the implicit rules of engagement functioning within the iA environment.

These examples provide further instances of social interaction for use in diagnosis and offer an alternative view to that implied in the ADOS-2. The lack of interaction with facilitators from most of the participants may have been due to their understanding of complex social roles, this not being something explored within the ADOS-2. Alternatively, it may have been that these participants were not as interested in the facilitators, perceiving them as less exciting than the characters. In either case, their presence provides more information and opportunities for live social interaction than currently would be available within the clinical ADOS-2 approach, which focuses on a one-to-one interaction with a person who is actively trying to engage the subject.

level of social interaction	facilitator		
	camera operator	technician	facilitator-practitioner
non-responsive	Ed and William		Emma
minimal		Amy and William	
interactive			Emma
proactive	Amy, William and Emma		Amy and William

*Table 32: summary of the level of social interaction between participants and facilitators in the iA environment*

### **Peers<sup>164</sup>**

For most of the sessions the participant had a peer in attendance. Ideally this was another participant, but when this was not possible a family member or friend was brought along who was in the age range specified for the project (see Table 33). Peer interaction was not forced but was encouraged where appropriate, meaning that for some children peer interaction did not occur. This is something that cannot currently be observed in the clinical ADOS-2, although questions are asked in module 3 which evaluate how the subject understands the

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<sup>164</sup> see Appendix 22 for detailed descriptions

concept of friendship. Therefore, in its observation of peer interaction, the iA environment distinguishes itself from the ADOS-2.

There were only a few examples where there was interaction between participants unknown to each other, due to circumstances beyond the author’s control. This causes issues for the analysis of peer interaction due to problems in generalising beyond the specific context. However, the examples will still be explored to consider what the behaviour displayed can contribute to the current understanding of autism and the impact of peer presence on assessment.

The discussion will begin with Annabelle and Amy as these were the only two participants who were unknown to each other and they attended both sessions together. Following this, the relationship between Annabelle, Ed and Amy will be considered as Ed came to their second session. Ed’s interaction with Harriet will then be explored, as this was the participant who he worked with in the first session (unfortunately he was absent for the second scheduled session with Harriet). Next, William and Megan will be discussed; however, because they were siblings, limited analysis can be applied to their behaviour, due to their mutual familiarity prior to participation in the research. Similarly for David and Emma, a relative (cousin) attended due to the unavailability of other participants.

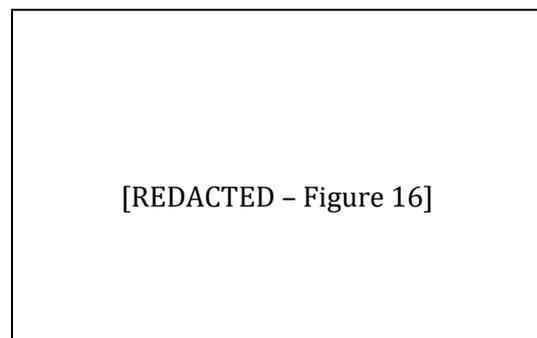
session code	participants present
1A	David and cousin
1B	David and cousin
2A	Harriet and Ed (Ed arrived late)
2B	Harriet (Ed absent)
3A	Annabelle and Amy
3B	Annabelle, Ed and Amy
4A	William and Megan (siblings)
4B	William and Megan (siblings)
5A	Emma and cousin
5B	Emma (cousin absent)

*Table 33: the list of participants in each iA session*

The framework which was used to analyse social interaction with practitioners and facilitators will not be used within this section as it is predicated on the willingness of at least one party in the interaction to actively continue it (the practitioners who performed as characters actively sought out the interaction and the facilitators would continue the interaction if this was made possible by the participant). Peer interaction differs in that it does not have to be reciprocated by either party, hence problematising the use of the framework in this section. However, any examples of proactive social interaction (predicated on both parties continually engaging in it) will be noted.

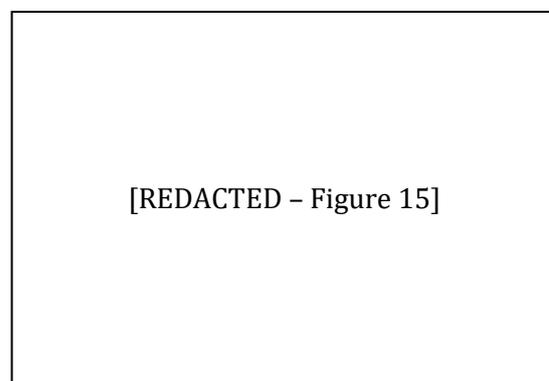
### ***Annabelle and Amy***

These two participants provided multiple examples of successful proactive social interaction. They established a connection almost immediately, with the initial interaction within the environment coming from Annabelle who offered a snowball to Amy to help wake the Snowman up. This occurred within minutes of entering the environment. They worked together



to help get the Snowman up (see Figure 16), communicate with him and then go fishing together (see Video 18 and Figure 15). Some more playful interaction occurred when Annabelle appeared dressed as a bear and attempted to scare Amy

(discussed on page 234-235). Amy understood this transformation and responded by saying 'Oh no. Run!', picking up some snow and throwing it at her. When Annabelle came out of the cave, Amy playfully screamed and threw a snowball at her. This engagement was continued in the second session and both participants clearly enjoyed interacting with each other. They dressed up as penguins, played hide and seek, and did the hokey cokey together.



This social interaction is the most interesting of the examples in this section as it clearly displays an ability and desire to engage in social interaction with peers. The participants could both successfully initiate and maintain friendship, which contrasts with some findings in the literature, and difficulties noted in the diagnostic criteria (APA 2013). The example where Annabelle appeared dressed as a bear and Amy clearly understood how this altered their relationship, demonstrates flexibility in social interaction and an understanding of ToM. It is interesting to compare their behaviours to those reported in the diagnostic letters. It was noted that Annabelle 'prefers to play alone and is often in her own world' and Amy 'struggles to engage with other children' and 'doesn't really show much interaction with peers although she doesn't actively avoid them'. This contrasts significantly with the behaviours witnessed in the iA environment.

### ***Annabelle, Amy and Ed***

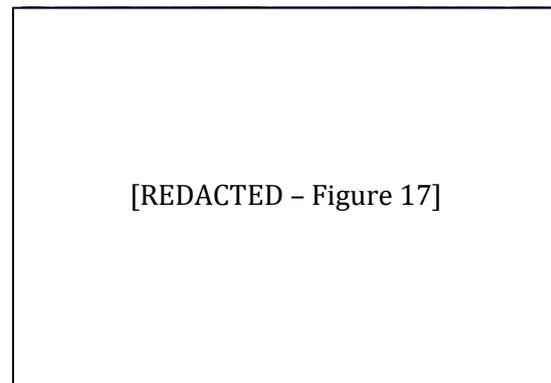
Annabelle and Amy were very interested in Ed when he attended their second session, having not been present in the first one. They attempted to interact with him, demonstrating their curiosity and desire for social interaction (see Video 19). They called for him on the microphone while he was outside of the space after this was suggested by the Inuit, initially calling 'friend' and then his name. He came to the edge of the pod and looked in at them and Annabelle and Amy responded positively. This interest was continued as Annabelle asked what it meant when Ed was making sounds (he was nonverbal) and offered concern towards him at the end of the session. Unfortunately, the relationship between the three participants was never fully realised, partly due to a lack of social approach or response from Ed and his lack of engagement in the pod (he spent most of his time outside of it).

Again, both Annabelle and Amy displayed a willingness to attempt social interaction with someone else and were particularly intrigued by him. Although they were guided through the interaction by the Inuit who suggested that they call for him on the microphone, they

continued to show interest in him displaying concern later in the session. The difficulties that Ed showed in social interaction aligned with difficulties that are perceived to be present in regard to autistic people's social interaction and this was noted in his diagnostic letter: 'he doesn't really play with them [other children]'. However, Ed did respond to his name being called and smiled as he went over to the edge of the pod, demonstrating some pleasure in social interaction.

### ***Harriet and Ed***

Ed arrived at the session late and as soon as Harriet was aware of his presence she found a bear hat and took this over to him (see Video 20). This interest and desire for social interaction was encouraged by the practitioner who was performing as the Inuit:



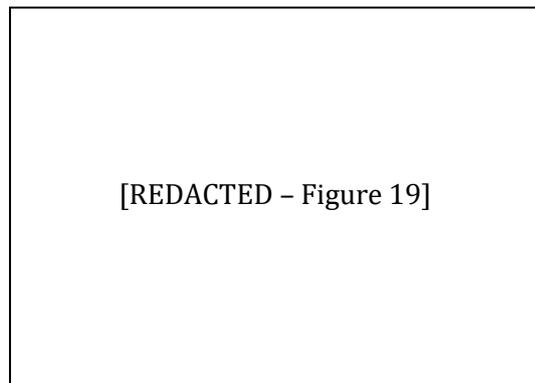
when [Ed] entered the space, she said to me 'he seems shy' and after I said 'yes he does seem a little bit shy doesn't he' she replied 'maybe he would like a hat too'. She then initiated finding a hat for [Ed] to wear to try and make him feel more comfortable in the space.

However, she did not get a chance to fully offer this to him – Ed got distracted by a toy that the Inuit was holding (see Figure 17). The Inuit had to draw attention to this verbally, asking Ed via Purdy if he wanted the hat. Harriet's curiosity and attempt to engage Ed continued and towards the end of the session she was actively trying to engage him (see Video 21). She called his name and tried to direct his attention by saying 'look'. She then took a toy over to him, operating it near him so that he could have contact with it and then giving it to him. Her interest in interacting with him was further documented in the practitioner's notes:

She also decided to stay round the entrance to the space, where [Ed] was whilst throwing snow, tickling and sneaking up on the snowman to try and get [Ed] to join in with her... She also helped to involve [Ed] too so she must have thought it was a good place to be and she was confident enough to try to involve him too.

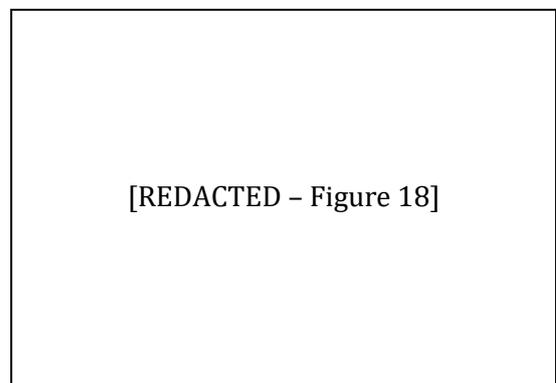
This behaviour shows a desire for social interaction and varying attempts to initiate this; however, this was met with rejection from Ed. This behaviour contrasted somewhat with Harriet's diagnostic letter, in which her parents reported that she 'had difficulty sharing with other children', even though her first interaction with Ed was an attempt to share a hat with him. This demonstrates that although there were skills present, there were also difficulties which were displayed by both participants: Harriet was unable to initiate social interaction in her first encounter with Ed; and Ed displayed an apparent lack of interest in engaging with her socially except when she had something that he wanted, e.g., the bubble toy, further illustrating the kinds of difficulties with social interaction present in autistic people.

### ***William and Megan***



These two participants were siblings so, as mentioned previously, any conclusions drawn from their interaction are done so with caution. As would be expected they showed several examples of social interaction. They worked together to wake up the Penguin and rescue the penguin toys from

the storm. They had a more playful interaction when they played the 'help, help' game set up by William (discussed on page 245). In the second session they demonstrated skills in turn-taking with their work on the microphone. William initiated this and blew a 'raspberry' on the microphone and then said 'your turn [Megan]' (see Video 22 and Figure 19). There were, however, some difficulties shown by William with social interaction, demonstrated on several occasions. He tended to interrupt Megan's engagement with the environment, attempting to shift her focus onto something he wanted to do. This was seen when Megan was working with the



Penguin and William came up and interrupted the action wanting to feed the Penguin. He walked up to Megan and said 'give that to me, taking the fish that she was holding and then offering it to the Penguin (see Video 23 and Figure 18). Later in the session when Megan was setting up the comic interaction (discussed on page 241-242), he pretended to need rescuing from the pond and then directed Megan to do so, interrupting her comic setup. In the second session he wanted her to come outside and play in the snow. He took her by the arm and pulled her outside when she was already interacting with the practitioners. Another example was seen when he was in the cave with the practitioners and invited Megan in. When she did not come, he went out of the cave to get her.

These examples demonstrate abilities to engage in social interactions that would be expected between siblings; however, generalisations need to be made with caution because of their pre-existing relationship. It is interesting to consider William's relationship to social interactions, as the examples demonstrate a lack of awareness from him as to how his peer was engaging with the environment and whether she would want to engage with him at that time. On four occasions he interrupted Megan's engagement with the environment, attempting to direct her attention elsewhere onto an activity that *he* wanted to do. This demonstrated a lack of awareness surrounding appropriate social approach and interaction, and a lack of consideration for her perspective i.e., that she might not want to engage with him at the time. This accords with existing concepts surrounding difficulties with social interaction and ToM, as previously discussed.

### ***David***

David engaged in very limited social interaction even though the peer was his cousin. There were some very brief moments of interaction but David did not initiate them and his cousin was too engaged in the environment to interact with David, who spent most of the time outside the pod. This was the case during both sessions. Therefore, not much can be concluded

from this other than that David tends to avoid social interaction, even with a familiar person, which accords with difficulties noted in social interaction in autistic people.

### ***Emma***

As with the analysis of the interaction between William and Megan, caution has to be exercised when considering the peer interaction that occurred between Emma and her cousin, who was present in Emma's first session but not the second. As would be expected from this relationship there were several moments of social interaction: they sung on the microphone together, woke the Penguin up and played hide-and-seek. There were some moments where Emma attempted to attract her cousin's attention, showing proactive levels of social interaction: she called her and then pointed, drawing her attention to the microphone; she suggested that they fix the Penguin's house; and she called for her on the microphone when her cousin was outside the pod. There was an active seeking of social interaction with her in the environment.

However, some problematic issues were evident. There appeared to be a tension within Emma about whether to interact more fully with the environment or copy her cousin who was less engaged. She would follow her cousin when she went outside the pod, even if it appeared that she wanted to be inside it herself. There were some instances where Emma copied her cousin's behaviour: when her cousin declared that she did not like birds (when Purdy entered), Emma copied this. Indications of her cousin's influence and then how her behaviour was altered when she worked on her own, were reflected in practitioners' comments. One practitioner noted, 'I think she enjoyed it but was interested in copying her cousin and wasn't confident in leading her own activities', further supported by the second practitioner: '[she] was at times more interested in copying/following her cousin'. Emma did, however, try to counteract this by attempting to draw her cousin into the environment and direct her attention, although this was not always successful. There was an interesting moment of attempted compromise by Emma (see Video 24). They had sung a song on the microphone to get the storm to go away and after

they had succeeded her cousin said to her 'I did it', which she repeated back. Her cousin then said it again and Emma replied 'we did it', to which the cousin responded 'I did it'. Emma replied with 'we did it' and her cousin then repeated '*I* did it'. There was a change in the nature of Emma's engagement noted in the second session due to her cousin's absence, with one practitioner suggesting that she 'interacted much better alone'.

This interaction between the two not only provides further evidence for strengths but also illustrates more difficulties with social interaction. Emma clearly wanted to engage more in the environment than she did in the first session but tended to copy her peer's behaviour. This fits in with theories surrounding imitation and coping strategies employed by females, which can be used to mask their autism. Her desire to copy her cousin was not an issue in the second session as her cousin was not present, and a significant improvement in her social interaction was noted.

In conclusion it has been demonstrated in the above examples that most of the participants in this study were capable of social interaction and had a desire for this with their peers. This was clearly demonstrated by Annabelle and Amy who were quickly and successfully able to develop a solid rapport, even though they had never met each other: they interacted in a playful and flexible way, actively seeking out peer interaction to enhance their experience. Even when there were issues with social approach, as could be seen with Harriet and her approach to Ed, there was still a spontaneous attempt at engagement, supported by practitioners but led by the participant. This desire for social interaction was also evident in William and Megan who proactively interacted with each other in both sessions. It is, however, problematic to draw conclusions based on the behaviour of these two participants because of their prior relationship to each other.

However, there were still some issues with engagement apparent which support the notion of autism involving deficits in social interaction. Both David and Ed had a seemingly limited interest in engaging or seeking out social interaction with their peers. It is interesting that both participants were assessed using module 1. This again reveals potential problems in assessing social interaction in nonverbal individuals. It may be that for these participants there is not a lack of interest or difficulty in social interaction, rather that it is approached differently and in a way not understood by observers, as suggested by Blackman (in Savarese and Zunshine 2014). Difficulties were also displayed by those participants assessed using module 3 who were more verbally able. Although Harriet was keen to engage with Ed, she did not necessarily have the right social approach and required support from the practitioners. In addition to this, William would often interrupt Megan's engagement with the environment in order to focus attention on something that *he* wanted to do. This demonstrates a lack of awareness as to when it is appropriate to approach an individual for social interaction. Emma also displayed several issues, compromising her own experience of the pod to copy and satisfy her cousin's needs. It appeared that she felt some social pressure to work with her cousin, rather than in the way she wanted to, which ultimately had an impact on her experience of the iA environment.

Gender differences were seen in peer interaction, with the females actively seeking out social interaction more than their male counterparts. Furthermore, two of the female participants (Megan and Emma) clearly allowed their experiences of the environment to be altered in order to satisfy their peers. Megan allowed William to interrupt her on several occasions, causing her to stop or alter what she was doing in the environment to fit in with what he wanted her to do (although the pre-existing relationship of the two makes it problematic to generalise from this). In addition to this, Megan was the older sibling and therefore may be inclined to interact with her younger sibling in a particular way, taking a caring and concerned role to suit the needs of William. Emma arguably interacted differently, and to a lesser extent, with the environment when her cousin was present. Her behaviour was significantly different in

the second session and she actively engaged with the practitioners and environment more. However, caution must be taken in generalising from this as it was not witnessed how she interacted with peers who were strangers. She may prefer to interact with adults or she may have felt more pressure to do so, being the only participant present in the session.

The role of peer interaction is very important and yet is not explored within the ADOS-2. Although it is explored through questions in higher module levels there is currently no space within the tool to *observe* how this occurs. This peer observation could be valuable in determining levels of social interaction with people of a similar age, rather than just with adults (as is seen within the clinical ADOS-2). This may reveal difficulties but also show strengths and would help to develop a more holistic view of the individual.

### **Puppetry (Purdy)<sup>165</sup>**

The final opportunity for social interaction available to the participants was through a small hand-held bird puppet called Purdy. He was the only puppet used in this research; however, other puppets have been used in the AHRC iA project with positive responses from the participants noted.<sup>166</sup> All of the participants engaged with him at some level but the focus of this section will be on David and Ed as they had more interaction with Purdy than with the practitioners or their peers. There will also be a brief note on one interaction between Purdy and William, one which shows some difficulties in participants understanding the role of the puppet.

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<sup>165</sup> see Appendix 23 for detailed descriptions

<sup>166</sup> In the Forest environment there was Dennis, a woodpecker, there was an alien puppet in Space and in Under the City there was. See Trimingham and Shaughnessy (2012) for a discussion on Dennis; Shaughnessy (2016a) the alien; Trimingham (2012) Roland the Rat; and Trimingham (2010) for a wider discussion of puppets.

## **David**

As discussed earlier in the chapter, there was limited social interaction seen between

[REDACTED – Figure 20]

David and the other people present in the environment, with his diagnostic letter indicating that he ‘took little enjoyment in interaction with the therapist’. However, he responded well to Purdy showing several instances of social interaction. In the first session the main interaction that occurred between the two was through a small Thomas the Tank Engine toy that David had brought into the environment and which made sounds when it was pressed (see Video 25). David offered this toy to Purdy who sniffed it and then made sounds indicating disgust, which made David

[REDACTED – Figure 21]

laugh (see Figures 20 and 21). This was repeated on several occasions during the session receiving positive responses from David. The repeated offering of the toy to Purdy indicated that David actively wanted the social interaction to continue and his enjoyment was displayed through smiling and laughing. Evidence for this was found in the practitioner feedback:

I felt he was very unresponsive throughout most of the session. The bird, however, was the best mode of interaction, he seemed to like it a lot. The attention was on the bird rather than myself, even when the bird was not being puppeteered... The key moment was when the bird came out and played with [David]. There was a sudden sense of interest that he didn't see with the other characters.... It was obvious he saw a comfort... in the bird.

This was further supported by the practitioner who was operating Purdy: ‘the puppet worked well and he responded better to the bird than when I didn't have it. He wouldn't interact with just me or the Inuit character I was playing.’ The practitioners also noted the differences in his use of eye contact: ‘he didn't make eye contact with me, he sometimes did with the puppet.’

These examples show that David has capabilities in social interaction which can be explored through puppetry. Although he demonstrated a lack of skills in social interaction with people, the connection that he established with the puppet allowed him to demonstrate skills in this area that were otherwise not apparent. Puppets are not currently used within the clinical ADOS-2, although there are toys available that may be used for a similar effect, e.g., animating them to tell a story. However, the puppet allows more flexibility and could arguably be perceived as being more 'alive' than the toy, due to a greater flexibility in what puppets can do in comparison to 'static' toys.

### ***Ed***

Ed also demonstrated skills in interacting with Purdy although there were less examples of interaction in comparison to David.<sup>167</sup> Ed enjoyed playing games with Purdy: Purdy would count to three and then 'fly' alongside Ed who was running on the outside of the space.<sup>168</sup> Another notable interaction between Purdy and Ed occurred in the second session when Ed was laying outside the pod and Purdy was by his side (see Video 26). Purdy attempted to interact with him and Ed allowed him to peck him gently while Purdy said 'peck, peck, peck'. After a couple of iterations of this, Ed imitated this back to him saying 'peck, peck, peck' and using a similar pattern of intonation. This was the only time that Ed made explicit vocal contact with something in the environment.

Despite Ed showing less examples of social interaction with Purdy, they still demonstrated certain capabilities. He clearly enjoyed the interaction with Purdy, shown through his smiling. His imitation of Purdy's pecking showed a desire to interact with the puppet, potentially using imitation as means to initiate this interaction. It may be that Ed

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<sup>167</sup> This may have been partly because Ed was late to the first session and therefore spent less time overall engaging in the environment.

<sup>168</sup> Within the diagnostic letter it was noted that Ed engaged in stereotypical play that included 'running up and down'.

preferred and had greater skills in, interacting with puppets, because of their reduced social communication (e.g. less non-verbal communication) which makes it easier to read than a human face, providing support for the notion of autistic people having difficulties with understanding nonverbal communication as reported in the DSM-5 (APA 2013).

### ***William***

The final example illustrates some difficulties involving a participant understanding the role of the puppet (see Video 27). William, who, as discussed earlier, demonstrated skills in interacting with the people in the environment, displayed such issues in an interaction with Purdy. Purdy called him into the pod, attempting to get William to come and find him (he was hidden under some bubble wrap but the puppeteer was not). Purdy said 'I bet you can't find me' and William responded, 'I can. There you are' and pointed to the puppeteer.

This section has demonstrated that participants interacting with the puppet was able to reveal abilities to engage in social interaction that were otherwise not displayed in interactions with people. This shows how puppetry could be a useful tool for engaging with some autistic people, further demonstrated by the fact that these participants interacted better with the puppet than with other people. Results from this study indicate that the participants who had lower verbal abilities preferred social interaction with the puppet, perhaps due to the prominence of nonverbal behaviours in puppets in comparison to people. This was also noted in Trimmingham and Shaughnessy (2016b): 'particularly towards the more severely affected end of the spectrum, [autistic children] interacts with it [the puppet] more readily than with a human' (p. 300). In any case, puppetry is not currently an interaction tool used within the clinical ADOS-2 and so the latter may fail to display the social interaction potential of some autistic people.

## Conclusion

In conclusion, this chapter has discussed a wealth of examples of social interaction with a wide range of people (as well as puppets), that illustrate skills in social interaction, thereby challenging current thinking which sees difficulties in social interaction as a core deficit in autistic people (APA 2013). Part of the analysis of these behaviours was carried out through an adapted framework based on the Sounds of Intent model. This helped to organise the observed behaviours into levels of interaction and demonstrated a range of skills in participants' social interaction, across the four levels proposed. The social interactions displayed in the iA environment demonstrated associated skills in ToM, empathy and play, further contrasting with existing notions of deficits in autism.

However, despite these skills, difficulties were still demonstrated, particularly with the module 1 participants who had significant problems in this area. Gender differences were also apparent, supporting theories of masked difficulties in autistic females. It is important that the difficulties in social interaction are witnessed, as the role of the iA environment and this research is not to remove these (and with them the diagnostic label), but instead to provide supplementary information to support the diagnostic process and present an alternative, strengths-based view of the individual.

The role of the iA environment in allowing the facilitation and observation of the social interaction behaviours has shown missed opportunities within the clinical ADOS-2 to assess practical explorations of social interaction, which could lead to a more complete understanding than simply interviewing an individual. The iA environment further expands on the ADOS-2, offering observation of peer interaction, as well as more complex multi-person interaction which is not possible in current ADOS-2 practices. Furthermore, the practitioners and space are reactive to the participant which allows for in-the-moment responses to be explored in a flexible manner – this approach differs considerably from scripted activities seen in the ADOS-2

presses. As was demonstrated in Chapter 4, information needed to fill out the ADOS-2 codes and subsequent algorithm can still be successfully gathered without relying on these scripted presses. This suggests that the more rigid presses of the ADOS-2 do not necessarily need to be completed to successfully diagnose and that engagement in the iA environment may in fact enhance knowledge related to social interaction, thus supporting the strengths-based model and perhaps also revealing more subtle difficulties in certain groups, e.g., females. These brief conclusions made here will be extended in Chapter 7 which will discuss the overall findings. The following chapter explores the performance intent that is elicited in the iA environment.

## CHAPTER 6: QUALITATIVE ANALYSIS – PERFORMANCE INTENT

This chapter will extend the discussion that was presented in the previous chapter surrounding the alternative information that can be provided for the diagnostic process by a drama-based environment, focusing on behaviours that are here described as those with ‘performance intent’. This term is taken from performance studies (e.g., Schechner 2013) but has meanings that extend beyond drama and theatre practices, as will shortly be discussed. Within the context of this thesis, performance intent is understood as a conscious alteration in behaviour of an individual for interaction with another that requires a transformation of body, presence and/or space, not necessarily reflective of any acting ability. The behaviours recognised as performance intent have been divided into subthemes: performing as other; prop interaction; humour production; authorship; and acknowledgement of artificiality.

As in the previous chapter, the data was retrieved through transcription of the footage of the practical sessions, this then being organised into themes that emerged from the data. These are ‘alternative’ behaviours in that they challenge the current understanding of autism and lead to alternative constructions of the condition that focus on strengths, viewing autism through the arts rather than the sciences (as discussed in Chapter 1). The behaviours classified here as performance intent contribute to the growing body of research and practice that demonstrates the positive role of drama with autistic people, challenging notions of deficits in imagination (e.g., Kempe and Tissot 2012; Godfrey and Haythorne 2013; Lewis and Banerjee 2013; Pimpas 2013), pretence and social interaction (e.g., Lerner, Mikami and Levine 2011; Guli et al. 2013; Corbett et al. 2014a, 2014b, 2016). The fact that such drama-based environments can reveal these skills demonstrates their importance in contributing to the understanding of autism, extending and challenging current understanding that is embedded within scientific and

medical models. A drama-based approach moves away from deficit-based models, focusing instead on capabilities, and aligns with more recent thinking surrounding differences rather than deficits in autism.

This chapter explores behaviours that are likely to be unique to a drama-based environment and are therefore not likely to be seen in the clinical ADOS-2, yet contribute to the alternative construction of autism by providing examples of participants' skills. The behavioural theme that has been derived from the analysis of the video footage from the sessions is performance intent. As in the previous chapter, the subthemes will be introduced within each section and discussed in relation to examples from the practical research, showing how these extend and contrast with the clinical diagnostic report and understanding of autism more widely. More detailed descriptions of the behaviours are found in the appendices, and video clips and photographs support the written descriptions where relevant. In addition to this, comments from the practitioner feedback forms are included where appropriate.

An alternative pre-existing framework to that which was used in Chapter 5 is used in this chapter to help construct the analysis. This is a framework developed by Intensive Interaction which was mentioned in the Introduction: the 'Framework for Recognising Attainment' in Intensive Interaction' (Firth 2011). This framework has been selected partly because of the similarities in methodological approaches that are seen between Intensive Interaction and iA, in particular the role of imitation and the intention to meet participants at their level of interaction/functioning. Furthermore, the framework is used as a recording system for an intervention that is based on a 'process' rather than a 'skills' based intervention', which aligns with the iA working methodology (Firth 2011: 2).<sup>169</sup> A different tool has been used to analyse performance intent in comparison to social interaction (see Chapter 5), as

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<sup>169</sup> This is similar to 'The Play Progression Model' developed by Sherratt and Peter (2002 and 2006) and used by Howarth (2011). This model is divided into encounter, awareness, response, engagement, participation, involvement and achievement.

engagement in drama and theatre practices can bring out behaviours in autistic people that are not seen in other environments, challenging perceptions of skills and deficits. This framework provides a more detailed analytical approach than was used in the Sounds of Intent framework for this thesis, offering a greater number of levels at which to analyse behaviour, helping to more effectively unpack and understand such (arguably more complex) performative behaviours.

The Intensive Interaction framework was originally developed to assess attainment within the Intensive Interaction programme and involves a series of steps of attainment, with examples used to document how the levels are achieved. The framework therefore fits into strengths-based models. This has been adapted for use in this research as an analytical tool for assessing the data. Instead of considering attainment (as seen in the original version) the focus has been shifted to viewing levels of performance intent, providing a framework for observing interaction as a basis for demonstrating creative engagement within the iA environment (see Table 34). The framework is predicated on interactions and so builds on the discussion of social interaction behaviour from Chapter 5.

level of performance intent interaction	description of performance intent interaction
encounter	The participant is present during a performance interactive encounter without any obvious awareness of its progression.
awareness	The participant appears to notice, or fleetingly focus on, a performance object, event or practitioner involved in the performative interactive encounter.
<i>declining</i>	<i>The participant rejects invitation into a performance interactive encounter.</i>
attention and response [positive and negative]	The participant begins to respond (although not consistently) to what is happening in a performance interactive encounter. This can be through showing enjoyment or dissatisfaction at the encounter.
engagement	The participant shows consistent attention to the performance interactive encounter that is presented to them.
involvement	The participant makes active efforts to reach out and consistently join in, or even comment in some way on, the performance interactive encounter.
participant initiated interaction	The participant independently starts a performance activity (that cannot be described as repetitive or self-absorbed behaviour) and engages another person in the encounter with social intent.

Table 34: the Performance Intent Framework used for analysis in this research which was adapted from the framework used for assessing attainment in Intensive Interaction

In adapting the original framework, one of the levels, 'participation', has been deleted. The behaviours that are described within this attainment level were deemed to be inappropriate as they were rarely displayed within the iA environment (aside from a few examples of turn-taking) and therefore unhelpful for analysis. An additional level, 'declining' (shown in italics in the table) was incorporated to include examples of when a participant acknowledges an offer of performance interaction but responds with rejection, causing the interaction to be terminated.<sup>170</sup>

## **Performance Intent**

The use of this term has arisen within the discussion surrounding 'performativity', a word which is used slightly differently across disciplines. Performativity has been used by philosophers of language to 'indicate that the issuing of the utterance is the performing of an action... not normally thought of as just saying something' (Austin 1975: 6). An example of this might be at a wedding where the person leading the ceremony pronounces the couple to be 'husband and wife'. Sociologists such as Goffman (1959) have used it to define human behaviour more widely. It has been used by philosophers in relation to gender theory, with gender being described as a repeated act that becomes ritualised and then a societal norm, and therefore performative (Butler 1993, 1999; Salih 2002). Additionally, the term has been used within theatre studies to describe a 'manipulation of the body' and 'the manipulation of space' (Féral 1982: 171-172), in which to experience 'one must simultaneously be there and take part in it, whilst continuing to be an outsider' (Féral 1982: 179). 'Performativity' can therefore be a problematic term to use due to the variety of its definitions. Therefore, the preferred wording

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<sup>170</sup> Examples of this level are not discussed in this chapter, although it is important to highlight the possibility of this type of interaction for future research.

used here will be 'performance intent' which grounds itself more firmly in theatre research, placing emphasis on an intentional and conscious alteration rather than an unconscious change of behaviour influenced by external sources.

Performance intent is not currently explored within the clinical ADOS-2 or used as part of the diagnostic criteria. However, the masking and imitation behaviours that are seen in autistic females (NAS 2012; Hiller, Young and Weber 2016; Attwood 2017; Dean, Harwood and Kasari 2017; Hull et al. 2017) could arguably be described as instances of 'performance intent'. The behaviours that are examined in this chapter help to challenge current understanding of autism focusing on the strengths and skills of the individual. This, in turn, could provide useful information for diagnosis (and post-diagnostic intervention and support) that would prove beneficial in generating holistic profiles of autistic people and contributing to the understanding of autism as a whole.

The role of play is central to the discussion surrounding performance intent. Play is present within the clinical ADOS-2 (which is offered as a play-based tool). Furthermore, there are specific ADOS-2 presses which test play. In module 1, two of the activities are specifically play-driven ('free play' and 'bubble play') and another is based on functional and symbolic imitation, which can be linked to play. The information from the presses is used to score two codes, 'functional play with objects' and 'imagination/creativity', but neither of these codes contributes to the algorithm scores. This is similar for module 3, in which two activities ('make-believe play' and 'joint interactive play') are conducted. In contrast to module 1, there is no coding section based on play it is instead described as 'imagination/creativity' and, similarly to module 1, this does not contribute to algorithm scores. While difficulties in play have been acknowledged in autistic people (Hammes and Langdell 1981; Baron-Cohen 1987; Rutherford and Rogers 2003; Lam and Yeung 2012), and play is used within the clinical ADOS-2 as part of

the interaction, analysis of the individual's play does not contribute to the overall scoring of autistic features.

This chapter will explore the subthemes that were developed from the footage: performing as 'other'; prop interaction; humour production; authorship; and acknowledgement of artificiality. These will be placed within the performance intent framework developed for this analysis, as well as related to current understanding of autism and considered, where appropriate, in relation to play. These links will be further discussed in Chapter 7. The chapter will conclude by discussing the role of performance intent in the diagnostic process, referring specifically to the ADOS-2 and the potential benefits of offering alternative diagnostic settings.

### **Performing as 'other'<sup>171</sup>**

This is defined as when a participant performs as something 'other' than themselves, consciously altering their behaviour to achieve this. Within the environment there were opportunities to do this through wearing a costume (either full-body or just a hat) and becoming a character, or bringing one of the toys to life through puppetry or personification.

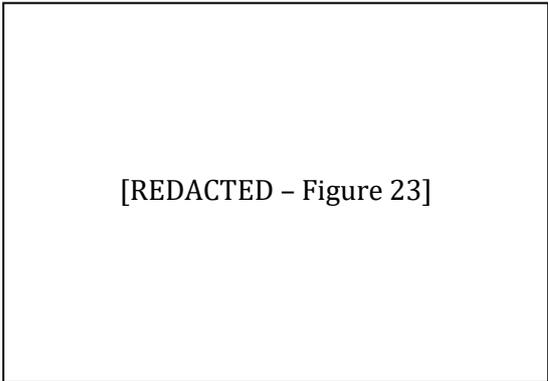
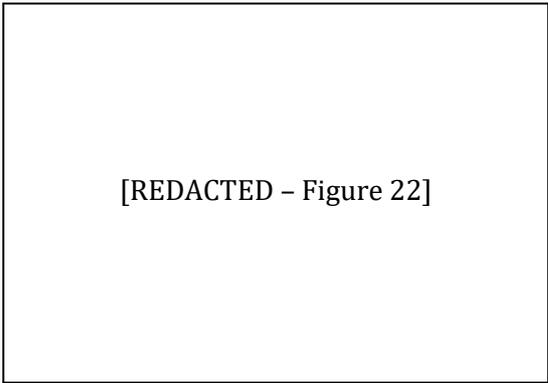
#### ***Full-Body Costume***

In addition to the costumes that the practitioners wore (which they could remove at the participant's request), there were full-body costumes that were hidden within the environment for the participants to discover and wear if they wanted to. The two types of costume available to them were a second snowman outfit (a costume made from a duvet) and another penguin outfit (a shop-bought onesie). These costumes were familiar to most of the participants to some degree as they had encountered a practitioner who was in a similar costume, performing as that character.

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<sup>171</sup> see Appendix 24 for detailed descriptions

Four of the participants chose to wear the costumes (Harriet, Annabelle, Amy and Megan), and performed the associated character to varying degrees. Harriet and Megan both altered their physicality when in the costume, taking steps towards performing as that character. Megan presented the most sophisticated level of performance intent, as she began to independently perform the snowman after discovering the costume and choosing to wear it when it was offered to her by a practitioner (see Figure 22). In contrast, Harriet was guided through the



performance of the penguin by practitioners who described and showed her how the character moved, including the practitioner who was performing as the Penguin (see Video 28 and Figure 23).

These two examples demonstrate that the participants understood the function of the costume: that once it was put on, a transformation should occur in the way they moved and interacted within the world. For Megan there was an independent transformation via pretend play, where the characterisation was taken on without support. She began to playfully interact with the world, finding a fish and pretending to eat it. This challenges the notion of deficits in pretend play among autistic people as noted in the diagnostic criteria and provides evidence of skills in pretend play as seen in other drama work (e.g., Kempe 2014). Furthermore, it contrasts with perceived issues in ToM: Megan could imagine how another character would interact with the space, thereby enabling her to transform herself into the 'other'. The performance intent displayed by Megan differed to that shown by Harriet, who required some assistance via imitation in learning how to become a penguin. This may well point to difficulties in more

advanced levels of play and ToM for this participant. However, Harriet still displayed some skills in ToM through her transformation, albeit to a lesser degree than Megan.

Both examples contrasted with the use of costume shown by Annabelle and Amy. They were assisted into the penguin costumes by a practitioner after they had discovered them. Once in costume, they did *not* transform into the character and perform as that role. This illustrates their lack of understanding of the importance of wearing a costume in the pretence framework set up in the environment. However, this may have been due to the actual costumes. The penguin costumes worn by the participants were onesies, which have limited affordances due to two factors. The first is that the costume is a relatively familiar and popular item of clothing at the time of writing. It is highly likely that the participants had either previously worn or owned a onesie, making it unlikely to be experienced as something 'other'. The costume has a minimal weight, as it designed to be a comfortable piece of leisure wear and therefore does not require any alteration of physicality to move around in. This contrasts with the snowman outfit which the participants were unable to have experienced before (it was made for the project). The fact that it is made from a duvet means that it is quite heavy to wear, requiring an alteration in physicality and adding a degree of restriction to movement. Wearing the snowman outfit is therefore more likely to alter a person's movements before a decision has been made as to whether to perform in that role. The other factor that may have contributed to the lack of performance was that the participants were not taught how to perform as the character by the practitioners (as Harriet had been). Some participants may have needed this kind of guidance to aid their understanding of the pretence framework (also perhaps demonstrating an inability to engage in pretend play), using imitation to access and understand the transformation. This may have been why, when Harriet wore the Snowman outfit, she failed to perform as the character – she needed to be guided through the experience as she had been when she wore the penguin onesie. Despite a lack of pretence shown by some participants when wearing the costumes, imaginative skills were still shown by Annabelle: she renamed herself 'Lucy' when in the

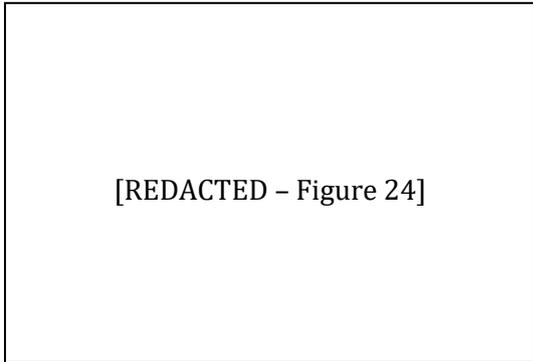
costume, demonstrating some understanding of the differences between herself in and out of costume.

In addition to the skills (or difficulties) shown in play and ToM in the above examples, the performing as 'other' demonstrated by some participants showed a desire for social interaction (as discussed in Chapter 5). Through the transformation of wearing a full-body costume, the participants performed as another, enhancing their social connection with the practitioners: Harriet interacted with the practitioners as she moved around performing as a penguin; when Megan was performing as a snowman she interacted with the Inuit; and Annabelle and Amy worked with each other and the practitioners when in costume. Moreover, skills in social imagination were revealed, as participants had to negotiate using flexibility of thought, considering how this 'other' character would now interact. In contrast, social imagination is currently understood to be a core deficit in autism (APA 2013).

Relating the examples involving full-body costume to the performance intent framework, they can be classified as 'attention and response' for Annabelle and Amy, 'engagement' for Harriet and 'involvement' for Megan. Annabelle and Amy began responding in character, e.g., Amy renaming herself Lucy; however, neither of them consistently performed in this role or creatively engaged in the interaction. Harriet was at the next level as she was consistently attentive to the social interaction, responding performatively through imitation. However, she did not consistently join in, or offer active efforts to reach out to others in the costume. In comparison, Megan was further engaged creatively and her behaviour can be classified as being in the 'involvement' level: she consistently joined in with the performance, making an active effort to continue this interaction by retrieving a fish, pretending to eat it and then bringing it back to the practitioners.

### ***Partial Costume***

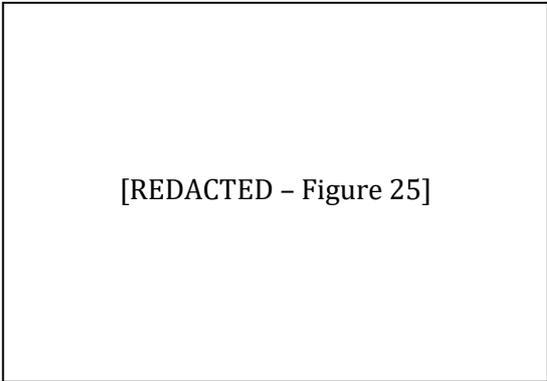
In addition to the full-body costumes that were available to the participants, there were some partial costumes (hats) placed within the environment. These were bear hats – although there was one which was sometimes interpreted as a monkey hat. The use of hats differed from the full-body costumes as these were not worn by the practitioners to perform a role. This meant that if participants altered their physicality and began to perform as ‘other’, this was done using their imagination rather than being an imitation of practitioners’ behaviour.



Four of the participants (Harriet, Annabelle, William and Megan) wore the hats. Annabelle and Megan used the hats as a catalyst for performance (see Video 29 and 30, and Figures 24 and 25). They both discovered the hats without any guidance

from the practitioners, wore them and then performed as a bear. They both transformed their physicality by raising their hands up like claws (see Figure 25) and then growling at another person. This behaviour was exhibited by participants who were in separate sessions, so they were not imitating each other or modelling their behaving on that of the practitioners.

The transformations that occurred in these examples where the hat was used as a performance tool are interesting as, compared to the full-body costumes, the hats are less likely to encourage characterisation. This is partly because they are not full-body but also because they are a familiar item of clothing, arguably more so than a onesie. Therefore, when one wears a hat there is not an assumption that this indicates a character transformation or an experience of ‘other’ (and hats that have characters on them are readily available to buy). This behaviour demonstrates spontaneous pretend play and skills



in ToM. The intention of both participants was to scare another and they therefore appear to have understood that the others would likely be fearful of a bear. They understood that their growling and using gesture, combined with the hat, would indicate that they were performing as a bear and therefore expected the others (both participants and practitioners) to react accordingly. Again, both participants showed a desire for social interaction: once they were performing as a bear they went to seek such interaction out, not only showing the character to another but also attempting to provoke a playful response from that person. This demonstrates further skills in social imagination and flexibility, both areas of deficit in autistic people which are used as part of the diagnostic criteria (APA 2013). Moreover, the examples contribute to the alternative construction of autism through drama models, with participants displaying skills in imaginative play (e.g., Lewis and Banerjee 2013).

There was a moment where Megan displayed some difficulties with ToM. When she went to scare the Penguin, she initially failed to recognise or acknowledge the Penguin's response of fear. She continued to scare the Penguin despite the clear indications of fear that were being portrayed by the practitioner. A moment later she removed the hat to indicate to the Penguin that it was pretend play, further supporting this by waving and saying 'hello', thus indicating that the performance had ended.

Additionally, both Harriet and William wore the hats but did not perform a role in conjunction with them. However, it was still reasonable for the hats to be worn as part of the pretence of the environment, keeping the participants 'warm' in the Arctic.

When assessing the behaviours of both Annabelle and Megan using the performance intent framework, they were evaluated at the highest level of 'participant initiated interaction'. They both spontaneously sought out the bear hats and put them on, using them as a tool to scare another person, initiating a playful and provocative interaction which demonstrated the ability to engage in more complex performative interaction.

## ***Animating Toys***

The final way in which participants could perform as 'other' was through the penguin toys. These were placed within the environment, usually hidden within the cave (a camouflage netting hung from the roof). There were two ways in which the participants could interact with the toys: (1) through anthropomorphism; or (2) puppetry.

[REDACTED – Figure 26]

Anthropomorphism was demonstrated by four participants (Harriet, Annabelle, Amy and Megan) to varying degrees. Megan empathised with the toys: during a storm she spontaneously left the 'safety' of the cave without the practitioners to retrieve them. She brought them back into the cave

so that they were protected and later tucked the penguin toys up in the cave, while being supported by the Inuit (see Video 31 and Figure 26). Megan led most of the work with some prompts from the Inuit. She tucked them up with snow as she claimed they were not used to the warmth. She named them (Luna, Jake and Pengu) and gave them ages (57, 57 and 2). Harriet demonstrated this behaviour when she acted out feeding a penguin toy with fish after the practitioners had encouraged her to do so (see Video 32). She continued this interaction and appeared to take pleasure in it, with the practitioners supporting her action by making the sounds of the penguin toys eating the fish. Harriet indicated whether or not the toy liked the fish by either continuing to feed it or by throwing it away. Although this interaction was guided, Harriet used her initiative to act out whether the penguin toy liked the fish or not. Annabelle and Amy engaged some basic anthropomorphising when they themselves were dressed up as penguins, with Annabelle naming her penguin toy as 'Lucy Whoop' and Amy designating hers as her boyfriend.

These examples show how the participants used anthropomorphism to perform (in a limited sense) with the penguin toys. The play was functional: they were using the toys according to their intention; however, they were doing so in a more imaginative way, starting to attribute emotions to them. The above examples demonstrate ToM: Harriet and Megan could attribute a variety of mental states to these toys, responding in a caring way. Both participants demonstrated a nurturing role towards an inanimate object: they cared and looked after them, engaging in the imaginative world of the (potentially harsh) Arctic environment. Although the empathic behaviour was not directed at a human, they had created something 'living'. This is particularly interesting in Harriet's case as it was noted in her diagnostic letter that she struggles with 'demonstrating empathy', yet she was beginning to do so in her work with the penguin toys. In addition to these skills, a desire to work with others was shown. They both wanted to actively continue and share their experiences with the practitioners.

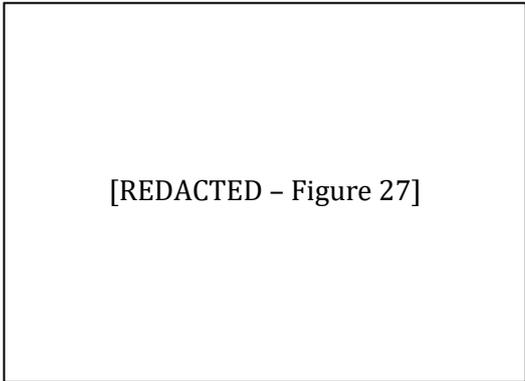
There were some difficulties in the social response that Megan gave when interacting with the Inuit – she did not always respond if the Inuit suggested an idea. The Inuit asked her if she wanted to go out of the cave to see what the others were doing but she ignored this and continued to talk about the penguin toys. A minute later Megan then suggested this back to the Inuit, almost as if it were her own idea. This possibly demonstrates some fixation on task completion and a consequent ignoring of a social offer from another – although it is difficult to determine whether this was intentional or not – or else slow mental processing of what the Inuit had offered.

Using the performance intent framework to analyse the examples discussed, Harriet is placed at the 'involvement' level and Megan at the level of 'participant initiated interaction'. In Harriet's case, although the game was initially introduced by the practitioners, she actively continued it, finding other fish to feed the penguin and performing the response of the penguin toy. Megan demonstrated a higher level: she was spontaneous and creative in her use of the toys

as a mode of performative communication and although this was supported minimally by the Inuit, she drove the performative interaction.

The other form of performance intent that the participants could have with the penguin toys was through the puppeteering of them, actively animating them to create a 'live' character.

Megan was the only participant who demonstrated this behaviour (see Video 33 and Figure 27). She animated the penguin toys to communicate with the practitioner performing as the Penguin. She did this by wiggling them both to indicate that they were 'alive' and performed different sounds for each of their voices.



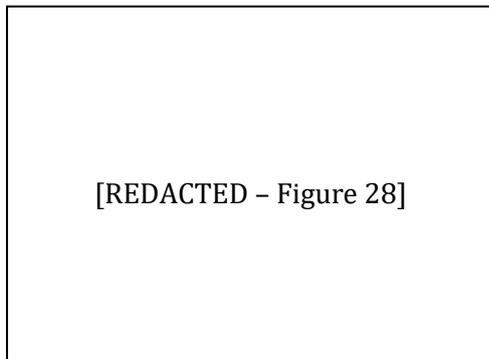
When asked about the different voices, she commented that one was from the 'south' and the other was from the 'north'. In the second session, when she was narrating a story (discussed on pages 243-244) she again animated a penguin toy, holding it to the microphone, wiggling it and making it 'talk'.

These examples demonstrate imaginative play skills in Megan as she could bring the toys to life and began to provide different characters for them. In addition to this, Megan displayed skills in ToM and again, a desire for social interaction. This was a spontaneous interaction and was used to facilitate communication with the Penguin (who did not communicate in words). Megan was also placed at the 'participant initiated interaction' level for this interaction.

### **Prop Interaction**

Another opportunity that was offered to the participants for demonstrating performance intent was through using props. There were a variety of these scattered around the environment: some were specific in their use, e.g., the cardboard fish; whereas others could

be interpreted more subjectively, e.g., a tube covered in white wadding material. The latter types of props gave the participants an opportunity for imaginative engagement in the environment.



There were several fish in the pond, for which all of the participants except David and Ed fished using the large tube, which they transformed into a fishing rod. Three of the participants (Harriet, Annabelle and Amy) extended their engagement with the fish through a game that was set up by practitioners, in which they

would all 'eat' the fish and inform everyone what they tasted like (see Video 34 and Figure 28).

The practitioners would give a ridiculous example of a taste, e.g., brussel sprouts, and then question the participants as to what their fish tasted like. Although there was never an explicit request for an unusual answer, the participants always gave one (gravy and tomatoes, zebra, peanuts and tuna, oranges).

The other props which the participants interacted with throughout the session were the snowballs (soft white balls) and snow (shredded paper). These were frequently thrown around by most of the participants, either at each other (Harriet, Annabelle, Amy, William, Megan and Emma – see

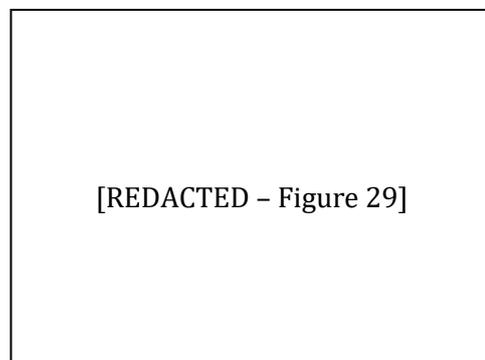


Figure 29) or around the environment as part of the narrative of the storm (Harriet, Annabelle, Amy and Emma). One participant (Amy) took the performance with props further and offered a pile of snow to Purdy (who was being blown around by the storm) as a cloud on which he could sit (see Video 35).

The engagement with props in the manners described above demonstrates skills in imagination through a willingness to engage in the pretence of the environment, and a desire to engage in social interaction (these examples all involved working with other people). The throwing of snow and snowballs was part of a playful interaction. For some participants this might have been imitation of behaviour that they saw from the practitioners and their peers but for others it was functional play. The participants describing the taste of the fish and Amy offering snow as a cloud, are examples of pretend play, as well as showing imaginative play. In the diagnostic letter for Amy, her skills in pretend and imaginative play were described as 'very limited'. These examples further challenge notions of autistic individual's deficits in pretend play as noted in the diagnostic criteria (APA 2013) and offer further support for the demonstration of such skills through engagement with drama (e.g., Lewis and Banerjee 2013).

When analysing prop interaction through the performance intent framework, these examples sit at the two highest levels: 'involvement' and 'participant initiated interaction'. The throwing of the snow and snowballs at each other and as part of the storm showed how some participants were joining in with the performance of the environment, actively seeking out the continuation of social interaction. This level of attainment was further demonstrated by Harriet, Annabelle and Megan when they were playing the game of eating fish. They all consistently joined in, offering novel and creative suggestions, extending the interactive episode. One participant, Amy, moved to the highest level on the framework when she spontaneously suggested the transformation of paper into a cloud to prevent Purdy being blown away. Although the interaction began with a request of help from Purdy that was directed at Annabelle, Amy spontaneously came up with this creative solution.

## Humour Production<sup>172</sup>

The use of humour was prevalent in the environment and was usually produced by the practitioners as a tool to engage with the participants. All of the participants responded to

[REDACTED – Figure 30]

various comic moments through laughter or expressions of enjoyment. They all laughed in response to other's actions, e.g., David laughing at Purdy 'eating' his Thomas the Tank Engine toy and then spluttering, and Amy laughing as the Snowman fell over in an exaggerated manner after he had been hit by a

snowball. Practitioners commented on Harriet's enjoyment of 'slapstick-type humour' in relation to her laughing when a practitioner fell over. This was further reflected in the diagnostic letter for Amy in which it was noted that she had an appreciation of slapstick. In addition to this, some participants (Harriet, Annabelle, Amy, William, Megan and Emma) laughed because of the action they were performing, e.g., Amy laughed as she threw a large ball of paper at the Snowman to wake him up and William laughed at the various people pretending to get stuck in the tunnel in the game that he created.

One participant, Megan, extended the role of humour through constructing and executing a slapstick comic scene which involved the practitioners (see Video 36 and Figure 30 and 31). Prior to the setup, the practitioners and participants had been playing a game

[REDACTED – Figure 31]

in which they pretended to get stuck in a tunnel and were 'rescued' by William.<sup>173</sup> Megan

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<sup>172</sup> see Appendix 25 for detailed descriptions

<sup>173</sup> This was a game that William created and is discussed on page 245.

spontaneously began to cover the tube in material to hide it. She then used the fish to draw the Penguin's attention over, who eventually walked over and fell into the tunnel.<sup>174</sup>

The comic setup showed clear examples of ToM in Megan. She understood that as the Penguin had not 'seen' the hiding of the tunnel that she would not necessarily know that it was there and therefore might fall into it. This situation corresponds to the classic Sally-Anne test which is used to examine ToM skills in autistic people (Baron-Cohen, Leslie and Frith 1985). Megan understood that the fish (see Figure 30) would get the Penguin's attention and that by supporting this with nonverbal communication (gesture, eye contact and eye direction), this would encourage the Penguin to walk over to her and fall into the tunnel. Both ToM skills and the use of nonverbal communication are meant to be areas of difficulty for autistic people, yet Megan used sophisticated examples of both. Furthermore, she engaged in pretend play, firmly grounding herself in the pretence of the environment and showing imaginative skills. She became a performer and took control of the action, guiding the practitioners through it (they were not initially aware of her intentions), and was able to anticipate what would happen. After the action had unfolded she smiled and applauded (see Figure 31). At the core of this interaction was (once again) a desire for social interaction. Megan used the performance of comedy to engage with the practitioners, even communicating nonverbally with the Penguin. Humour has been noted to be important for socially connecting (e.g. Fraley and Aron 2004) and a mechanism to establish social relationships (Treger, Sprecher and Erber 2013), suggesting that Megan may have been using humour to help establish a social connection with the Penguin and the other practitioners who were helping to set up the comedy. Interestingly, humour has been noted to be problematic for autistic people with Asperger commenting on his original cases that they showed an absence of humour (Asperger [1944] 1991). However, despite this, Megan

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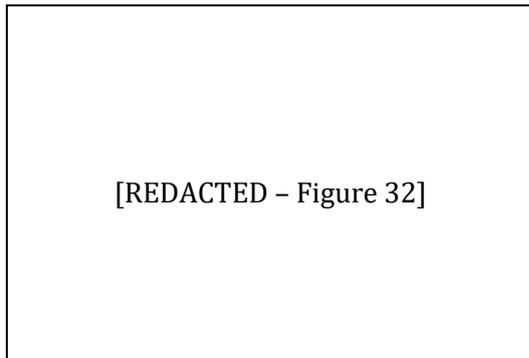
<sup>174</sup> The falling over was not caught on camera but you can hear the response from Megan and the practitioners.

demonstrated some complex skills in not only the understanding of humour, but also the production of it.

Megan's use of humour put her at the highest level the performance intent framework – 'participant initiated interaction' – as she spontaneously started the event, inviting the practitioners into it: Purdy and the Inuit to help create the setup and the Penguin to be its star performer.

### **Authorship<sup>175</sup>**

'Authorship' refers to the ability of a participant to be the creator of actions, interactions and performances within the environment, e.g., through narration. As the environment was responsive to the participants, with the practitioners willingly following their leads, there was a potential for participants to engage with the environment in this way and this was demonstrated by three of the participants (Megan, Amy and William).



Megan demonstrated authorship twice by working on the microphone, narrating and guiding the action in the second session. In the first example, she used the microphone and started a conversation with Purdy and the Penguin, who responded to her appropriately (see Video 37 and

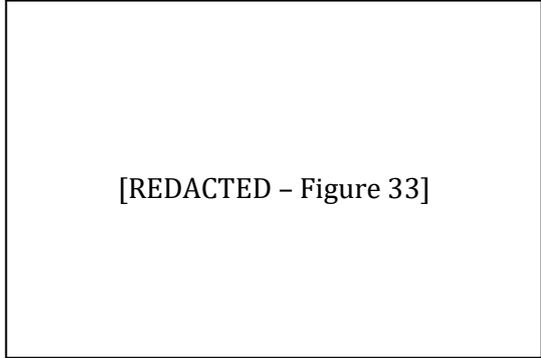
Figure 32). She began developing this into a performance role (possibly aided by the microphone, which has connotations of performance) as she sang and later used an Australian accent.<sup>176</sup> The song was responsive to what Megan was seeing. For example, as she began to sing the Penguin stood up and started to dance, which she then incorporated into the song. As the conversation developed, Megan moved into a directorial role and guided the action. This role

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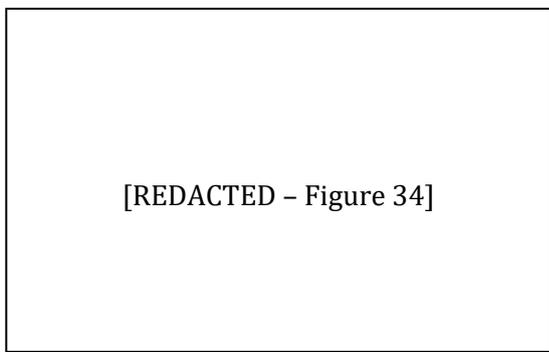
<sup>175</sup> see Appendix 26 for detailed descriptions

<sup>176</sup> The puppeteer had accidentally begun talking with this accent and self-commented on it in the moment.

was later extended in the session where she spontaneously began to tell a story on the microphone (see Video 38 and Figure 33). The practitioners were sitting in the cave with her and became her audience, with their roles later shifting to those of performers in her story. For example, when she said, 'they all had to run out of the cave' (from the bear she was performing as), Purdy said 'Quick! Run!' and the practitioners and William left the cave. As well as the role of a narrator she performed as different characters: wearing a bear hat and roaring (see Figure 33); animating the penguin toy; and making the sound of the storm.



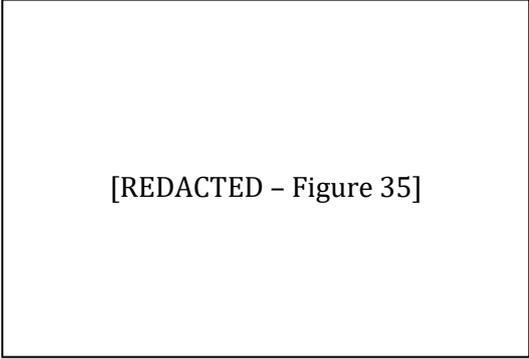
Amy took on a different authorship role when she discovered that she could control the lighting and the sound within the pod (see Video 39 and Figure 34). She spontaneously suggested to the Inuit that she could use a magic spell to stop the storm, as the Snowman had become upset by it and she was trying to make him feel better. She summoned the storm, which to her surprise, the technician started. Similarly to Megan, Amy then began performing in her



own narrative, throwing snow and moving around like she was being blown by the wind. This authorship continued into the session as she offered different ways to call for the storm, e.g., through a poem that she had made up

(accompanied by gesture), the use of 'magic fingers' and later the phrase 'abracadabra'. Amy extended the use of her control over the technical aspects, calling for the storm to brighten the environment so that they could find the Snowman's nose, which had been lost. In the second session, she tried to command the storm but, due to the technician being unavailable, this could not be fully realised as it had in the previous session.

The final example of authorship was shown by William in the first session (see Video 40 and Figure 35). The practitioner who was performing as the Penguin had accidentally got stuck in the tunnel and was being assisted by the practitioner operating Purdy when William came over to help. Once the practitioner had been assisted out of the tunnel, William said 'me now' and got into



the tunnel and said 'help, help'. Once he was rescued, he directed the practitioners and Megan to get stuck in the tunnel, which he then saved them from, giving them lines to say. Similarly to Amy and Megan's experiences of authorship, he played a part and became the protagonist, saving everyone who had got stuck.

All of the above examples demonstrate clear instances of pretend play and strong imaginative capabilities. Although William's game initially started out as an imitation of what he had seen, he soon developed this further extending the play. In his diagnostic letter it was noted that there was a lack of 'engaging in truly collaborative and reciprocal play'; however, he was able to show some skills in this within the environment, although the play was still coordinated by himself. One practitioner commented that Megan 'seemed to use her imagination as she made up her own stories about the space, which showed some engagement with the 'magic/pretence' of it all'. Amy and Megan showed skills in flexible thinking as they responded to the environment, finding new ways to interact with it. In addition to this, a clear example of ToM was shown by Megan in her comic setup, where she demonstrated a solid understanding of the situation (effectively passing the Sally-Anne test for ToM). Amy also showed some skills in ToM, offering empathy towards the Snowman when he was afraid of the storm.

As might be expected, the behaviours in these examples fit into the two highest levels of the performance intent framework: 'involvement' and 'participant initiated interaction'. The

tunnel game set up by William would have been in the highest level, but the game was possibly repetitive/self-absorbed, and therefore cannot be classified as such (although he was clearly reaching out and making performative decisions on the behalf of the participants in the game). The highest level was demonstrated by Amy and Megan. Amy creatively performed different ways to bring the storm into the environment and then to get it to leave. Although this was supported by practitioners at times, she generally took the lead, performing poems and actions to the practitioners to alter the environment. Megan also used performance intent on this level, initiating the two performative instances on the microphone and driving the narrative of the action: storytelling and performing as other characters.

### **Acknowledgement of Artificiality<sup>177</sup>**

As discussed in Chapter 3, the structure of the environment made it clear to the participants that this was 'pretend'. Therefore, in order to engage imaginatively within the pod, there had to be an awareness of the pretence framework that existed within it. Some participants acknowledged the artificiality by: (1) drawing attention to the artificial components; and (2) by 'playing the game' (this refers to when participants clearly indicated to others that they were aware of the pretence of the environment and used this to engage with the environment).

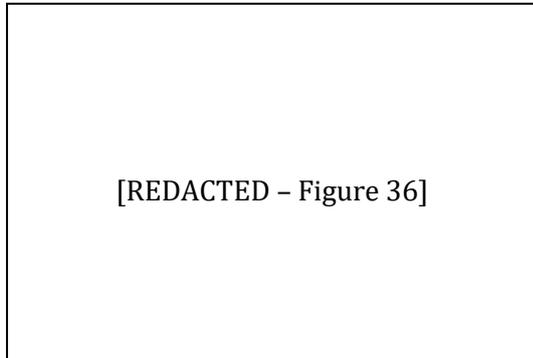
Annabelle, Amy and William all acknowledged the artificial nature of the environment. Early in the first session, when Amy was asked whether the snow felt crunchy, she said 'it's card', pointing out the material that the snow was made from. Annabelle made a similar comment about the fish: stating that it was made of rubber with pen marks on it (it was made from sponge). In his first session, William asked the camera operator if everyone was pretending that the pond was the sea. The participants appeared to be testing the parameters of

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<sup>177</sup> see Appendix 27 for detailed descriptions

the environment to clarify what was expected of them and how they were meant to engage with it. Once they had acknowledged the artificiality they appeared to be happy to engage with the environment. This was supported by practitioners' comments. In the first session, one practitioner noted that Amy 'really seemed to believe in the imaginative world and invested in it herself' and 'really got into the world of it'. This contrasted with the second session, in which practitioners commented that 'she wasn't investing in the pretend aspects of the session much', 'she seemed aware that her parents were outside and therefore [she] wasn't transported to the Arctic, whereas last time I think she was', and 'I don't think she found it as magical or exciting'. A similar comment was made about Annabelle's behaviour in the first session, where she 'seemed to believe in the pretend world' and 'lost herself in the fun of it'. In the second session, her engagement dropped: 'I think she didn't find it as exciting as last time because there were no 'new' elements... She wasn't as interested in the environment as last time'. Interestingly, this was the other way around for William who, as noted by practitioners, had a deeper engagement in the pretence in the second session. In the first session: 'I don't think he was enchanted by the space. He didn't seem to be interested in the magic or make believe of the experience – i.e., characters, narrative of storm, going to sleep, etc.' This contrasted with the second session where 'he seemed to engage with the 'make believe' of the space better than the first session – the storm for example he believed in'. This illustrates the different ways in which the participants engaged with the artificiality. Amy was caught up in the pretence in the first session as it was new and exciting, but in the second session the familiarity with it and lack of 'new' elements may have caused a decrease in engagement. William may have required more familiarity to fully engage, which would explain why the second session was perceived to be better for him. He was more familiar with the setup, which may have made him feel more comfortable to engage. These individual differences need to be accounted for and demonstrate the importance of participants encountering the environment more than once to allow for differing behaviours, and possible explanations of these, to be explored.

The second way in which the participants could interact with the artificiality was through 'playing the game'. Four participants (Annabelle, Amy, Megan and Emma) clearly indicated to the others present that they were aware of the pretence framework within the



environment and used this to engage with others. Emma demonstrated a clear example of this when she played hide-and-seek (see Video 41). She saw where the Snowman was hidden and looked back to the other practitioners, raising her finger to her lips to indicate that her discovery was a secret (see

Figure 36). She declared loudly that she was unaware of where the Snowman was hidden, knowing that the Snowman would hear this and therefore believe it to be true. When Emma uncovered the Snowman it was a 'surprise', as she believed that Emma was unaware of her whereabouts.

Another example of this behaviour was shown by Megan and Emma when they threw snowballs at the Penguin and then denied knowledge of doing so. Although in both examples the game was introduced by practitioners, the participants maintained the playing of it, showing enjoyment in the interaction. Emma developed her responses to being caught: initially she just pointed at the Snowman, blaming her; then she pretended to be interested in the material that was hanging down from the pod roof (see Video 42). This was comparable to Megan's behaviour: she pretended to ignore the Penguin, blamed Purdy for throwing the snowball and then pretended to be interested in the icicles that were hanging down from the pod roof.

Again, these two examples demonstrate skills in ToM which are similar to those tested for in ToM tests which are generally thought to reveal difficulties for autistic people in ToM. Emma believed that the Snowman would not be aware that she had found her hiding place because she (Emma) stated verbally that she had not. In these examples of Megan and Emma

playfully denying responsibility to remove accountability from themselves, ToM underpinned their lying. They both understood that as the Penguin had not seen who had thrown the snowballs, the Penguin would believe their denial and blaming of others. These examples provided further demonstration of pretend play, although it could be argued that Emma was demonstrating imitation of learnt behaviour as the way she interacted was similar to the way that adults interact with children when they are playing hide-and-seek. Despite this possibility she did spontaneously and successfully apply the behaviour appropriately to a new situation. Her use of imagination to complete this task is important to consider, especially as it was noted that Emma's 'imaginative play was limited' in her diagnostic letter. These examples also demonstrate how participants used the games (that were set up for them), to develop and maintain social interaction in a playful manner. The humour that began to develop between participants and practitioners, particularly the comradery surrounding who the participant and practitioner could blame for throwing the snowballs and how many times they could get away with it, solidified participants' enjoyment of the social interaction, helping with the development of social connections.

A final example (although arguably different in its intent) was when Annabelle and Amy denied responsibility for making a mess of the Inuit's home, instead blaming the Snowman when the Inuit asked who had made the mess (see Video 43). This example differed from the more playful games discussed above, as it appeared to be a more genuine denial of responsibility. This may have been because the Inuit was showing some distress at the mess and both participants were concerned that they would get into trouble, whereas the other examples had playful and humorous ramifications. This potentially demonstrates a blur between reality and play for these two.

This section fits less easily into the performance intent framework because, at times, the lines between the 'performance' of the interaction and reality were more blurred (e.g., with the

examples of Annabelle and Amy denying responsibility of the mess in the house) than, e.g., a participant dressing up in a full-body costume and performing as that role. When Annabelle and Amy pointed out the artificiality of the props, they were at the 'attention and response' level. They had interacted with the practitioners and were responding to the environment but they were not wholly engaged in the pretence of it, highlighting the artificiality and arguably 'testing the waters' of the pretence framework of the session. By denying responsibility for their part in creating the mess, they moved to the next level, 'engagement'. They lied to maintain a positive engagement with the Inuit, perhaps fearing for the negative ramifications if the Inuit discovered that they had made the mess. They blamed the Snowman, showing a level of engagement in the interactive encounter. When William queried whether the practitioners were pretending that the pond was the sea, although he was acknowledging the artificiality, he was already partly immersed in the pretence, referring to the silver material as the pond, therefore appears to have been testing how far the imagination that he required to engage in the environment would go. This placed him at the next level 'involvement'. The final examples can all be classified at the highest level 'participant initiated interaction'. When Emma was playing hide-and-seek, she actively reached out to the practitioners by pretending that she did not know where the Snowman was hidden, directly indicating to the practitioners that this was part of the game. This was similar to Megan and Emma's throwing of snowballs: they were playing within the pretence of the game setup performing ignorance and consistently joining in with the interaction that had been set up by the other practitioners.

## **Conclusion**

In conclusion, despite difficulties noted in several areas for autistic people, performance intent has provided many examples that run contrary to these perceived difficulties, particularly deficits present in autistic people (principally ToM, empathy, imagination, play and social

interaction). Part of the analysis of the performance intent behaviours was carried out through a framework (adapted from Intensive Interaction) (see Table 35). This framework enabled behaviours to be analysed based on assessment of the levels of performance intent achieved and showed that some participants possessed a variety of skills in this area, contrasting with the perceived deficits in the areas noted above that are prevalent in scientific and medical constructions of autism. Instead, these examples provide further evidence supportive of the development of arts-based practices with autistic people to challenge current perceptions of the condition.

analysis of participants in the iA environment	
PIF level	participants
encounter	-
awareness	-
declining	-
attention and response	Harriet: as the Snowman Annabelle: as the Penguin; anthropomorphising; pointing out artifice Amy: as the Penguin; anthropomorphising; pointing out artifice
engagement	Annabelle: lying about mess Amy: lying about mess
involvement	Harriet: as the Penguin; anthropomorphising; throwing snow; fish game Annabelle: throwing snow; fish game Amy: throwing snow; fish game William: throwing snow; 'help help' game; checking the artifice Megan: throwing snow Emma: throwing snow
participant initiated interaction	Amy: using the hat; cloud; storm calling Megan: as the Snowman; using the hat; anthropomorphising; puppeteering; comic setup; microphone conversation; narrating; denying of snowball throwing Emma: hide and seek; denying of snowball throwing

Table 35: a summary of the analysis of the participants in the iA environment using the Performance Intent Framework.

Several of the performance intent behaviours contest the supposed deficits in ToM found in autistic individuals. ToM is arguably a prerequisite to some forms of performance and has been noted to be higher than average in actors (Goldstein, Wu and Winner 2009-2010; Goldstein and Winner 2010-2011; Goldstein 2011; Goldstein and Winner 2012). The use of

costume allowed participants to perform as an 'other', using ToM skills to transform themselves, inform the way they engaged with the environment and understand how others would interact with them. This was further demonstrated through anthropomorphism and puppetry, as the participants were able to bring 'life' to inanimate objects, imbuing an object with emotions and mindsets. Sophisticated examples of ToM showed strong understanding of other's perceptions (seen within the 'playing the game' section and the comic setup). This work extended into empathy, with participants demonstrating some skills in this area, caring for the penguin toys and trying to alter the environment to make the Snowman feel better through performance intent. The demonstrations of empathy in a drama environment are not surprising as actors have been found to have greater-than-average empathy (Goldstein 2011; Goldstein and Winner 2012). The examples involving empathy are at odds with some scientific and medical models which see deficits in empathy in autistic individuals. These examples instead provide evidence for empathic potential, as demonstrated in other drama-based work (e.g. Guli et al. 2013; Trowsdale and Hayhow 2013).

Many of the participants demonstrated skills across various levels of play. Although there were some examples of imitation, these extended into functional and pretend play, contrasting with perceptions of play skills in autistic children. The behaviour displayed further revealed some strong imagination skills in both the authorship examples and in the willingness of participants to engage in the pretence of the environment. Even when the participants acknowledged the artificiality of the environment, they were still aware of the pretence framework and clarified the parameters of the framework within the space.

Further supporting the examples discussed in Chapter 5, most of the performance intent behaviours observed were motivated by desire for social interaction, with performance intent being used as a means to explore this in a flexible and fun manner. Participants even showed

skills in adapting their communication to suit the communication level of the character they were interacting with.

However, difficulties were still demonstrated by participants which showed their autism. There was a general lack of performance intent shown, with some participants not performing in the role of the costume that they were wearing, potentially revealing deficits in ToM, the ability to perform as another (and, arguably, understanding of this), imagination and a full engagement in pretence. Even when in costume there were issues with reading others' emotions. In addition to this, some difficulties were noted in social response, with one participant rejecting and ignoring offers from the characters. As mentioned in Chapter 5 it is important that the difficulties that participants display are noted so as not to 'remove' their autism. The point of the engagement in the drama environment is to provide behavioural information which could aid current diagnostic practices. As illustrated throughout this chapter and in Chapter 5, several behaviours that are listed as symptoms of autism in the DSM-5 have been shown by autistic children in this environment. This provides supplementary evidence to the growing body of drama-based research that notes skills in autistic people that challenges current thinking by noting certain skills in autistic people and provides evidence that such skills can be cultivated in autistic people through the use of drama (e.g. Lerner, Mikami and Levine 2011; Corbett et al. 2014a, 2014b, 2016; Guli et al. 2016).

It is interesting to note that all of the examples discussed in this chapter involve participants who were assessed using module 3 in the ADOS-2. This suggests that (based on this sample), higher levels of performative engagement will be more commonly seen in individuals with a higher level of verbal functioning. David and Ed did not offer any examples of performance intent and therefore were not included in the discussion. It may be that the module 3 participants were able to engage with the performance framework of the environment at a more complex level than were the module 1 participants. It is of further interest that those

participants (Amy and Emma) who displayed the most examples of performance intent behaviour at the highest level, participant initiated interaction, were those participants who were closer to the autism threshold at clinical diagnosis on the ADOS-2. For example, in her clinical ADOS-2 Amy had an overall total of six, which gave her a non-diagnosis according to the ADOS-2, although she was diagnosed as autistic based on information from other measures. Emma had an overall total of seven and therefore an ASD diagnosis with low severity. As Megan's ADOS-2 clinical data is unavailable, comparisons cannot be made. By engaging in a different environment, in particular iA, this can lead to a more accurate diagnosis for some individuals, as it could capture a more precise reflection of their behaviour, and latent skills may be more readily facilitated. This is of central importance to this thesis.

It is relevant here that all of the female participants provided examples of performance intent, whereas only one male showed this. This may allude to a preference for females to engage with drama-type interactions. It is noteworthy that drama research with autistic participants tends to have either all female participants (Schuler 2003; Kempe and Tissot 2012; Pimpas 2013) or female-weighted ratios (Loyd 2013; Reading et al. 2016). This contrasts to a large proportion of other autism research based outside of the arts which tends to have a male-weighted ratio in participants. This is something that may be worth investigating further. However, it would be unwise to generalise as all of the female participants were scored on module 3, whereas only one of the male participants was. It is therefore difficult to determine from this study whether this gender bias in performance intent is reflective of ability or a gender preference.

As most of the behaviours associated with performance intent are not covered by the tasks within the ADOS-2, it is clear that this diagnostic tool lacks the ability to demonstrate certain skills that were readily demonstrated within the iA environment. The performance-based environment allows for strong skills to be seen in the aforementioned areas that would

not be likely to be seen within the ADOS-2, or at least not to the extent that they were present in the environment. This is because of the performative nature of the environment which requires skills in imagination and play in participants who seek to engage more fully with it. There are multiple possibilities for performance that are offered to the participants, and these can help to reveal a variety of skills and interests. In any case, to engage with performance and demonstrate associated skills, behaviours that are considered to be problematic for autistic people are challenged. This therefore suggests that the diagnostic process and particularly the ADOS-2, would benefit from engagement in a drama-based environment, particularly as the focus within this performance environment is on interaction, which is at the core of the ADOS-2. This supports the view that an alternative way is needed to analyse individuals on the autistic spectrum through models that explore individual differences, difficulties and strengths more than current diagnostic practices are able to. The iA environment offers explorations that more appropriately fit the spiky IQ profile of autism than the ADOS-2, therefore it will tend to produce a more holistic view of the individual.

## **CHAPTER 7: DISCUSSION**

This chapter brings together the results of the research discussed in the previous three chapters, summarising their significance within the wider research context and clinical practice. A research summary and a summary of results will be presented, followed by a discussion of the limitations of the research conducted. Following on from this, an examination of the results will explore how they fit into the wider research context in relation to the themes introduced in Chapter 1. The central part of the chapter will address questions about what this research contributes to the diagnostic process more specifically, and to the understanding of autism more broadly.

### **Research Summary**

The research presented is, to the best of the author's knowledge, the first to look at how a drama environment might aid current diagnostic practices for autism in children. The main research question was to see how working in such an alternative environment, in comparison to the traditional clinical setting, could enhance the profile of strengths, difficulties and differences found in autistic children, moving towards a strengths-based rather than deficit-based model. Secondary questions included whether the ADOS-2 could be completed successfully in an alternative non-clinical environment and whether additional information about the individual could be provided through their engagement in this environment. This would prove to be a useful source of information to support the diagnostic process and could show behaviours that are not currently assessed in the ADOS-2, this being potentially beneficial in presenting a more holistic view of the individual as well as providing further challenges to current thinking surrounding autism which is predominantly based in scientific and medical models.

## Summary of Results

### Quantitative Analysis

The qualitative analysis occurred in two parts: the first compared the clinical data to the data from the iA ADOS-2; the second analysed the possibility of successfully completing the ADOS-2 within the iA environment.

#### *Clinical Data and the iA ADOS-2*

All of the participants who received a clinical diagnosis (which consists of the ADOS-2 together with additional diagnostic measures – see Chapter 4 for individual participant details) scored within the autism or autism spectrum range in the iA ADOS, showing a 100% match between the two environments on a diagnostic level. Even though there was a small number of participants, these results are promising for the use of the ADOS-2 in non-clinical environments and demonstrate how an ADOS-2 diagnosis can be maintained across different settings. This outcome was fundamentally important to the research as although part of the focus was on exploring the skills and strengths of autistic children, the aim was not to remove the diagnostic label.

When looking in more detail at the ADOS-2 scores between the two environments (clinical and iA), fair agreement was found when analysing the overall ADOS-2 classification (non-spectrum, autism spectrum, and autism), good agreement was reported in the ADOS-2 severity level (minimal-to-no evidence, low, moderate and high) and comparison scores (1-10) and poor consistency was noted when module 3 was broken down into the separate total scores (social affect, restricted and repetitive behaviours and overall total). The results are fair considering the small number of participants (either  $n=6$  or  $n=5$ ) that were analysed, as this can affect the results of the measure causing a reduction in agreement rates. The agreement between the overall ADOS-2 classification, comparison and severity scores were positive and provided some support for the use of the ADOS-2 across different environments. The poorer

agreement results for module 3 were anticipated due to the range in which the participants were to be scored (0-28) and the likelihood of differing behaviours being demonstrated in the clinical and the iA environments.

The mean scores for the social affect total and the overall totals were smaller within the iA environment, suggesting that positive social behaviours in relation to the ADOS-2 measures were more readily demonstrated within the iA environment than the clinical one. This was an anticipated outcome due to the social nature of the iA environment. There was a very slight difference in the mean restricted and repetitive behaviours scores, with the iA environment demonstrating a marginally higher mean. Again, this was anticipated as the iA environment was likely to encourage more of these behaviours due to the possibility for participants to freely move around the space (rather than being encouraged to remain seated as in the clinical setting) and the fact that these behaviours might be elicited by the highly stimulatory nature of the environment, either as a means to display excitement or to help the individual cope. In addition to this, there were more opportunities for sensory play in the iA environment which may have led to more unusual sensory play (and therefore higher ratings in the restricted and repetitive behaviour domain of the ADOS-2) than in the clinical setting.

### ***ADOS-2 Completion***

The completion of the ADOS-2 focused on modules 1 and 3, examining these via the presses, codes and algorithm scores. A large proportion of both module 1 and 3 presses could easily be completed from the iA environment, with only minor amendments needed. In module 1, four of the sections had all of their codes completed with some difficulties arising in connection with the reciprocal social interaction. The results were similar for module 3, with three sections able to be completed. The two sections which were more problematic and had slightly lower completion rates were the social interaction section and the language and communication section (although in both sections only one code could not be completed). In the

algorithm scores for module 1 (on both 'few to no words' and 'some words') only one code was found to be problematic in the social affect section ('showing'). Although this was not specifically probed for within the iA environment it was possible that it would occur spontaneously. However, future research would need to ensure that this was tested for to allow for total completion. All of the restricted and repetitive behaviour scores could be completed. This pattern was also seen in module 3 with one code ('reporting') being challenging to code in the social affect section. Although this was acknowledged during the process and an attempt was made to adapt the iA environment to accommodate this for one participant, future research would need to involve such an adaptation to allow for full algorithm completion.

These results are encouraging as they demonstrate that it is possible to complete the ADOS-2 within an alternative environment when not adhering to the specific probes or using the props provided. A relatively high proportion of the ADOS-2 could be completed at the level of presses and codes. The most important part of this completion is the algorithm which generates scores for diagnosis. In both modules only one score could not be completed in the social affect total; however, the environment could easily be modified to incorporate these codes in the future.

### **Qualitative Analysis**

The qualitative results from this study involve a variety of behaviours demonstrated by participants in the iA environment that provided supplementary information to the ADOS-2 and which were analysed into two categories, social interaction and performance intent. These results support the quantitative results but also extend the findings and illustrate strengths in the individuals. The results presented are considered in the context of existing scientific research which tends to emphasise difficulties in autistic people; the behaviours of the participants in the iA environment challenge such understanding, which further underlies the value of drama-based research (as discussed in Chapter 1).

## ***Social Interaction***

Three different possible opportunities for social interaction were offered in the iA environment (with practitioners, with peer and with a puppet). Examples were presented in Chapter 5 that described demonstrations of this by all participants in at least one of these areas.

Among the examples of social interaction with practitioners, a range of abilities was demonstrated by participants across the framework devised for this research (based on the Sounds of Intent framework). Difficulties were shown by some of the participants, these being compatible with problems in social interaction presented in diagnostic criteria (APA 2013). Annabelle, Amy and William demonstrated examples of non-responsive behaviour by rejecting or ignoring social invitations by practitioners, despite otherwise generally showing good levels of social interaction. Minimal responses were offered by David and Ed, who engaged in restricted interaction with practitioners, principally centred around their own interests. Further difficulties were noted with Harriet, whose social interaction was largely at the interactive level (although there were some demonstrations of proactive social interaction): she worked 'tentatively' within the environment, often needing support and guidance with social interactions. Although she displayed difficulties in interacting with practitioners, she still showed a desire for them. There were numerous examples of proactive engagement shown by participants that was demonstrated via skills in verbal communication (Harriet, Annabelle, Amy, William, Megan and Emma), shared attention (Annabelle, William, Megan and Emma), empathy (Annabelle, Amy, Megan and Emma) and playful engagement (Harriet, Annabelle, Amy, William, Megan and Emma). These skills were all used as tools to initiate or demonstrate engagement with practitioners, thus demonstrating some very good social interaction skills.

In addition to interaction with practitioners, some participants initiated interaction with facilitators, e.g., the camera operator (Amy, William and Emma) and the technician (William). This is noteworthy, as the primary role of these facilitators was not to interact with the

participants (in contrast to the practitioners' role), thus demonstrating the participants' active seeking of social interaction with people who were less forthcoming with and open to social interaction. Further evidence of this was noted in Amy's and William's interactions with the facilitator-practitioner, a more ambiguous role which involved a blurring of the lines set within the pretence framework of the iA environment, demonstrating their more complex understanding and use of social interaction.

Peer interaction provided a further opportunity to demonstrate skills in this area, as some participants were able to form successful working relationships within the iA environment that were maintained in the following session. This was most explicitly demonstrated by Annabelle and Amy who were strangers prior to the research and yet quickly and effectively established a working relationship that was maintained in play outside the environment. However, some difficulties were noted along the lines of problems in social interaction described in diagnostic criteria (APA 2013): Harriet failed to appropriately approach Ed; Megan and Emma both (separately) compromised their experiences of the environment in order to suit the desires of other peers; David and Ed showed a limited interest in engaging or seeking social interaction with their peers.

The use of the hand-held bird puppet Purdy produced examples of social interaction with participants who had otherwise demonstrated poor social interaction with people (David and Ed). This provides support for the use of alternative modes of interaction such as puppetry to assess skills in social interaction that could provide more accurate diagnostic information for those individuals who struggle to engage with people, as well as their possible post-diagnosis intervention.

### ***Performance Intent***

The performative quality of the iA environment which the participants interacted allowed for the participants to demonstrate performance intent. Analysis of these behaviours

divided them into performing as 'other', prop interaction, humour production, authorship, and acknowledgement of artificiality. The analysis presented in Chapter 6 used the "Framework for Recognising Attainment' in Intensive Interaction' (Firth 2011) as a basis for developing an analytical tool to assess the performance intent behaviours displayed by participants: the performance intent framework.

Participants demonstrated 'performing as 'other'' behaviour through using costume and working with the penguin toys. Some participants used full-body costume (Harriet, Annabelle, Amy and Megan) or partial costume (Harriet, Annabelle, William and Megan) to demonstrate varying degrees of skill in their ability to transform into another: performing in the role suggested by the costume to varying degrees within the performance intent framework; and understanding how they should move and/or talk differently and how this would alter their interaction with other people and the environment. Despite this, difficulties were noted in participants who when wearing the costume, did not perform as 'other' (Harriet, Annabelle, Amy and William), perhaps misunderstanding the role of the costume and the transformative possibilities of wearing it. The penguin toys also offered further opportunities to perform as 'other' as was demonstrated to varying degrees by Harriet, Amy and Megan, with participants either bringing the toys to life and animating them (essentially turning them into puppets), or through attributing emotions and feelings to them. These examples fit across four levels of the performance intent framework (attention and response, engagement, involvement and participant initiated interaction) and demonstrated some examples of pretend play, empathy, ToM and a desire for social interaction.

Most of the participants engaged in prop interaction, either using props to contribute to the environment (e.g., throwing the snow and snowballs around) or as part of play within the environment (e.g., fishing). When the examples were analysed through the performance intent

framework, the two highest levels involvement and participant initiated interaction, were found to have been attained – participants demonstrate imaginative engagement and pretend play.

Humour was present in all of the sessions and all participants experienced and responded to it as audience members. Some participants created amusements for themselves and one participant, Megan, extended this and set up a complex slapstick comic interaction in which she initiated and guided the action. Her humour production was assessed as being at the highest level of the performance intent framework. Significant ToM skills were shown in this example, in contrast to some research findings, with the comic interaction she set up effectively showing her ability to pass a Sally-Anne test (Baron-Cohen, Leslie and Frith 1985).

Skills in authorship were shown by three participants (Amy, William and Megan) who all found different ways in which to take control of and direct the action within the iA environment: Megan developed narratives on the microphone, directing the action and performing as multiple roles within the story; Amy controlled the technical elements of the pod, calling the storm to come and go in a variety of imaginative ways; William began to construct a game which he both participated in and directed the action of through giving his ‘performers’ lines to say. These examples fit into the two highest levels on the performance intent framework and provide further evidence of autistic children’s skills in pretend play, imagination, ToM and empathy.

Finally, some of the participants (Annabelle, Amy and William) acknowledged the artificiality of the environment and appeared to be testing the boundaries of the pretence framework within the space. Other participants (Annabelle, Amy, Megan and Emma) also demonstrated a clear understanding of the artificiality of the environment by ‘playing the game’, indicating to others that they were aware of the pretence framework and were willing to engage with it. The examples fitted across four domains of the performance intent framework

(attention and response, engagement, involvement, and participant initiated interaction) and showed further demonstrations of ToM, pretend play, imagination and social interaction.

What is particularly interesting about the qualitative results is that they challenge preconceived notions of deficits in autistic children, instead revealing skills in these areas and providing further support for alternative constructions, as seen in other drama-based practices (to be discussed shortly). On an individual level, several of the participants' diagnostic letters and parental reports highlighted difficulties in specific areas that were not present within the iA environment – and yet some of the participants displayed skills in exactly these specific areas. This reveals the role that an environment can play in behaviour. It may be that the responsive and multisensory environment of iA helps to facilitate behaviours that are elsewhere found to be problematic (even if the skills are presented in a restricted manner in comparison to typical expectations). However, it is important to note that difficulties were still shown by the participants that align with deficits presented in medical and scientific literature – the aim of the research was not to remove the autism diagnosis but to produce a more complete view of the individual.

## **Limitations**

This study has a number of possible limitations, as well as several methodological issues. Although the initial plan was to counterbalance participants, this was not possible due to the practicalities of recruitment which meant that all of the participants experienced the iA environment post-diagnosis. Ideally, participants would have been recruited both pre- and post-diagnosis to counteract any effect that having the diagnosis (or not) may have had on behaviour. Additionally, it may have been useful to have a group who engaged in a different form of arts-based practice to see how this affected the results, or a control group to assess 'normal' standards of behaviour in the iA environment (discussed shortly).

The recruitment of participants posed particular difficulties for this research, as due to ethical considerations, the recruitment was carried out by staff at the local NHS diagnostic services. Unfortunately, the research recruitment was not a staff priority and it became apparent when there was no uptake from participants that the information packs and consent forms were not being distributed as agreed. When this was realised and brought to the attention of the relevant supervisor within the NHS, staff actively began to distribute these and participants began to return consent forms. This caused significant delays to the practical research and led to a secondary research site, Sussex Partnership NHS Foundation Trust, to become involved in the project to encourage further recruitment. This secondary site was not ideal as they had recently altered their diagnostic practices so that there was only a very small number of potential participants who fit the inclusion criteria and who could be contacted. The difficulties in ensuring that the information packs and consent forms were received by potential participants appear to have directly affected the recruitment and are likely to have resulted in the small number of participants recruited. Had there been no difficulties with recruitment, the timescale of the practical research could have been extended, with a higher participant uptake (originally it was hoped that there would be twenty participants).

In addition to the difficulties in recruitment, the timing of the recruiting may also have been problematic. At the diagnosis, parents/caregivers are likely to receive a considerable amount of information, as well as having to deal with the actual diagnosis (or non-diagnosis) itself. This may mean that they are less amenable to participating in research and that following this up a few months later or initiating contact at referral, might have increased participation.

In relation to the practical research, the participants would ideally have experienced the same practitioners across the two sessions but unfortunately this was not always possible due to practitioner availability. This would have reduced potential variables that may have affected the way that the participants engaged in the environment. This is also true for the peers present

in each session, although that was beyond the control of the author. Additionally, it would have been preferable for the pod to have been set up within the same studio space for each session. Instead the layout was mirrored across studios which, again, may have had some effect on the participants' behaviour.

Although the ADOS-2 was successfully completed and analysed in the alternative environment, it was noted (see Chapter 4) that some of the ADOS-2 codes were problematic to complete during the analysis process. Solutions for this were proposed but unfortunately these were never fully realised. Future research would need to take steps to ensure that all of the ADOS-2 codes could be successfully completed.

The current construction of the iA pod is able to accommodate five environments but only one of these was used in this research. The Arctic environment was selected because it was felt to be the most appropriate due to its lightness which, it was thought, might alleviate potential anxiety for participants who were coming to a place they had never been before to engage with strangers. To determine the influence of the actual environment on the participants and their behaviour, the other environments would need to be tested and results compared. In this way, it would be possible to determine whether any adverse effects occurred because of the particular environment that the participants engaged with. Furthermore, elements of the methodology of iA could be tested outside the pod to discover which essential qualities of the iA framework could be used to support diagnosis.

Notable issues were present in the retrieval from the NHS of the diagnostic data required for the analysis in this research. Unfortunately, this meant that not all of the data needed to complete the analysis could be obtained, which further reduced the number of participants whose data could be used in the quantitative analysis. Similarly to the recruitment issues presented earlier, the retrieval of data was not a priority for the NHS, and the division of the diagnostic services within East Kent, caused further issues. Although participants would

initially go to the approved site for research, Kent and Canterbury Hospital, several of the assessments were then outsourced<sup>178</sup>, making the retrieval of the assessment data problematic, as additional ethical approval had to be gained for some of the participants.

Furthermore, the small sample size limited the statistical power that could be employed and caused issues with generalisation beyond the study. Additionally, the research was conducted within a small geographical location which would further affect the generalisability of the results, so caution should be exercised in generalising beyond the specific research conditions presented here.

Finally, there are inherent difficulties in the same individual designing, conducting, analysing and evaluating this research. It was not possible for additional individuals to assist in the research to counteract this, although close supervision from the supervisory team was offered to alleviate any issues that this may have incurred. Future research would need to incorporate additional researchers to avoid any undue bias.

However, despite these limitations, the results are encouraging and provide further evidence for the growing body of research that uses arts-based practices with autistic people, and adds to the alternative construction of autism that is present within these research contexts (as well as social models of disability) that shift focus from deficits and difficulties to strengths and capabilities.

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<sup>178</sup> Across Kent, the referral pathways for autism are different: in East Kent referrals are now through an external provider, Psicon; in West and North Kent they are through the Kent Community Health NHS Foundation Trust; in Swale they are through the Medway NHS Foundation Trust Community; and if 12-17 years, they are through the Child and Adolescent Mental Health Service (CAMHS), which is provided by Sussex Partnership Foundation Trust (Kent County Council 2017).

## How do the results relate to existing research?

The summary of results includes a variety of strengths and skills that were demonstrated by participants, as well as some difficulties, but how do these examples fit into the existing understanding of autism? This section will explore this matter, not only reviewing the scientific and medical construction of autism but also demonstrate how this research adds to the growing body of research that uses the arts (specifically drama and theatre) with autistic people, discussing how this extends current thinking surrounding the condition. The examination is organised under a series of subheadings that were devised based on the information derived by the participants' behaviour (these often overlap) and which were used to frame the alternative constructions of autism as presented in Chapter 1<sup>179</sup>: social interaction; ToM; imagination; play; empathy; and shared (joint) attention.

### Social Interaction

One of the core deficits of autism is in social interaction (and communication), this constituting part of the diagnostic criteria (WHO 1992; APA 2013).<sup>180</sup> This means that deficits in social interaction feature significantly in diagnostic tools (e.g., the ADOS [Lord et al. 1989] and the ADI-R [Lord et al. 1994]). These difficulties have been observed in research (e.g., Szatmari et al. 2016) and social skill interventions have been found to be successful tool for teaching and enhancing social skills in autistic individuals (e.g., Webb et al. 2004).

A variety of theatre projects have been found to be beneficial for autistic people enabling skills to be demonstrated in social interaction through engaging in drama-based settings (Glass, Guli and Semrud-Clikeman 2000; Peter 2003; Kempe and Tissot 2012; Lerner and Mikami 2012; Guli et al. 2013; Loyd 2013; Corbett et al. 2014a, 2014b, 2016; Reading et al. 2016; Beadle-

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<sup>179</sup> The existing research is compared briefly to this thesis research and the reader should refer to Chapter 1 for more details about the individual research projects discussed.

<sup>180</sup> See Lord and Jones (2012) for a review of the social communication and interaction dimension of ASD.

Brown et al. 2017). Furthermore, these benefits have been extended into therapeutic contexts (Miller 2005; Müller, Schuler and Yates 2008; Andersen-Warren 2013; Godfrey and Haythorne 2013; Wilmer-Barbrook 2013; Porter 2014).

The results from this thesis are broadly consistent with results within the wider research context, demonstrating that abilities in social skills in autistic people can be elicited by drama-based projects. Although the thesis research is not intended to be an intervention and therefore gains beyond the two sessions that the participants attended were unable to be measured, clear skills in social communication and interaction were still noted, with participants able to flexibly and appropriately interact with a variety of people. In communicating with the facilitators, some of the participants initiated social interaction with non-performing practitioners, thereby showing skills in social contact as well as a desire for it. This supports research which suggests that, on implicit assessment, autistic children possess an automatic tendency for social approach (Deckers et al. 2014), as well as other research that has found autistic children to have high levels of social initiation (Bauminger, Shulman and Agam 2003). This therefore suggests that some autistic people have a desire for social interaction but that the way this is expressed may not meet normal expectations and therefore maybe misinterpreted.<sup>181</sup>

The alternative roles that were presented to participants by the practitioners (characters, facilitators and Purdy) allowed for different participants to interact with a variety of roles, both simple (the puppet) and complex (the Inuit). For example, most of the participants interacted very well with the practitioners, but some (David and Ed) struggled with this. Instead they interacted much more effectively with Purdy in accordance with comments made by Trimmingham and Shaughnessy (2016b: 300) to the effect that those who are more severely

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<sup>181</sup> For example, Williams, Costall and Reddy (1999: 373) have highlighted how research should be established into 'autistic people, others and objects...incorporating objects into the 'realm of the social''.

affected respond particularly well to the puppets. Puppets may be, at least for some people on the spectrum, easier to interact with due to their reduced nonverbal communication which makes them easier to read, linking to current research that highlights difficulties with nonverbal communication (e.g., Morgan, Maybery and Durkin 2003). Similarly, William had a surprising amount of interaction with the camera operator when compared to his rate of spontaneous interaction with the performing practitioners. This may indicate a preference for interacting with those who are not performing in role or in costume. In addition to this, the use of humour by Megan clearly helped to develop and maintain relationships with the practitioners, further contributing to the growing body of drama-based research that challenges traditional ideas surrounding autistic deficits in social interaction. In short, drama is a useful tool to remedy some of the social difficulties that some autistic individuals have, as demonstrated within this thesis research. Furthermore, it is pertinent to consider that the skills the participants displayed with social interaction were demonstrated in a short period of time (sessions lasted for thirty minutes) with people who were initially unknown to the participants, indicating strong capabilities in social interaction and contact.

Research outside of drama has found that social interaction is possible for autistic people, provided it is presented in an appealing matter, e.g., in social stories (Quirnbach et al. 2009) and when using perservative interests. Moreover, Trimmingham and Shaughnessy (2016b: 217) discuss how “typical social environments’ (such as schools) do not provide the right keys of intensity for social learning or imaginative development in autism’, with the iA environment possibly offering these ‘right keys’ for autistic children who otherwise demonstrate difficulties in social interaction.

Another key element in iA, one which further distinguishes it from traditional diagnostic settings, is the presence of peers, allowing the possibility of interaction with them being observed. The findings from the thesis research resonate with the aforementioned research on

the use of drama-based interventions with autistic people. Positive peer interaction was noted in particular between Annabelle and Amy who had been strangers prior to the sessions. They were able to quickly and effectively establish a friendship that extended beyond the environment (in the second session they commented on how they had been playing outside prior to the session). They were able to work together to interact with the environment, demonstrating skills in sharing and working together in accordance with results shown by other drama-based research (Schuler 2003; Lerner and Mikami 2012; Andersen-Warren 2013; Loyd 2013). Moreover, they worked flexibly within their relationship – they understood when their relationship playfully altered, e.g., when Annabelle appeared dressed as a bear.<sup>182</sup> Annabelle and Amy were also very interested in the appearance of Ed in their second session. This interest was also demonstrated by Harriet who immediately found something to offer to Ed when he entered the environment, further echoing other research within drama-based practices, as well as more general research on skills in social approach and initiation (Bauminger, Shulman and Agam 2003; Deckers et al. 2014).

However, some of the findings in this thesis are consistent with research that focuses on difficulties in peer relationships. Two of the participants (David and Ed) lacked skills in peer interaction and did not demonstrate any significant desire to participate in these interactions, even when the peer was familiar (David). There some further difficulties demonstrated in knowing how to socially approach (Harriet) and when it was appropriate to do so (William).

The examples of social interaction seen align with much of the research from drama-based practices, emphasising the social interaction potential of such environments. This contrasts with the medical and scientific constructions of autism suggesting instead an alternative view denoting ability in social skills in particular environments. However, difficulties were still present that accords to deficits in autistic people presented in medical and scientific

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<sup>182</sup> This is further reflective of ToM, which will be discussed shortly.

literature. For example, issues with social interaction were displayed by David and Ed who did not appear to want (or be capable of) engaging socially unless it was predicated on an interest of theirs, e.g., Thomas the Tank Engine. Additional support in interactions was also needed for Harriet who often remained as an observer until she was invited in to the action.

## **ToM**

As introduced in Chapter 1, ToM has been found to be problematic for some autistic people in medical and scientific constructions of autism, and autistic people have been found to fail ToM tests (e.g., Baron-Cohen et al. 1985), although ToM interventions have found increases in ToM skills, suggesting that these can be acquired (Beeger et al. 2015; de Veld et al. 2017). These ToM tests however, have been criticised within drama frameworks, with some research suggesting that the current experimental testing for ToM 'may not reflect the breadth and flexibility of perspective taking in real-world social contexts' (Loyd 2013: 13) and that in fact engagement with drama-based projects may test ToM more appropriately.

Overall ToM skills have been reported to be above average in actors (e.g., Goldstein, Wu and Winner 2009-2010). Several drama and theatre programmes have reported skills in ToM for autistic people (Corbett et al. 2011, 2016; Godfrey and Haythorne 2013; Hodermarska 2013; Lewis and Banerjee 2013; Loyd 2013), suggesting that ToM skills can be improved after participating in such programmes.

The research participants demonstrated skills in ToM that align with the research which is grounded in drama-based practices and suggests ToM capabilities. Harriet and Megan performed as the Penguin and Snowman, and Annabelle and Megan spontaneously and independently began to perform as bears, demonstrating an understanding of the role of a bear and how it might frighten others, using this in a playful manner. This corroborates Loyd's (2013) work on perspective taking that shows an understanding of role-play in autistic individuals. Participants (Harriet and Megan) were able to attribute a variety of mental states to

the penguin toys, offering concern for them. When engaging in play centred around throwing a snowball at a character and then denying responsibility, Megan and Emma both independently displayed an understanding of ToM. They both recognised that the Penguin (who had not seen who had thrown the snowball) would believe them when they denied it. They explicitly understood the Penguin's perspective on the situation. These examples provide additional support for autistic children's skills in ToM and for taking an alternative perspective, as demonstrated by Corbett et al. (2016). Megan's comic setup displayed more complex skills in ToM. The setup could be compared to the Sally-Anne test used to test ToM (Baron-Cohen, Leslie and Frith 1985). Her application of ToM within this setup would suggest that she would pass this test, as she has a practical understanding of ToM. This supports research which has found that 50% of autistic participants can pass ToM tests, contradicting the notion of autistic deficits in this area (Lam and Yeung 2012). This further relates back to Loyd (2013). Furthermore, this contrasts with perceived deficits in humour (e.g., Samson, Huber and Ruch 2013; Weiss et al. 2013), with ToM understood to be a central part to understanding jokes, and suggestions that ToM issues may affect an autistic person's ability to understand humour (Wu et al. 2014). Types of humour in which ToM skills are less important (e.g., slapstick) have been reported to be enjoyed by autistic people (Reddy, Williams and Vaughan 2002; Weiss et al. 2013). A demonstration by participants that was arguable more relatable to 'real-life' was when Annabelle and Amy denied responsibility for creating a mess in the Inuit's home – instead they blamed the Snowman. In contrast to the example by Megan and Emma of denying responsibility, this did not appear to be playful and it could therefore have been a more 'real-life' demonstration, with Annabelle and Amy concerned about the perceived negative ramifications of their behaviour.

Despite some participants demonstrating skills in ToM, there were still difficulties shown that provide support for medical and scientific constructions of deficits in ToM.<sup>183</sup> The rejection and ignoring by some participants (Annabelle, Amy and William) of offers of social interaction from practitioners could demonstrate issues with ToM as the participants appeared to either misunderstand the approaches or were unconcerned with the negative social implications that this type of behaviour might have on establishing and maintaining social relationships. Additionally, when Megan took on the role of the bear and scared the Penguin, she misread the Penguin's response. Instead of immediately altering or ending the interaction, she laughed and continued to scare the Penguin briefly. Again, this could have had negative impacts on the maintenance of social relationships, as well as possibly demonstrating a slow processing of emotions, and a lack of understanding of when empathy would normally be expected to be demonstrated.

Acting facilitates the use of ToM, encouraging the performer to view the world from an alternative perspective, understanding how this role would interact with the world and others differently, and how others might react to this role in return. This clearly demonstrates why drama-based practices may be useful in better understanding and assessing ToM in autistic individuals.

## **Imagination**

As previously discussed imagination can be problematic to define. Regardless of this, deficits in imagination are involved in the diagnostic criteria, as well as observed in research (e.g., Scott and Baron-Cohen 1996; Craig and Baron-Cohen 1999; Craig, Baron-Cohen and Scott 2001; Low, Goddard and Melsner 2009; Eycke and Müller 2015). However, some research in the medical and scientific models has contradicted this, instead reporting no differences between

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<sup>183</sup> There is no discussion here of David and Ed who did not display skills in ToM; however, as false belief develops in typically developing children between four and five years old, this is not surprising and would need to be factored into any assessment of ToM.

autistic and other participants in various tests of imagination (e.g., Leevers and Harris 1998; Dillon and Underwood 2012; Angus et al. 2015; Allen and Craig 2016).

Research that contradicts the perception of autistic deficits in imagination has also been provided by work grounded in arts and drama practices (Kempe and Tissot 2012; Godfrey and Haythorne 2013; Lewis and Banerjee 2013; Pimpas 2013). Several instances of imagination in the AHRC iA project are discussed qualitatively (Shaughnessy 2013, 2016b; Trimmingham 2013, 2016; Trimmingham and Shaughnessy 2016a). Peter (2003) has shown how drama naturally allows children to develop their skills in thinking more creatively and flexibly, with the added benefits of being capable to motivate 'hard-to-reach' children. This flexibility is a key component, as it means that drama practitioners can alter their approach to each individual to suit, for example, their communicative needs.

The research grounded in drama-based practices is broadly consistent with the research completed for this thesis on several levels. Social imagination was used by some participants, in which they imaginatively and flexibly communicated with characters who did not speak conventionally, e.g., with the Snowman who made sounds: Annabelle translated his language into English; and Amy spoke back to him in gibberish. Another example of this was Megan's puppeteering of the penguin toys to communicate with the Penguin in non-traditional language. Megan even offered different voices for the two different penguins that she used, later referring to them as being from the 'North' and the 'South'. This helps to supplement research which provides support for the use of drama in peer (or, in this case, practitioner) interaction (e.g., Lerner, Mikami and Levine 2011). Another example of how social imagination was displayed was through the performing of 'other'. Participants were able to perform as another character, usually through wearing a costume. Particularly striking were the participants' abilities to spontaneously alter their relationships to others once in role, showing solid skills in social and recreative imagination (Currie and Ravenscroft 2002). For example, when Amy and Megan

performed as bears (aided by wearing hats), they understood that these were creatures that were likely to be feared by others, using playful exchanges with practitioners and their peers to demonstrate this.

In addition to this, some of the participants (Harriet, Annabelle and Amy) engaged in imaginative play with the fish game, offering surprising responses to what the cardboard fish tasted like, e.g., zebra. This contrasts with suggestions of autistic deficits in imaginative play (e.g., as noted in the DSM-5) and outcomes of research into imagination tested through drawing (e.g., Scott and Baron-Cohen 1999). Not only were the participants engaged in the pretence of the fish being edible – all pretending to eat them – but they gave imaginative descriptions of their taste that clearly demonstrated a further willingness to engage in the pretence of the environment and an ability to transform something into the impossible, such as a zebra-tasting fish. This contrasts with research suggesting that autistic people have difficulties with the impossible and the unreal in drawing tasks (Scott and Baron-Cohen 1996; Craig, Baron-Cohen and Scott 2001). Another example of creative imagination (Currie and Ravenscroft 2002) was demonstrated when Amy offered a pile of snow as a cloud for Purdy to sit on when he was being blown around by the wind, also demonstrating a clear use of creative and flexible thinking, as described by Peter (2003), which was used to problem solve. A further example was Megan developing her own narrative. She spoke on the microphone, devising a story which she articulately conveyed, and performed as other characters when the narrative required this. This clearly demonstrates storytelling skills and aligns other research using drama based-practices which has noted such skills (Lewis and Banerjee 2013). Flexibility of thought and some basic imagination was further displayed in the transformation of props by some participants (e.g., the tube becoming a fishing rod). The examples demonstrated by research participants illustrate how drama may be a useful tool for supporting imagination in some autistic individuals (e.g., Kempe and Tissot 2012) and for helping to develop these skills (e.g., Corbett et al. 2014a).

Regardless of the examples illustrating autistic imagination skills in the thesis, existing research suggesting deficits in imagination was supplemented by some of the behaviours shown by participants. One would expect that the participants would respond imaginatively within such an environment as iA. In any case, to be able to engage at all in such an environment requires some basic understanding and application of imagination. However, there were moments when a lack of imaginative engagement was shown by some of the participants e.g., when William became confused over the role of the puppeteer and Purdy. He interpreted literally what the practitioner who was voicing Purdy said about William not being able to find him, responding by saying he could and pointing to the puppeteer. He had misunderstood the role of the puppet and was unable to engage with the imaginative potential of the situation. Furthermore, there was a questioning of the pretence of the environment, with participants noting the artificiality of the space (although once their questions/observations had been addressed they appeared to accept the pretence framework of the environment and were able to engage with it in the imaginative aspects).

Outside drama-based practices, the notion of autistic deficits in imagination has been critiqued. Scott (2013) points out that while there is a widespread assumption of imagination deficits in autism, what this entails is not clearly specified, a claim that someone (or indeed a group) lacks imagination being a sweeping statement. She focuses on three areas of interest in autistic imagination (mental imagery, pretence and creativity) and after reviewing research into the autistic imagination suggests that the central issues are linked to the 'spontaneous generation of ideas and concepts that do not adhere to rules or boundaries, explicitly contrast with conformity, and allow the thinker to be flexible enough to move outside real-world possibility and into a realm of fantasy in which anything is possible' (Scott 2013: 512). She argues that it cannot be assumed that the *difference* in autistic imagination is necessarily a *deficit*. This is supported by Bogdashina (2003: 118), 'a more precise definition of impairments in imagination, therefore, would be that imagination in autism is qualitatively different from

non-autistic imagination', with Roth (2007a: 282) suggesting that, in fact, 'creative imagination is preserved in autism, because it operates relatively independently of mentalizing, executive function, or projective forms of imagination, and is less cognitively demanding'. Furthermore, Roth (2007a: 146) attacks the assumption of a lack of imagination in autistic people, as this denies 'their essential humanity' and 'seem[s] to imply that autistic persons do not really have an inner life'.

Another important point is that most of the tests for imagination and creativity are currently based on drawings. This may not be capable of revealing every autistic person's imaginative skill; a more active engagement in imagination or creativity (e.g., through drama-based practices) may help to showcase the imaginative potential of these individuals more clearly. Moreover, difficulties with imagination have been discussed in relation to ToM (e.g., Baron-Cohen et al. 1985) and demonstrated in experimental conditions (e.g. through drawing tasks [Scott and Baron-Cohen 1996]). This is problematic, as the results do not necessarily map onto real-life situations and contrasts with autistic individuals' accounts (e.g. Grandin 2006 who describes her visual imagery), and accomplishments in creativity by other autistic individuals (e.g. Steven Wiltshire's architectural drawings<sup>184</sup>).

## **Play**

Similarly to imagination, play is difficult to define. Deficits, specifically in imaginative play, are noted in diagnostic criteria (APA 2013) and more generally reported in research (e.g., Hammes and Langdell 1981; Baron-Cohen 1985; Sigman and Ungerer 1987; Rutherford and Rogers 2003; Lam and Yeung 2012). Specific difficulties have been noted in pretend play (e.g., Charman et al. 1997), particularly in spontaneous pretend play (e.g., Baron-Cohen 1987). Interventions have been used to help combat difficulties with play skills and positive changes have been noted, e.g., Pivotal Response Training (Thorp, Stahmer and Schreibman 1995), play

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<sup>184</sup> <http://www.stephenwiltshire.co.uk/>

therapy (e.g., Portman Minne and Semrud Clikeman 2011; Hodermarska 2013; Lewis and Banerjee 2013), and play-drama intervention (Peter 2003). Interestingly, it has been reported that play can be demonstrated if it is supported (Charman and Baron-Cohen 1997; Jarrold 2003).

Drama-based practices have reported benefits for play on autistic people (Peter 2003; Guli et al. 2013; Trowsdale and Hayhow 2013), particularly in relation to peer-based play (Dauphin, Kinney and Stromer 2004; Wolfberg, Bottema-Beutel and DeWitt 2012) and as described in the AHRC iA project (Shaughnessy 2013, 2016b; Trimmingham 2017; Trimmingham and Shaughnessy 2016a).

Results from this thesis research complement those found by other drama-based practices. The dressing up by participants as other characters demonstrates skills in dramatic play which further supports Kempe (2013). The participants demonstrated play skills by engaging with others through pre-existing games (e.g., hide-and-seek) and new games (e.g., the fishing game), and as a way to engage with the environment (e.g., the throwing of snow). These games were generally rule-based, e.g. hide-and-seek, which ties in with research suggesting a preference for such games (Dewey, Lord and Magill 1988). Another interesting example that perhaps supports this notion of rule-based play comes from the fishing game in which participants caught fish and pretended to eat them. The practitioners ate the fish first and gave ridiculous descriptions of what they tasted like, then asked what the participants thought they tasted like. No explicit rules were given to the participants but all of those who were involved understood the implicit rule that they should offer an equally ridiculous answer, showing a sophisticated and arguably spontaneous demonstration of rule-based game play. Functional play was demonstrated by some of the participants (Harriet, Annabelle, Amy and Megan) in their use of the penguin toys. Interestingly, these examples involved engagement in social play, which supports research surrounding the benefits of play for autistic people in developing their

social skills (e.g., Corbett 2016). The use of play to socially interact with others was also demonstrated through skills in pretend play by Megan and Annabelle, who performed as 'other' (the Snowman and a bear) to interact with their peers and the practitioners. These examples of participants' performances as bears provide examples of spontaneous acts of pretend play, contrasting with research which suggests that autistic individuals have difficulties in producing spontaneous or novel examples of pretend play (Baron-Cohen 1987; Charman et al. 1997; Charman and Baron-Cohen 1997). This was further demonstrated by Megan's narration which she spontaneously began, showing more developed play and further engagement within the environment. This example provides further support for drama's potential to enable skills in play to be displayed (Peter 2003). It allowed Megan to develop her understanding and use of pretence, enabling her to very clearly have a pleasurable play experience that was shared with others. Furthermore, this is consistent with Kempe (2014: 270) who refuted a 'lack of ability to engage in dramatic play' from autistic participants. It may be that the iA environment is one that encourages play and allows autistic participants to demonstrate it, arguably supporting the research of Charman and Baron-Cohen (1997) and Jarrold (2003).

As previously noted, research from within the scientific construction reports deficits in play in autistic children and some of the participants in this thesis research appeared to confirm this. Not all of the participants could fully engage with the environment, particularly David and Ed, which may predominantly be because of their deficits in play abilities – they were unable to navigate the play-based world of the environment. Further difficulties were noted in the behaviour of some of the other participants. It is possible that the failure of some of the participants to perform in the costume that they were wearing (e.g., Annabelle and Amy as penguins and Harriet as the Snowman) was due to their issues with understanding the pretence framework and arguably therefore their issues with pretend play.

Understanding that pretend play is very important to children's development, particularly to their social competence, problems may arise in children with severe and/or complex needs if they lack opportunities in which to demonstrate a spontaneous drive to interact with others and their environment (Peter 2003). It therefore follows that 'if children are denied the opportunity to engage in pretence, then their social understanding will be necessarily impaired' (Peter 2003: 21). This points to the importance of drama-based practices, particularly if they are embedded in play practices, as they offer opportunities for play that autistic individuals may otherwise not experience. Shaughnessy (2013: 311) highlights how play is 'often neglected post-diagnosis' which, if play's a fundamental element in development, may have detrimental effects on the individual.

## **Empathy**

Deficits in empathy are noted in autistic people (Charman et al. 1997; Baron-Cohen et al. 2001; Baron-Cohen and Wheelwright 2003; Goldenfeld, Baron-Cohen and Wheelwright 2005; Wakabayashi et al. 2007). Emotion recognition interventions have helped to support the development of empathy in autistic individuals (Goldenfeld, Baron-Cohen and Wheelwright 2005), suggesting that it can be taught.

In the general population, drama has been found to increase empathy, as discussed in previous chapters (e.g. Goldstein 2011). Increase in empathy following involvement in drama-based projects have also been reported in autistic people (Guli et al. 2013; Trowsdale and Hayhow 2013; Beadle-Brown et al. 2017) and demonstrated in therapeutic contexts (Lewis and Banerjee 2013).

The findings relating to empathy in the drama-based research literature and the AHRC iA project were supported by the thesis research. Several of the participants offered to help or look after characters, e.g., offering fish to the characters (Annabelle, Amy, Megan and Emma), offering to fix the Penguin's fallen house (Emma) and helping to find the Snowman's nose

(Annabelle and Amy). These examples all demonstrate skills in empathy through participants caring for, and offering concern directed towards, others, as well as their reading and understanding of emotions. In addition to this, a test of empathy was purposefully included within the sessions which gave the participants an opportunity to spontaneously display empathy: Annabelle, Amy, Megan and Emma responded appropriately to this. Concern was further offered towards the penguin toys, demonstrating how empathic skills can be translated to objects and showing further skills in pretence (Harriet [feeding] and Megan [protecting them from the storm]). The practical testing of empathy in this environment may be more appropriate for autistic people, e.g., some tests focus on responses to facial expressions in order to determine whether someone has empathic skills. If this is problematic for an autistic individual, it is taken to indicate a deficit in empathy rather than a difficulty in reading facial expressions. Furthermore, as argued in connection with the double empathy problem, our understanding of what empathy is may need to be reshaped in order to account for differences in styles.

However, despite these skills, not all of the participants responded to the prompted empathy situation and some failed to respond 'appropriately'. This provides support for the deficits in empathy noted the within scientific literature on autism.

### **Shared (Joint) Attention**

Issues linked to shared attention are part of the clinical diagnostic criteria in the DSM-5 (APA 2013) and are included in diagnostic tools (e.g., the CHAT). These issues are further observed in research (Mundy et al. 1986; Sigman et al. 1986; Mundy, Sigman and Kasari 1994; Osterling and Dawson 1994; Charman et al. 1997; Kasari 2008). Skills in joint attention have been developed through joint attention interventions that significantly improved language outcomes (Kasari et al. 2008).

Drama-based research has noted improvements in shared attention (Corbett et al. 2011; 2013; 2016; Guli et al. 2013), including examples from the AHRC iA project (Shaughnessy 2011; Trimingham and Shaughnessy 2016b).

The behaviour demonstrated by several of the participants in this research contrasts with several of the deficits noted in the existing scientific literature and is consistent with that reported in other drama-based research. Participants engaged in shared attention to initiate or continue social interaction with practitioners, revealing these skills through a combination of verbal and nonverbal examples. Nonverbal communication was used to draw others' attention, e.g., through the use of pointing by Annabelle and William, facial expression and eye direction by Annabelle or a combination of facial expression, pointing and eye contact by Megan when setting up the comic interaction. The presence of these particular skills runs contrary to current understandings of autism, as reflected in the diagnostic criteria which suggests difficulties in nonverbal communication (also demonstrated in research [Morgan, Maybery and Durking 2003; Dawson, Webb and McPartland 2005]) are the norm.

## **What does the thesis research contribute to the diagnostic process?**

The main focus of this research was on how a drama environment could aid the diagnostic process for autism. As noted in Chapter 5, the ADOS-2 could be completed successfully and the participants' diagnoses were maintained within the iA environment, even though many examples of 'atypical' skills were displayed by participants. Furthermore, this was supported by the analysis of the ADOS-2 at different levels (overall ADOS-2 scores, severity levels, comparison scores and module 3 scores [social affect, restricted and repetitive behaviours, overall total]), which was generally supportive of the diagnostic results from the clinical ADOS-2 (although agreement between the two ADOS-2's did decrease on module 3 scores).

In addition to this, the iA environment involves several key elements that distinguish it from the clinical setting and, as has been argued, allow for an increase in certain behaviours to be displayed and, in some cases, a deeper exploration of specific skills. This is because of the unique quality of the drama environment which, in contrast to the clinical setting, enables: (1) a practical exploration of behaviours; (2) a greater flexibility; (3) peer interaction; and (4) an immersive environment.

### **Practical Exploration**

One of the key aspects of engagement with iA which contrasts with the clinical ADOS-2 is the possibility for a practical exploration of behaviour that is enabled within the drama environment. One area that this relates to is social interaction. Several sections of the ADOS-2 are explored through verbal questioning in module 3, through more simple interaction between the examiner and examinee in both modules 1 and 3, and in the case of module 1 also with a caregiver. The complex social setting provided by the iA environment allows for multiple opportunities, through a variety of encounters (e.g., practitioner, character and puppet), as well as the presence of peers, to demonstrate an understanding of social interaction that goes beyond the theoretical. The social behaviour of the participants directly affects their experience and therefore this is arguably a more 'real-life' exploration of skills than that which is currently undertaken in the clinical environment.

Another key element that is practically explored in the iA environment is ToM (and consequently empathy). Skills in ToM are practically explored in a way which can function similarly to the Sally-Anne test, except that instead of passively observing an interaction and then responding to questions, the participants were offered the opportunity to explore and practice ToM skills practically. In the ADOS-2, toys and stories are used to facilitate ToM which are restrictive in responses, whereas in the iA environment ToM is facilitated through interaction with people and the participants response to others, directly impacts the

environment. The iA environment also allows for multiple ways to explore this, rather than relying on tests that investigate empathy through only one mean, e.g., facial expression recognition. Additionally, the experience of humour is a good way to test ToM but currently is not a key part of the diagnosis (although within module 3 there are a couple of references to humour within the tasks 'Telling a Story From a Book' and 'Cartoons'). Moreover, humour can help to make a potentially intimidating or unfamiliar environment more comfortable and engaging, and so is likely to have furthered enjoyment, encouraging the research participants to demonstrate their skills. This is also the case for the empathy test included within the iA environment, again, eliciting a practical demonstration of empathy with a character that they have possibly connected with, rather than responding to a fictional character from a story or a cartoon. This may encourage an engagement that is closer to 'real-world social contexts', as argued by Loyd (2013: 13).

Another area that is practically explored is the role of imagination, which, although it does not explicitly contribute to current diagnostic practices, is a beneficial skill to have in real-life. Although imaginative tasks are present in the ADOS-2 (in module 3) and a demonstration of social imagination is elicited through the asking of questions, the pod provides a physical space in which to *practically* explore their imagination, in a way which the participants are free to lead. Much of the testing for imagination (and creativity) in the wider research context occurs through drawing tasks, which, while appropriate for some individuals, do not offer the same active engagement and experience that would likely be explored in environments such as iA. The latter may well help to showcase the imaginative potential of the individuals without relying on drawing skills. In the AHRC iA project, no significant differences were noted within the creativity/play domain of the ADOS-2 (Beadle-Brown et al. 2017) even though qualitatively imaginative and creative incidents were reported (e.g. Shaughnessy 2013; Trimmingham, in press). This could potentially draw attention to difficulties with the analysis of this domain within the ADOS-2. This matter is discussed by Shaughnessy (2016b: 405) who notes that

'performance processes are too complex to be contained in conventional cognitive experiments. They demand a range of qualitative and quantitative measures'. While this relates to performance processes that are not an essential part of the ADOS-2 and the diagnosis of autism, the fact that alternative behaviours demonstrating 'atypical' skills have been displayed within the performative environment argues for their inclusion in the diagnostic process in order to produce a more holistic view of the individual.

### **Greater Flexibility**

The iA environment is considerably more flexible than the clinical ADOS-2 setting, enabling it to be more responsive to the participants. In regard to social interaction there is a variety of ways in which the participants can engage, e.g., with the puppet. This has allowed skills to be seen in some participants (David) which were otherwise not documented in other interactions and therefore may have been missed if this opportunity were not present. Additionally, the way in which the participants can communicate with others is more flexible, e.g., engaging in nonverbal communication with some of the characters. Again, this enabled communication that may otherwise not have been seen (e.g., with David) or the demonstration of skills in complex social interaction, as well as imaginative communication, which are not currently tested for in the ADOS-2 (e.g., when Amy and Megan changed their mode of communication to suit the nonverbal characters). Furthermore, deviations are possible from the 'script', e.g., playing the *Thomas the Tank Engine* theme tune to help draw David into the pod to facilitate his engagement with the environment. It is possible for the environment to be changed by practitioners to suit the needs of the participant. Opportunities are even offered in which the participant can alter the environment themselves, e.g., through changing the technical lighting and sound elements. Not only can this help to facilitate engagement that, in turn, may provide a more accurate picture of their behaviours and skills, it also allows the participants to have agency, something that they may not often experience in their daily lives.

In the clinical ADOS-2, apart from the examiner, a range of toys is used to help facilitate the interaction. These are replaced in the iA environment by practitioners, who almost become 'life-size toys' for the participants to interact with<sup>185</sup> but who are able to offer much more flexible interactions than the toys (which are limited in their functions) and respond to participants in a wide range of ways to support interaction, enabling engagement to be maintained and, arguably, explored at a deeper level.

### **Peer Interaction**

Another key element of social interaction that is more fully explored is peer interaction (which has been discussed previously). This is not practically explored within the clinical ADOS-2 and is a key quality that distinguishes the two settings. The possibility for this to be practically observed and assessed (as opposed to being 'interviewed about'), offers a more 'true to life' exploration of the relevant skills and difficulties. Furthermore, it enables examiners to observe and assess the participants' interactions with people of similar ages, which are arguably more relevant to real-life e.g. within school.

### **Immersive Environment**

For some individuals, performance of 'other' or engagement with an immersive environment might be more appealing and thereby lead them to more clearly demonstrate their skills. This provides an argument for carrying out part of the diagnostic assessment in an immersive, drama-based setting as opposed to the traditional clinical one. The former approach can produce examples of practically explored imagination via an immersive and responsive environment set up to elicit imaginative possibilities, which contrasts with the clinical ADOS-2, where presses ask the examinees to tell a story using toys or from a cartoon. Furthermore, the iA environment is more likely to encourage engagement because it is exciting and immersive, in contrast to the clinical setting that the ADOS-2 is often conducted in. Additionally, the

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<sup>185</sup> although penguin toys are still present in the environment

immersive quality of the environment is more likely to encourage participants to display skills in play that may otherwise not be displayed, e.g., with pretend and imaginative play.

In addition to these areas, it may be a useful environment for more accurately assessing those who have more subtle manifestations of autism or those whose behaviour fails to conform to stereotyped understandings of autism, such as females.<sup>186</sup> The complex nature of the environment, e.g., the multiple social interactions, may reveal more about the behavioural profiles of those who use masking techniques (as has been reported in females). It has been noted that females sometimes fail to get a diagnosis or support because they may be just regarded as 'odd' or because the wrong signs are being looked for (Dix 2017: 77). It may be that by engaging in the iA environment, which elicits the imaginative and creative strengths noted in females (Dix 2017), the females relax into the environment, allowing their imitation and masking behaviours to be revealed so that their autistic behaviours become more detectable.

Despite the benefits that the iA environment offers for the diagnostic process when compared to the clinical ADOS-2, the advantages of the clinical environment should also be considered. For example, the fact that the clinical environment is standardised and easily recreated enables the diagnosis to be reliable. In comparison, the iA environment has many variables that might cause issues in replicating results and producing reliability. Additionally, emphasis in the clinical environment is placed on the skills of the clinician – those who have extensive experience are able to notice subtle behaviours and alternative manifestations, e.g., as in the case of autistic females.

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<sup>186</sup> A recent report ('A Lifetime Lost or a Lifetime Saved') stated that girls were less likely to be diagnosed with ADHD as they 'present with fewer disruptive behaviours, which can be more difficult to recognise; [and] as a result, this, in combination with gender expectations, could lead to a gender bias in ADHD in terms of identifying patients and initiating referrals' (Born to be ADHD 2017: 7). This is similar to the experience that some autistic females have as they do not present in the anticipated way and therefore may be less likely to be identified and be put forward for a referral.

## **What does this research contribute to the understanding of autism?**

The results and subsequent analysis discussed above contribute to the conceptualisation of autism. This is done through several ways:

- (1) through the strengthening of existing understanding of autism;
- (2) by demonstrating that skills can be facilitated in specific environments;
- (3) through clarifying how this work can facilitate the spontaneous demonstration of such skills;
- (4) by focusing on the relevance of strengths-based approaches that aligns with more recent thinking on disability.

As discussed in the previous section, the research reinforces research findings that are emerging from drama-based practice and that challenge the current understanding of autism. In addition to this, the work has provided evidence of its fluidity. As highlighted in Chapter 2, the diagnostic criteria, understanding and labelling of autism are fluid and continue to develop as research advances. The thesis research builds on this, offering alternative insights into autism and the perceived deficits associated therewith. Furthermore, the fluidity of behaviours demonstrated by participants in the iA environment contrasted with the contents of diagnostic and parental reports. This ties in to the concept that, at the behavioural level, autism significantly varies, as reflected by the phrase 'once you have met one person with autism, you have met one person with autism' (Spectrum n.d.). Not only did the participants differ in their individual behaviours, but across the sample very different representations of autism were demonstrated that spanned the spectrum. This variability meant that there were significant differences in the behaviours presented and the ways in which the participants engaged with the environment and the elements housed within it. In addition to this being useful for the diagnostic process at the individual level, it also has the potential for use beyond the clinical setting. The techniques that are used in iA could be adapted and applied in interventions that

are used by families and schools to assist the development of certain behaviours as discussed in the previous section (e.g., social interaction), which would further demonstrate the benefits of such alternative environments that use strength-based approaches to elicit skills. Another important point is that the iA environment was able to accommodate varying skill levels and engage all participants (regardless of capabilities) at some point during the session, adding to the information provided by the AHRC iA project (which also had participants across the breadth of the autistic spectrum). Even though there were still considerable difficulties at the behavioural and individual level, the universality of difficulties at the core level of autism was still present across a range of varying individual presentations.

Another area that this research can contribute to is the understanding of autism in females. As mentioned in the Introduction, views on gender and autism are shifting, with research suggesting that there are complex issues with the diagnosis of females (Shattuck et al. 2009; Giarelli et al. 2010; William et al. 2012; Rutherford et al. 2016) that include issues involving masking behaviours (Attwood 2017; NAS 2017) and females appearing more social than they actually are (Head, McGillivray and Stokes 2014) (see Chapter 2). It is interesting to note that for this research the gender ratio was 5:3 in favour of females, in contrast to the usual male-weighted ratios of diagnosis. The thesis research helps to enhance the understanding of the female autistic profile. All of the female participants provided examples of performance intent, possibly indicating a preference among females for engaging with such drama- (and arts-) based practices. Furthermore, they all displayed empathic behaviour, as tested for in the environment (excluding Harriet, who, despite being aware of the situation presented, failed to express empathy). This supports the alternative concept that some autistic women do not lack empathy (Dix 2017). Moreover, females actively sought out social interaction more than their male counterparts (although the females were all assessed on module 3, which indicates greater communicative capabilities). The above information could be very important in aiding the understanding of, and therefore being able to recognise, autism in females more successfully.

Additionally, in drama research (particularly the scientifically evaluated methods) the participants are often diagnosed with Asperger's, regarded as 'high-functioning', or if their IQ is below a certain point, excluded from research ([SENSE Theater Program] Corbett et al. 2014a, 2014b, 2016, 2017; [SCIP] Glass, Guli and Semrud-Clikeman 2008; Guli et al. 2013; [SDARI] Lerner and Mikami 2012; Lerner, Mikami and Levine 2011). This excludes a significant proportion of the spectrum from participation and hence from the analysis of such work. In comparison, iA is able to work across the spectrum, manifesting as a sensory exploration or a more complex narrative, depending on the needs of the individual. By including non- (or limited) verbal participants, this research adds to the current understanding of autism in drama (e.g., the use of puppetry being a beneficial mode to demonstrate social interaction skills with David) and provides further information about this group of autistic people.

The second way in which the research contributes to the conceptualisation of autism is through demonstrating that perceived deficits (those discussed above: social interaction; ToM; imagination; play; empathy; and shared [joint] attention) can in fact be demonstrated as skills if facilitated with the right approach. These results (from both the thesis research and the wider research context) offer an alternative view of autism and demonstrate how for some autistic individuals, certain drama-based environments can elicit skills that are not necessarily evident in other environments. This validates the use of methodologies which tend to use an individual approach, working *with* the person.

On an individual level, a clear way to assess how a participant's behaviour differs from typically developing behaviour, or at least what they displayed in the clinical diagnosis, is through comparing behaviour in the pod to that described in the diagnostic letter. This has been discussed throughout Chapters 5 and 6, although some examples will now be presented that involve skills being displayed. Amy showed several behavioural contrasts to her clinical assessment: despite the letter reporting that she had low levels of language, she effectively

adapted her language to enable her to communicate with the nonverbal characters; she demonstrated solid skills in pretend and imaginative play; and she engaged in empathy in the pod, when all of these behaviours were reported to be limited in the diagnostic letter. Annabelle similarly displayed behaviours which diverged from those described in her diagnostic letter: she was reported to prefer solitary play, yet demonstrated some sophisticated skills in peer play; and she displayed in empathy, despite this being noted to be a difficulty for her. Some of the other participants showed examples of 'contrasting' behaviours: Harriet's parents reported that she had issues with sharing, yet her first social advance to Ed was offering a bear hat to him; William was able to show some basic collaborative and reciprocal skills in play, even though this was reported as being an issue for him; and despite Emma supposedly having limited imaginative play, she was able to engage in some imaginative play within the pod. These examples all illustrate how engagement within a creative environment may have helped to facilitate behaviours that were perceived to be problematic for the individual (in accordance with the model of deficits in autism).

Not only does the research reveal unexpected skills, but the participants demonstrated several examples of spontaneity in displaying these, showing a more sophisticated and deeper level of understanding of the skills and how they can be applied in novel contexts. The most advanced of these were demonstrations of spontaneous play, which is noted as being problematic for autistic people (Baron-Cohen 1987; Charman and Baron-Cohen 1997; Charman et al. 1997; Rutherford and Rogers 2003; Rutherford et al. 2007). Several participants demonstrated clear examples of this. Annabelle and Megan dressed up as bears, performing as them and interacting with others. Amy transformed the shredded paper (snow) into a cloud for Purdy to perch upon and also spontaneously offered creative ways to manage the storm. Megan showed several examples, e.g., setting up the comic interaction and giving characters to the penguin toys. William commented that it was cold even though it was a warm day, suggesting an engagement in the pretence of the Arctic. These examples further demonstrate skills in

imagination and imaginative play, showing some surprising skills that shift conceptions of capabilities in autistic people.

In addition, spontaneity was demonstrated in social interaction: Emma offered to help fix the Penguin's home after it had collapsed; Harriet approached Ed and attempted to engage him in the environment; William spontaneously initiated and maintained social interaction with the facilitators; and Megan communicated with the Penguin. Again, this adds to the conceptualisation of autism: it illustrates how some of the participants were actively seeking social interaction and were capable of doing so in a variety of ways, challenging how we perceive autism in terms of deficits. This suggests that instead of a lack of desire for social interaction, it may be that social interaction is approached in a different way.

As has been argued throughout, the thesis research (as well as the broader arts-based research), focuses on the skills of autistic people, shifting the focus away from deficit-based models that currently prevail in the scientific and medical constructions of autism. Instead the research aligns with the social model of disability, in which the focus is shifted away from the limitations of the disabled individual, to how society (and environment) 'constructs' disability and affects how disabled (or abled) an individual is. These ideas, and the results that are emerging from arts-based practices, have the potential to have far-reaching significance in society's understanding of autism. Furthermore, Evans (2017: 433) has suggested that the conceptualisation of autism may soon experience another metamorphosis involving 'new 'styles of reasoning' about society, individuality and the right to have individual children's needs recognised'.

## **Implications for Research and Practice**

In this section the implications of the findings from the study will be considered in relation to clinical practice (in particular the conceptualisation of autism) and further research.

The debates and tensions surrounding diagnostic categories will be discussed, following on with a consideration of what the research contributes to this, as well as its potential to enhance the understanding of autism and its contributions to further research.

Diagnostic categories are useful in helping to provide access to resources and support (Molloy and Vasil 2002) and potentially to help redefine children seen as ‘problematic’ in terms of diagnoses with legitimate conditions (McLaughlin 2005). Moreover, for some individuals they help to provide a framework or a reasoning for their behaviour and the difficulties they may have experienced earlier in their lives – this is particularly the case for individuals who are diagnosed in adulthood. However, the use of a medical model approach to diagnose developmental disorders (which is common practice) has been criticised for being largely counterproductive (Molloy and Vasil 2002: 660–661). Molloy and Vasil argue that once a label is given to someone, the individual becomes defined purely by that diagnosis. This is a particularly interesting point in regard to the ‘Aspie’ subculture, in which those diagnosed or self-identifying as autistic use their diagnostic label as an integral part of their identity. There are an increasing number of autistic self-advocates and events such as ‘Autistic Pride’ (see <https://autisticuk.org/autistic-pride/>) in which autistic people come together to show ‘the world that we are proud of being autistic and that we are not diseased or defective or in need of a cure... we can... be ourselves’ (Hendry 2018). Such events are described as being ‘inspired by and follow[ing] the same philosophy as Gay Pride Events’ (ibid.). Some autistic people are reclaiming the previously negatively perceived term of autistic in a similar way to the reclaiming of terms such as ‘queer’ in the LGBT+ and ‘slut’ in the female communities. However, Molloy and Vasil argue that by being purely defined by a label there is a loss to a person’s individuality and a lowering of others expectations of them (p. 661) – a person can become defined by what they cannot do. Furthermore, any behaviour exhibited by the individual is filtered through this diagnosis as a symptom rather than being understood as an expression of their own unique personality (ibid.), thereby, reducing their behaviour to a list of autistic

symptoms. This means that the emphasis of the diagnosis is placed solely *within* the individual, which is problematic, particularly for those diagnosed as autistic or Asperger's, as the conditions are 'never simply located within the individual: no gene or discovery of different neurological 'wiring' arrangements will wholly explain AS [Asperger's Syndrome]' (Molloy and Vasil 2002: 665). Viewing the diagnosis purely through the individual supports the medical model of autism, shifting responsibility away from society and the acceptance of those within it.

Moreover, embedding a diagnosis within a medical model implies that any such illness or disability has an underlying biological problem which could potentially be eradicated if an appropriate treatment were found. That there is no known biological cause for autism which wholly explains the condition in every case (as discussed in Chapter 1), and therefore no way of finding an 'appropriate treatment' for the condition, arguably raises questions about the position of the diagnosis of such a condition in the medical model. The cure or treatment of autism is a particularly controversial issue within the autistic community, which in part contributed to the creation of events such as 'Autistic Pride'. In addition to this, the continual alteration of the diagnostic label given and criteria used provides further problems for the diagnosis with 'variability in interpreting the absence or presence of some features and the severity of these' further confounding the diagnosis (Molloy and Vasil 2002: 661). This issue is problematic, for example, with those whose diagnosis becomes a fundamental part of their identity e.g. the 'Aspie' subculture as mentioned above. The altering of the specific wording of the diagnosis, could potentially impact the communities that the individual connects too. Autism is a complex condition which despite having a core symptomatology, has huge variability in its behavioural manifestations. Therefore, as this thesis proposes, it is not unreasonable that a holistic approach to, and understanding of, the condition should be considered, enabling a more nuanced and personalised view of an autistic individual. An approach which is tailored to the immediate experiences of the individual, as exemplified by the way that practitioners engage with participants in the iA environment, is likely to lead to an increased understanding of the

individual's autism and thus allow a holistic profile to be created rather than just assigning a label to the person without a deeper exploration of their individual behavioural manifestations.

As a result of the competing models of autism present and the resulting attitudes towards autistic people, as well as the changing attitudes of autistic people towards their own diagnosis, there has been a significant and deep underlying tension in this thesis. The competing models have been highlighted here through the comparison of the clinical diagnosis that is informed by the medical model and the (arguably more social) model of autism that is explored in the drama environment, which is further highlighted in the use of the ADOS (a medical tool) in both the clinical and creative environments. As was discussed in Chapter 1, these two models offer very differing views of the condition and the factors that influence it, this contributing to difficulties in comparatively analysing the diagnostic process across the two environments (iA and the clinical one) discussed in the thesis. While the results indicate that it is possible to complete diagnostic procedures that are embedded within a medical model using an environment based on a social model perspective and obtain comparable results, there is a limited extent to which the results from this study can *really* influence the current diagnostic practices. However, the shifting of emphasis from purely what an individual cannot do or the difficulties they face to also exploring the skills of the said individual could be beneficial to the diagnostic process, particularly the individual and their family's experience of it. Rather than receiving a list of what the individual cannot do (as was the case in one of the participants' diagnostic letters), a report detailing their strengths and what they enjoyed doing within the iA environment, could support the standard diagnostic material provided. This notion is supported by a participant in another study who emphasised the importance of not only the weaknesses of the individual being named but also the highlighting of the individual's strengths (Bertilsdotter Rosqvist 2012: 125). This research has demonstrated that the unique quality of the drama environment, one that enables a practical exploration of behaviour, greater flexibility, peer interaction and an immersive environment, making it arguably more useful for collecting

information for a holistic profile than current diagnostic practices allow. Furthermore, by employing an environment like this in addition to the current diagnostic practices could also potentially provide information that could be used as the basis of an interventional method beyond the diagnostic setting (for example, that David responded well to working with Purdy). Information such as this could provide additional post-diagnosis support and help to alleviate some of the difficulties that are involved in receiving a diagnosis. Another potential benefit of providing more information on an individual's skills is that this could help support the individuals and their family's acceptance of their diagnosis: moving away from perceptions of autism as 'foreign' or something being lost, it instead could have the potential to have a positive effect. Therefore, it is possible that this research holds the most significant impact in helping to alter perspectives on autism both within the diagnostic environment, as well as more generally.

The research did show, when considering the results and how they affect the diagnosis, that the diagnostic tool uses (inevitably deficit-based) can be completed successfully in non-clinical environments and still reliably diagnosed individuals, even when the environment is one that offers an alternative social model perspective on the condition. This provides further support for such diagnostic tools and their ability to detect autism in multiple environments.

Despite the positive results that have been demonstrated in the research, particularly in relation to the skills of autistic individuals, the direct impact that this research may have on current diagnostic practices is likely to be minimal, as the diagnosis is unlikely to shift away from the medical model perspective in the near future. Although the social model of disability is gaining more traction with society generally shifting towards a more accessible environment, this is unlikely to become the perspective through which autism is assessed in the clinical environment. As long as autism is framed and diagnosed through clinical manuals that are based within the medical model and therefore founded on a deficit-based view, the tension between the differing models discussed will continue.

The arguably more significant impact that this research could have is on the understanding of autism more broadly. Within this research (as mentioned above) and other arts-based practices, perception of the condition is moving away from viewing it purely grounded in the medical model towards an alternative perspective. This is demonstrated in the work of Richard Hayhow (the director of Open Theatre<sup>187</sup>). He asks

not to know anything about the children he will meet unless there is an absolute medical necessity. He seeks to learn about the children as individuals through his theatre-based practice and contends that diagnoses will interfere with the sense of possibility that an interaction with a child might communicate. (Trowsdale and Hayhow 2013: 72–73).

Hayhow makes a very important point, as the diagnostic label given to an individual ultimately influences how they are then seen by others and therefore how they are interacted with. When a diagnosis is grounded in a deficit-based model, this is likely to mean that the individual is perceived by others in terms of what they are unable to do, as was indicated above. For example, with autism there may be a perception that the individual is unable to have any friends due to difficulties with social interaction. However, by presenting an alternative view of autism the perceptions of expected autistic behaviour could be expanded. Currently much of the understanding of autism is taken from research that originates from a medical model perspective and focuses on finding a biological cause which would thus enable more effective diagnosis and potential intervention. Therefore, the presentation of an alternative view offers different possibilities and outcomes for autistic individuals that is currently offered, with implications to the wider understanding of autism, helping to enhance knowledge of the condition. The research that has been presented within this thesis has demonstrated behaviours by the participants that run contrary to the generally expected standards of behaviour for autism people. This research has been explored in more detail on pages previously and demonstrate how this research further supports a growing body of arts – (and in particular) drama-based research that focuses on skills and strengths in autistic individuals. This highlights

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<sup>187</sup> Open Theatre do not only work with autistic children, but also those with learning disabilities.

the importance of the environment in which engagement occurs, further demonstrating how an environment can alter an individual's behaviour. Working in the iA environment, which is based on creating a liminal space between neurotypicality and neurodiversity, and is founded on individual interactions that are guided by the participant, potentially offers a more suitable setting to facilitate engagement in comparison to a more controlled clinical environment. Therefore, meaning that this kind of approach may be a more suitable method for ascertaining interests and skill levels than is possible within the current diagnosis. Not only could this influence the understanding of autism on an individual level, but it also potentially has wider implications. Furthermore, the holistic framework also allows for the variability of the condition to be explored and addresses some of the problems that Molloy and Vasil (2002) have with the medical model approach.

The use of the ADOS within this research has proved to be a significant limitation in relation to the discussion of deficit-v. skills-based models. Fundamentally, the use of this tool accepts a deficit-based model and certain assumptions that come with that. However, it does not assume that every autistic person has difficulties in all areas that it tests for and allows for the demonstration of skills to be seen in some areas. This is supported by the idea behind the ADOS being that the individual is given as many opportunities to demonstrate their skills as is feasible in such a test, demonstrated by the different levels that are offered to participants on some of the presses. Therefore, it could be problematic to assume that the skills that were demonstrated by the participants in the iA environment were entirely absent within the clinical setting and only made apparent by the individuals' engagement in the iA environment. As the ADOS is essentially from a deficit-based perspective of autism, it is difficult to use it as a tool to challenge the medical model in an environment that moves perspectives closer to a social model view. However, the additional information that was provided by the diagnostic performance tool introduced in this research to supplement the ADOS may help to counteract this inherent tension. A related issue that further problematises the results of this research is that there was

not a comparison group of children without autism (although it was originally hoped that there would be some participants who were undiagnosed). This makes it impossible to compare the behaviour of the autistic participants to normative standards of behaviour in the iA pod, making it problematic to assume that the positive behaviours that were demonstrated within the iA environment by the autistic participants indicate the presence of skills in the individuals, rather than typical behaviour that would be seen within the pod.

Despite the intrinsic conflicts within the research between the strength- and deficit-based views of autism, it does have an important role to play. The shift in understanding could inevitably feedback into the diagnostic process, further support by research that has been supplied by other drama projects. As McLaughlin (2005: 285) has pointed out, 'diagnosis does not occur in a social vacuum; both medical professionals and parents bring with them existing discourses of disability that influence the way in which they discuss and frame a diagnosis'. This could be where this research becomes particularly important. By offering an alternative understanding of autism which is not grounded solely in deficits and difficulties, the discussion of what autism is and what this means for an individual post-diagnosis could be altered. Therefore, the framing of autism may shift away from the sense of 'something being lost' because of a medical label. This could be hugely beneficial to patients and their families, as well as to the wider community's understanding of autism.

Additionally, this research has highlighted problems within the local NHS diagnostic services (which have since been shut down and are now the responsibility of another area<sup>188</sup>). The privatisation and outsourcing of testing made it extremely difficult for the author to navigate the services and to access patient records, highlighting the potential difficulties that parents and patients may face. The widespread adoption of alternative testing methods could help to alleviate pressures on busy services.

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<sup>188</sup> <https://www.kmpt.nhs.uk/services/autistic-spectrum-conditions-diagnostic-service/7185>

The research findings warrant further investigation and this could be approached in several ways. Larger studies with more robust procedures, e.g., randomised control trials, would reduce the influence of certain variables and allow for more thorough statistical analysis (which was limited in this research). Furthermore, this could help to tease apart the specific elements of the iA environment which contribute to the potential success of working in such a setting. Currently, the practical research is not optimised for use in a diagnostic setting as the iA pod takes up a large amount of space, is not practical to construct and deconstruct regularly, and is potentially costly to run with experienced practitioners. Further research could be conducted into making the pod more practical to use in a clinical environment, e.g., through using particular elements of it such as the puppets or the audio-visual technology. This exploratory study developed new coding tools for: (1) observational data collection; and (2) the analysis of this. Further research could refine these tools, as well as applying them to different drama-based settings to further explore their validity and reliability. Interesting, unexpected behaviours were noted, in particular from the female participants, and these certainly warrant further investigation. As mentioned earlier, females are generally under- or misdiagnosed and it may be that engagement with such an environment could provide more accurate behavioural information about this group that could help us to see beyond their coping strategies and offer a more accurate representation of their behaviour, one that could support the diagnostic process and make it more effective than is currently seen.

## **Conclusion**

In the Introduction the question ‘why drama?’ was posed and some examples from the wide range of drama approaches that can be used with autistic individuals were offered, mapping the triad of impairments onto the drama triad.

Key methodologies that have emerged from both the thesis research and the AHRC iA project (and which are not exclusive to iA) include the role of turn-taking, responding intuitively

and creatively, creating a liminal space and improvisation. These have become of great importance and offer methodological insights into why drama practices may be useful for engaging autistic individuals, and how this subsequently affects understanding of autism beyond the arts. What becomes centrally important when viewing drama-based practices is that the development of the methodologies is intuitive and based on trial-and-error methods. The ones that are successful are developed and refined and become second nature to practitioners working with autistic individuals, very much emphasising the felt experience (as highlighted by O'Sullivan [2015]), a difficult thing to capture which does not always fit neatly into scientific evaluation methods.

The thesis opened with a quote from Shaughnessy (2017b) which highlights the differences between the scientific approach (to observe and measure) and the arts (to engage and interact). There is a growing number of interdisciplinary projects, including this thesis, that utilise the strengths of each domain and it is through these interdisciplinary methods that knowledge can be enhanced: 'the clashing point of two subjects, two disciplines, two cultures... ought to produce creative chances' (Snow 2008: 16).

## CONCLUSION

This is the first study, to the best of the author's knowledge, to investigate the benefits of engaging in a drama-based environment (Imagining Autism) for the process of diagnosing ASD. The exploratory study used a repeated measures design to assess the completion of one autism diagnostic tool the ADOS-2, in an alternative environment to the clinical one. Eight participants each engaged in iA on two occasions and a novel coding tool (the diagnostic performance tool) collected observational behaviour data which was used to complete the coding section of the ADOS-2. Results of the ADOS-2 in the two environments were compared and, encouragingly, were found to have some good agreement. In addition to the difficulties seen which maintained the diagnosis, several areas of strengths were noted which helped to present a more holistic view of each individual, as well as challenging the deficits-based model present in much of the scientific and medical literature surrounding autism. The primary research question asked whether engagement could enhance the profile of autistic children, highlighting strengths as well as difficulties and differences and the results suggest that it could, with the key benefit of engaging in such an environment being the promotion of certain skills which were demonstrated in several different areas, e.g., social interaction. The results of this thesis research further contribute to the growing body of arts-based research that confronts the scientific and medical model of autism, and provides an alternative construction of autism.

One of the key results was that, despite a range of skills being displayed, the participants all still retained their diagnosis when comparing the clinical and iA ADOS-2 diagnoses. It is all too easy to romanticise autism when engaging in a project like this, with benefits being seen in short periods of time, meaningful engagement occurring and behaviours being demonstrated that challenge current concepts of autism. This is why it is vital that the diagnostic status remained unchanged for all of the participants. The participants were all still autistic and this could not be 'removed' from them, nor was this the aim of this research. While positive

behaviours were demonstrated, this should not take away from the difficulties that the individuals (as well as their family members and friends) experience daily because of their condition.

The study, while only an exploratory one, emphasises the presentation of a more rounded diagnosis that considers skills as well as difficulties, something which could have direct practical relevance to diagnostic services. By shifting thinking and practice to focusing on alternative perspectives from deficit-based ones, the diagnostic process could be enhanced and offer more practical skills to help, e.g., parents interaction with their children beyond the clinical diagnostic setting.

The research initially set out to explore how the diagnosis of autism could be supported by the participants' engagement with a drama-based environment; however, the results and the behaviours demonstrated by the participants showed how the research also contributes (arguably more significantly) to the understanding of autism more broadly. The thesis supports the growing body of research that demonstrates how skills can be facilitated in autistic people through engagement with the arts, highlighting how alternative approaches may help to show these behaviours, which challenge preconceptions and current thinking, aiding understanding about autism more widely. As has been discussed in the previous chapter and noted throughout the thesis, this research has offered alternative perspectives on the abilities of autistic people in social interaction, theory of mind, imagination, play, empathy and shared attention.

The underlying theme of the thesis has been to support a strengths-based model of autism, viewing not only the difficulties present in autistic individuals, but also the potential skills that can contribute to generating a more holistic view than is currently held in diagnostic practices. This is very important: 'labels, language, and diagnostic criteria matter, because they influence the behavior and perceptions of the people they purport to define' (Quirici 2015: 73).

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## APPENDICES

### Appendix 1: adult information sheet



#### **Drama environments as a tool to help aid the diagnosis of Autism Spectrum Disorders – PhD Exploratory Study Information about the Research**

I would like to ask for your permission for your child to participate in this exploratory study. Participation in the study is voluntary and entirely up to yourself (and your child where appropriate). This sheet will explain the study in more detail. However if you have any questions please feel free to ask myself Hannah Newman. My contact details are at the bottom of the sheet.

Your child has been selected by staff members within the NHS who were involved in the diagnostic process for your child. They believe that your child is suitable for this study as they have previously gone through the diagnostic process for autism in the last year and is within the right age bracket.

#### The Study

Previous research has been carried out on the drama environment that will be used, *Imagining Autism* (iA) that has proven to have positive benefits for children on the autistic spectrum. Parents and teachers reported that the children really enjoyed the sessions and wanted to go back. You can see more about the project at [www.imaginingautism.org](http://www.imaginingautism.org).

This exploratory study will look into the diagnosis of autism, comparing the standard ADOS assessment and the drama environment, to see whether the drama environment can enhance the traditional methods of testing for autism. It is hoped if the research is successful that the role of alternative diagnostic methods may be considered in enhancing the current diagnostic tools, presenting a more rounded view of each individual. It may also help further confirm the use of drama based approaches as beneficial for individuals on the spectrum. It will also look to create an individual profile for each child which will show what their strengths were, what they particularly enjoyed and any difficulties they may have experienced.



The study will involve the child spending two sessions with the iA team across a week (e.g. a consecutive Wednesday and Saturday). They will work with the iA team, and other children where appropriate, for two short half hour sessions in which they will encounter one of the environments, Arctic (see pictures). The children will be encouraged to interact in play-

based activities with the iA team and other children. The sessions will be videoed so that we can see if the environment brings out different behaviours in each child.

I will need to see a copy of the assessment report either provided by yourself or directly by the clinician who carried out the assessment, providing that you are happy for me to contact them.

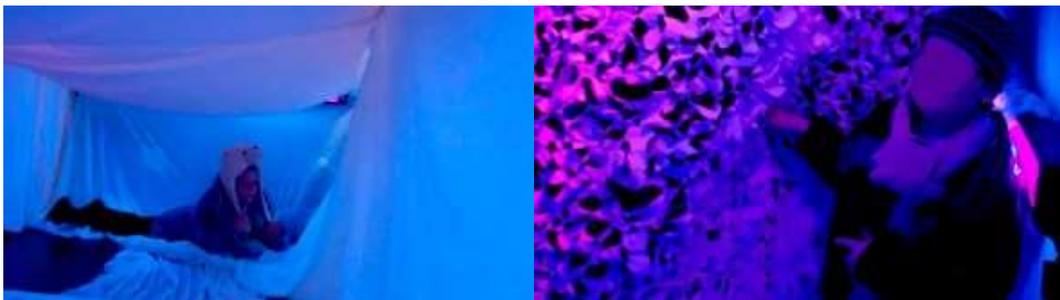
After your child has participated in the environments twice, you will be given a brief report on the child's strengths and examples of anything they particularly enjoyed. The project will be based at the University of Kent, Canterbury.

#### What information will be collected and how?

From your child: The child will be observed live in the session, as well as via video footage. I will be looking for specific behaviours from the child displayed within the session that are both typically shown within those on the spectrum (e.g. flapping) and behaviour that is commonly thought to be uncommon with those on the spectrum (e.g. imaginative play and humour). I will compare this to their ADOS assessment, and would do this by requesting a copy of the paperwork that is filled out as part of the assessment.

From you: I will ask you to fill in a short form before the iA session that will question typical behaviour of the child, and anything we should be aware of e.g. what the child is afraid of. You will be asked to escort the child to the sessions at the University of Kent, but will not remain with them during the environment. If during the drama environment your child displays any signs of distress they will be removed and taken for a short break. An attempt will be made to reintegrate them in to the work. If that is not possible you will be called to come and collect them.

From iA team: Shortly after each environment I will ask the iA team to complete a short questionnaire or interview to highlight any observations they made about their interaction with your child. These will supplement the video footage.



#### What will be done with the information collected?

The information will be stored securely at the University of Kent. Any footage will be accessed only through University Computers and my personal laptop. Only people involved with the project will view the footage. All computers and laptops are password protected.

Any paper information (such as consent forms) will be stored separately to any other paper information (such as notes from practitioners) and these will be numerically coded so the identity of each child is kept anonymous. The paper copies will be destroyed, after the project has finished.

As the research is being used for my PhD project the results will be put into the thesis.

Any reports, articles or presentations about the research will be anonymised, so that your child is not identifiable.

The footage and stills from the environment will only be used for the purpose of the PhD research and educational purposes within that context.

I would like to keep **anonymous** data for future research and to potentially share with other researchers.

#### What do you need to do?

If you would like the child to be involved in the project, please fill out the attached consent form and send it back in the pre-paid envelope. Alternatively you can email me an electronic copy to [hn55@kent.ac.uk](mailto:hn55@kent.ac.uk).

**If you do not wish for your child to participate that is fine. You are also free to withdraw from the study at any point without giving reason.**

#### Risks and Benefits

There is a risk that the child will show some levels of distress at participating in the environment. If this happens they will be removed for a short break and then we will attempt to reintegrate them in. If, however, they are unable to be reintegrated you will be contacted to collect them.

A main benefit for participating is that you will receive a short report about how your child interacted with the environment, noting their strengths, anything they particularly enjoyed and any difficulties. This may also be accompanied by stills and short clips from their interaction. This is something that you would not normally get.

#### What if you have any questions?

If you have any questions, or would like to change your mind about your child's participation in the project at any point please feel free to contact me, Hannah Newman, at either the address below or via email, [hn55@kent.ac.uk](mailto:hn55@kent.ac.uk).

Alternatively, you can contact the Sussex Patient Advice and Liason Service (who are independent from this project) on 01903 843049 or [pals@sussexpartnership.nhs.uk](mailto:pals@sussexpartnership.nhs.uk).

#### What if you have a complaint?

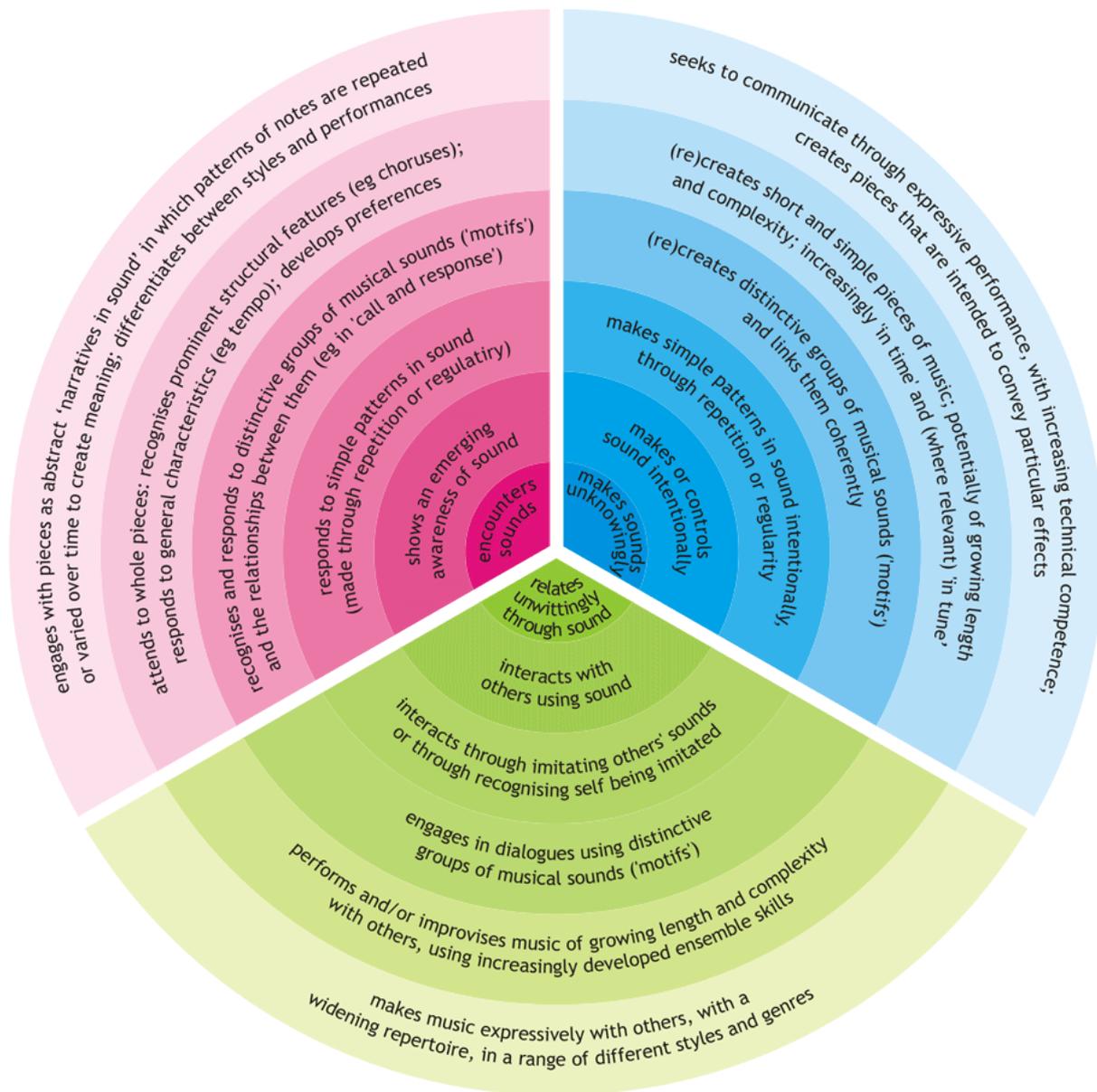
I hope that you will not have any complaints about the project. However, if at any point you do have a complaint in relation to this research a copy of the University's Complaint Procedure can be given to you. Alternatively you can contact Julie Beadle- Brown, my supervisor on [j.d.beadle-brown@kent.ac.uk](mailto:j.d.beadle-brown@kent.ac.uk).

Thank you for your time.  
Yours sincerely,

Hannah Newman  
Chief Investigator of the study and PhD Candidate  
[hn55@kent.ac.uk](mailto:hn55@kent.ac.uk)  
School of Arts, Jarman Building, University of Kent,  
Canterbury, Kent, CT2 7UG



## Appendix 2: sounds of intent framework



### Appendix 3: coding version 1

	Reactive	Interactive	Proactive	Behaviour Shown	N/A
Social-emotional reciprocity					
Another Child					
Practitioner					
Non-verbal Communication					
Another Child					
Practitioner					
Developing and Maintaining Relationships					
Another Child					
Practitioner					
Stereotyped/Repetitive Movements					
Insistence on Sameness					
Ritualised Behaviour					
Unable to Adapt to Changing Environment					
Restricted Interests					
Unrelated Fixed Interests					
Fixed Interests within Environment					
Interests in Sensory Aspects					
Imaginative Play					
Other Children					
Practitioners					
Interaction with Puppets					
Interaction with Media					
Emotions					
Embodying Characters					
Object Transformation					

Additional Notes and Observations:

## Appendix 4: coding version 2

### Social Communication and Social Interaction (Positively Marked)

*Social-emotional reciprocity*: child engages in reciprocal interaction successfully/child engages in reciprocal interaction and other children.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

If there is considerable duration (over 5 minutes) please score this as 2.

*Non-verbal communication used for social interaction*: instances where children used non-verbal communication e.g. gestures, such as pointing.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

*Developing and maintain relationships*: child engages with a practitioner/another child in play.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

If there is considerable duration (over 5 minutes) please score this as 2.

### Restricted and Repetitive Behaviours or Interests (Negatively Marked)

*Stereotyped or repetitive movements*: child demonstrates repetitive movements or speech, including 'stimming' behaviour.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

*Insistence on Sameness*: inflexible adherence to routines or ritualised behaviour/child unable to adapt to changing environment or demonstrates ritualised behaviour.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

If there is considerable duration (over 5 minutes) please score this as 2.

*Restricted interests*: child has fixed interests/child unable to detach from fixed interests in environment or becomes fixated on certain elements to environment (exclude instances where a child responds to the development of a fixed interest).

0. No evidence of this.
1. One or two instances of this.

2. More than two instances.

If there is considerable duration (over 5 minutes) please score this as 2.

*Interests in sensory aspects:* hyper- or hyporeactivity/child reacts in an unusual way to sensory elements.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

Please note whether this was a positive, neutral or negative reaction to this.

#### Additional Areas of Interest (Positively Marked)

*Imaginative play (practitioner initiated):* child engages in interaction with practitioners/other children.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

If there is considerable duration (over 5 minutes) please score this as 2.

*Imaginative play (child initiated):* child engages in interaction with practitioners/other children.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

If there is considerable duration (over 5 minutes) please score this as 2.

*Emotions:* child conveys emotions e.g. smiling.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

Please note whether this was a positive or negative emotion.

*Embodying Characters:* child takes on a role of another person or character.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

*Object Transformation:* child uses an object in a way that is different to its traditional use and/or uses it imaginatively.

0. No evidence of this.
1. One or two instances of this.
2. More than two instances.

## Appendix 5: coding version 3

Reactive – there is a reaction from the child that suggests engagement with action but they continue with other things.

Interactive – the child reacts and interacts with another. This could be physical or verbal and is in response to a joint stimulus.

Proactive – child reacts/initiates original interaction and continues to develop.

### Criteria According to DSM-5

#### Social Communication and Social Interaction (Positively Marked)

##### *Social-emotional reciprocity:*

Child engages with another child e.g. back and forth conversation, sharing of interests, displaying emotions.

0. Child displays no behaviour in this category.
1. Child reacts to other children.
2. Child interacts with other children.
3. Child is proactive with other children.

Child engages with a practitioner e.g. as above.

0. Child displays no behaviour in this category.
1. Child reacts to practitioners.
2. Child interacts with practitioners.
3. Child is proactive with practitioners.

##### *Non-verbal communication used for social interaction:*

Child uses types of non-verbal communication to engage with another child e.g. eye contact, facial expressions, gesture.

0. Child displays no behaviour in this category.
1. Child reacts to other children's non-verbal communication e.g. smiling when smiled at.
2. Child interacts with other children's non-verbal communication e.g. imitation.
3. Child is proactive in responding and initiating other children's non-verbal communication e.g. pointing to show child something in the environment.

Child engages with a practitioner e.g. as above.

0. Child displays no behaviour in this category.
1. Child reacts to practitioner's non-verbal communication e.g. smiling when smiled at.
2. Child interacts with practitioner's non-verbal communication e.g. imitation.
3. Child is proactive in responding and initiating practitioner's non-verbal communication e.g. pointing to show practitioner something in the environment.

##### *Developing and maintaining relationships*

Child engages with another child and can negotiate the relationship e.g. through play, appropriate behaviour.

0. Child displays no behaviour in this category.
1. Child reacts to other children.
2. Child interacts with other children.
3. Child is proactive with other children.

Child engages with practitioners and can negotiate the relationship as above.

0. Child displays no behaviour in this category.
1. Child reacts to practitioners.
2. Child interacts with practitioners.
3. Child is proactive with practitioners.

### Restricted and Repetitive Behaviour or Interests (Negatively Marked)

*Stereotyped or repetitive movements:*

Child demonstrates repetitive movements or speech including 'stimming behaviour, when engaging with another child.

0. Child displays stereotyped or repetitive movements throughout most of the intervention and ignores other children.
1. Child displays stereotyped or repetitive movements but reacts to other children.
2. Child displays stereotyped movements whilst interacting with other children.
3. Child displays stereotyped or repetitive movements whilst engaging proactively with other children.

N/A No display of stereotyped or repetitive movements.

Child demonstrates repetitive movements or speech including 'stimming behaviour, when engaging with a practitioner.

0. Child displays stereotyped or repetitive movements throughout most of the intervention and ignores practitioners.
1. Child displays stereotyped or repetitive movements but reacts to practitioners.
2. Child displays stereotyped movements whilst interacting with practitioners.
3. Child displays stereotyped or repetitive movements whilst engaging proactively with practitioners.

N/A No display of stereotyped or repetitive movements.

*Insistence on sameness:*

Child displays ritualised behaviour.

0. Child displays ritualised behaviour throughout most of the intervention, ignoring engagement from other children or practitioners.
1. Child reacts to others continuing to display ritualised behaviour.
2. Child interacts with others, displaying some ritualised behaviour.
3. Child is proactive with others whilst displaying ritualised behaviour.

N/A No display of ritualised behaviour.

Child is unable to adapt to changing environment.

0. Child does not remain in the environment and refuses to engage outside of the environment.
1. Child reacts to changes in environment e.g. looking up when there are light changes.
2. Child interacts with changing environment e.g. interacting with a puppet.
3. Child is proactive in responding and/or initiating with changing environment e.g. calling for rain sound effects.

#### *Restricted Interests*

Child has fixed interests that are talked about or physicalized within the environment that are unrelated.

0. Child only engages in talk or physicalises about their fixed interest.
1. Child engages at points in fixed interests unworried about others interests.
2. Child interacts with others about their fixed interests reciprocally.
3. Child engages with others either through initiation or development or reciprocal interaction.

N/A No behaviour displayed.

Child has fixed interest on something within the environment.

0. Child only engages in fixed interest.
1. Child reacts when fixed interest is interrupted but continues.
2. Child interacts with another, sharing their fixed interest.
3. Child is proactive in sharing fixed interest through initiation and/or development of fixed interest.

*Interest in sensory aspects:* hyper- or hyporeactivity/child reacts in an unusual way to sensory elements e.g. lights, sounds, media, textures.

0. No evidence of this.
1. Child reacts in an unusual way to sensory elements.
2. Child interacts in an unusual way to sensory elements.
3. Child is proactive in using sensory elements in some unusual way (creativity?)

### **Additional Areas of Interest**

#### *Imaginative play:*

Child engages in playful behaviour with other children.

0. No evidence of this.
1. Child reacts to imaginative play offered by another child.
2. Child interacts in imaginative play with another child.
3. Child is proactive in initiating and/or developing imaginative play with another child.

Child engages in playful behaviour with practitioners.

0. No evidence of this.
1. Child reacts to imaginative play offered by practitioners.
2. Child interacts in imaginative play with practitioners.

3. Child is proactive in initiating and/or developing imaginative play with practitioners.

*Interaction with puppets:*

Child engages with puppets and/or puppeteer.

0. No evidence of this.
1. Child reacts to puppets and/or puppeteer.
2. Child interacts with puppets and/or puppeteer.
3. Child is proactive in initiating and/or developing imaginative play with practitioners.

*Interaction with media:*

Child engages with one or more of the media present within the environment e.g. lighting, sound, projection, live feed.

0. No evidence of this.
1. Child reacts to media.
2. Child interacts with media e.g. through freezing when the snake sound comes on.
3. Child is proactive in initiating and/or working with the media e.g. taking control of the lights.

*Emotions:*

Child conveys emotions e.g. smiling.

0. No evidence of this.
1. As a reaction to another person.
2. As part of a shared interaction with another.
3. Child encourages emotions from another e.g. through attempting to get someone else to laugh.

Please note whether this was a positive or negative emotion.

*Embodying Characters:*

Child takes on a role of another person, character or puppet.

0. No evidence of this.
1. They take on the role purely for their own entertainment.
2. They involve themselves in an interaction with another through invitation.
3. They try to initiate and/or develop interaction with others.

*Object Transformation*

Child uses an object in a way that is different to its traditional use and/or uses it imaginatively.

0. No evidence of this.
1. They carry out object transformation purely for their own entertainment.
2. They share the object transformation with another through invitation.
3. They initiate and/or develop interaction with others to share the object transformation.

## Appendix 6: coding version 4

NB: As most of the document remained the same, only the amendments have been included here and highlighted where needed to provide clarity.

### Diagnostic Criteria (According to DSM-5)

#### *Social-emotional reciprocity:*

Child engages with a practitioner (**practitioner as themselves and not character/puppet**)  
e.g. as above.

0. Child displays no behaviour in this category.
1. Child reacts to practitioners.
2. Child interacts with practitioners.
3. Child is proactive with practitioners.

#### *Non-verbal communication used for social interaction:*

Child engages with a practitioner (**practitioner as themselves and not character/puppet**)  
e.g. as above.

0. Child displays no behaviour in this category.
1. Child reacts to practitioner's non-verbal communication e.g. smiling when smiled at.
2. Child interacts with practitioner's non-verbal communication e.g. imitation.
3. Child is proactive in responding and initiating practitioner's non-verbal communication e.g. pointing to show practitioner something in the environment.

### Restricted and Repetitive Behaviours or Interests

#### *Stereotyped or repetitive movements:*

Child demonstrates repetitive movements or speech including 'stimming' behaviour.

0. Child displays behaviour throughout or for most of the interaction, remaining in their 'own world' for all/most of the time.
1. Child displays behaviour when action is not being directed towards them.
2. Child displays behaviour during an interaction with another and appears to be out of excitement and enjoyment.
3. Behaviour not displayed.

N.B. Please make note describing type of behaviour shown.

### Additional Material

#### *Imaginative play:*

Child engages in playful behaviour with character and/or puppet.

0. No evidence of this.
1. Child reacts to imaginative play offered by character and/or puppet.
2. Child interacts in imaginative play with character and/or puppet.
3. Child is proactive in initiating and/or developing imaginative play with character and/or puppet.

*Interaction with characters e.g. Snowman:*

Child engages with characters:

0. No evidence of this.
1. Child reacts to character.
2. Child interacts reciprocally with character.
3. Child proactively initiates and/or develops interaction with a character.

*Embodying Characters*

Child takes on a role of another person:

0. No evidence of this.
1. They take on the role purely for their own entertainment.
2. They involve themselves in an interaction with another through invitation.
3. They try to initiate and/or develop interaction with others.

Child takes on a role of a character and/or tries on costume:

0. No evidence of this.
1. They take on the role purely for their own entertainment.
2. They involve themselves in an interaction with another through invitation.
3. They try to initiate and/or develop interaction with others.

Child uses puppets:

0. No evidence of this.
1. They take on the role purely for their own entertainment.
2. They involve themselves in an interaction with another through invitation.
3. They try to initiate and/or develop interaction with others.

## Appendix 7: coding version 5

NB: As most of the document remained the same, only the amendments have been included here and highlighted where needed to provide clarity

### Additional Behaviour

#### *Empathy:*

Child shows signs of empathy towards another child, practitioner, character and/or puppet.

0. No evidence of this.
1. As a reaction to a request from someone else.
2. -
3. Child is proactive in showing empathy.

#### *Humour:*

Child engages with elements of comedy.

0. No evidence of this.
1. Reacts to comic incidents.
2. Is interactive with comic incidents.
3. Starts and/or develops comic interactions with others.

## Appendix 8: coding version 6

### Diagnostic Criteria

#### Language, Communication and Interaction

##### *Verbal Communication:*

Child talks and/or makes sounds in response to the environment and/or others.

##### Other Children:

0. Child is non-verbal or does not communicate in this instance.
1. Child verbally reacts to other children, but this is primarily for themselves.
2. Child verbally interacts with other children although it does not always make sense, or flow.
3. Child is verbally proactive with other children, making an effort to continue conversation, which primarily occurs in a fluid fashion.

##### Practitioners and/or environment:

0. Child is non-verbal or does not communicate in this instance.
1. Child verbally reacts to practitioners and/or environment, but this is primarily for themselves.
2. Child verbally interacts with practitioners and/or environment although it does not always make sense, or flow.
3. Child is verbally proactive with practitioners and/or environment, making an effort to continue conversation, which primarily occurs in a fluid fashion.

##### *Non-verbal Communication:*

Child engages in non-verbal communication e.g. through eye contact, facial expression and/or gesture.

##### Other Children:

0. Child shows no sign of non-verbal interaction with other children.
1. Child reacts to other children's use of non-verbal communication.
2. Child interacts with other children, using some non-verbal communication
3. Child is proactive with other children by responding to and/or initiating non-verbal communication, and/or using it appropriately.

##### Practitioners:

0. Child shows no sign of non-verbal interaction with practitioners.
1. Child reacts to practitioners use of non-verbal communication.
2. Child interacts with practitioners, using some non-verbal communication
3. Child is proactive with practitioners by responding to and/or initiating non-verbal communication, and/or using it appropriately.

##### *Social-Emotional Reciprocity*

Child is able to engage with another in a reciprocal fashion e.g. sharing of interests, back and forth conversation, sharing of emotions.

#### Other Children:

0. Child shows no signs of social-emotional reciprocity.
1. Child reacts to other children's social-emotional advances.
2. Child interacts with other children's social emotional-advances.
3. Child is proactive in responding to and/or initiating other children's social-emotional advances.

#### Practitioners:

0. Child shows no signs of social-emotional reciprocity.
1. Child reacts to practitioners' social-emotional advances.
2. Child interacts with practitioners' social emotional-advances.
3. Child is proactive in responding to and/or initiating practitioners' social-emotional advances.

#### Restricted, Repetitive and Stereotyped Behaviour or Interests

##### *Stereotyped and/or Repetitive Movement*

Child displays repetitive movement and/or speech e.g. hand flapping, body rocking or other self-stimulatory behaviour.

0. Child displays this behaviour for most/all of the time, refusing intervention from others.
1. Child reacts to the environment but displays this behaviour when action is not directed to them.
2. Child is interactive with others but still displays this behaviour.
3. Child is proactive in engaging with others and/or environment and this behaviour is not displayed.

##### *Restricted Interests*

Child has fixed interests that are vocalised and/or physically demonstrated that are either related or unrelated to the environments.

0. Child displays this behaviour for most/all of the time, refusing intervention from others.
1. Child reacts to the environment but displays this behaviour for some/most of the time.
2. Child is interactive with others and shares their fixed interest.
3. Child is proactive in engaging with others and/or environment and this behaviour is not displayed.

##### *Unusual Sensory Interests*

Child responds to environment with sensory seeking behaviour and/or an unusual sensory response.

0. Child displays this behaviour for most/all of the time, refusing intervention from others.
1. Child reacts to the environment using this behaviour for some/most of the time.
2. Child is interactive with others whilst displaying this behaviour for some of the time.
3. Child is proactive in engaging with others and/or environment and this behaviour is not displayed.

##### *Insistence on Sameness*

Child insists on consistency within this environment.

0. Child displays this behaviour for most/all of the time, refusing intervention from others.

1. Child reacts to the environment using this behaviour for some/most of the time.
2. Child is interactive with others whilst displaying this behaviour for some of the time.
3. Child is proactive in engaging with others and/or environment and this behaviour is not displayed.

### **Additional Material**

#### Communication and Interaction

##### *Interaction with Others*

Child engages with others in the environment.

Puppets (a character separate from the whole body e.g. Purdy).

0. Child does not engage or interact with puppets.
1. Child reacts to the puppets advances but does not take the interaction further.
2. Child interacts with the puppet.
3. Child is proactive in their interaction with the puppet by continuing and/or expanding the interaction.

Characters (costumes that encompass the whole/most of the body e.g. Snowman).

0. Child does not engage or interact with characters.
1. Child reacts to the characters advances but does not take the interaction further.
2. Child interacts with the character.
3. Child is proactive in their interaction with the character by continuing and/or expanding the interaction.

Media (any of the technological aspects within the environment e.g. sounds and lights).

0. Child does not engage or interact with the media.
1. Child reacts to the media e.g. looking up when the lights change.
2. Child interacts with the media e.g. watching themselves in the projection.
3. Child is proactive with the media that causes a change in the environment e.g. calling for a sound effect.

##### *Emotions*

Child displays emotions within the environment.

0. Child does not display this behaviour in this instance.
1. Child displays emotions as a reaction to action.
2. Child interacts with others using emotion.
3. Child is proactive in initiating emotions from others.

##### *Empathy*

Child displays empathy towards others via vocal and/or physical interaction e.g. saying sorry or hugging.

0. Child does not display this behaviour in this instance.
1. Child displays this behaviour as a reaction to a request from someone else.
2. -
3. Child is proactive in initiating on their own accord.

#### Creativity and Imagination

### *Imaginative Play*

Child engages with others in playful behaviour that is creative and/or spontaneous.

Other children.

0. Child shows no sign of imaginative play in this instance.
1. Child reacts to imaginative play offered by other children.
2. Child interacts with other children in imaginative play.
3. Child is proactive in responding to and/or initiating other children in imaginative play.

Practitioners.

0. Child shows no sign of imaginative play in this instance.
1. Child reacts to imaginative play offered by practitioners.
2. Child interacts with practitioners in imaginative play.
3. Child is proactive in responding to and/or initiating practitioners in imaginative play.

### *Embodying Others*

Child takes on the persona of another.

Puppet.

0. Child shows no signs of embodying a puppet in this instance.
1. Child uses puppet in a reactive manner to the environment and/or others mainly for their own entertainment.
2. Child uses puppet to interact with others.
3. Child uses the puppet to proactively respond and/or initiates interaction with others.

Character.

0. Child shows no signs of embodying a character in this instance.
1. Child takes on the character in a reactive manner to the environment and/or others mainly for their own entertainment.
2. Child uses the character to interact with others.
3. Child uses the character to proactively respond and/or initiates interaction with others.

### *Humour*

Child responds and/or uses comedy.

0. Child shows no sign of humour in this instance.
1. Child is reactive to comic instances displayed by others.
2. Child is interactive to comic instances displayed in others.
3. Child is proactive in responding and/or initiating comic instances with others.

### *Object Transformation*

Child uses an object in a way that is different to its traditional use and/or uses it imaginatively e.g. turning a cuddly toy into a puppet.

0. Child shows no sign of object transformation in this instance.
1. Child reacts to the object transformation without sharing this with others.
2. Child interacts with others using the object transformation.
3. Child is proactive in initiating and/or sharing object transformation with others, taking it beyond the original transformation.

## Appendix 9: final coding tool

Absence of Normal Developmental Features			
Criteria	Indicator	Present	Absent
Social communication and social interaction	<b>Social and emotional reciprocity</b> <ul style="list-style-type: none"> <li>• Appropriate social approach</li> <li>• Conversational skills (reciprocal, good flow)</li> <li>• Sharing of interests</li> <li>• Sharing of emotions/affect (enjoyment of interaction)</li> <li>• Responds to social interaction from others</li> </ul>		
	<b>Non-verbal communication used for social interaction</b> <ul style="list-style-type: none"> <li>• Integrated use of verbal and non-verbal communication (sign language included)</li> <li>• Appropriate use of eye contact</li> <li>• Understands and uses gesture, body language and facial expressions (non-verbal communication)</li> </ul>		
	<b>Developing, maintaining and understanding relationships</b> <ul style="list-style-type: none"> <li>• Adjusts behavior appropriately for situation</li> <li>• Shares imaginative play</li> <li>• Interest in peers</li> </ul>		

Presence of Abnormal Developmental Features			
Criteria	Indicator	Present	Absent
Restricted, repetitive patterns of behavior, interests or activities	<b>Stereotyped or repetitive motor movements, use of objects or speech (e.g.)</b> <ul style="list-style-type: none"> <li>• Flapping</li> <li>• Spinning</li> <li>• Rocking</li> <li>• Repetitive Questions</li> <li>• Echolalia</li> <li>• Lining up toys</li> <li>• Idiosyncratic Speech</li> </ul>		
	<b>Insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or non-verbal behavior (e.g.)</b> <ul style="list-style-type: none"> <li>• Activities have to be completed before they can move on</li> <li>• Reverting to an obvious routine</li> <li>• Inability to cope with changes to the environment</li> </ul>		
	<b>Highly restricted, fixated interests that are abnormal in intensity of focus (e.g.)</b> <ul style="list-style-type: none"> <li>• Fixating on something with an inability or considerable difficulty to be brought away from it</li> <li>• Talking about a particular subject and not aware of lack of interest from others or appropriateness of topic to situation</li> </ul>		
	<b>Hyper (over stimulated) or hypo-reactivity (under stimulated) to sensory input or usual interests to sensory aspects of the environment (e.g.)</b> <ul style="list-style-type: none"> <li>• Self-stimulatory behavior</li> <li>• Seeking sensory behavior</li> </ul>		

	Being overwhelmed and avoiding sensory stimulation (e.g. hands over ears)		
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Additional Information for Profile		
Criteria	Indicator	Observations
Other observations of behavior and skills  Note if elicited or spontaneous/initiated	<b>Peer interactions</b> (is this appropriate? Are they able to handle the relationships?)	
	<b>Interaction with Other</b> e.g. puppets, media, figures and characters	
	<b>Verbal communication</b> (is this appropriate? Are there differences between different people?)	
	<b>Functional play/use of objects</b>	
	<b>Imagination</b> e.g. object transformation, trying on a costume, using a puppet.	
	<b>Unusual skills</b> e.g. skills that appear to not match their level of ability and/or demonstration of creativity	
	<b>Humour</b> (what kind? Do they share the humour with others?)	
	<b>Empathy</b> (do they display any kind of physical or verbal empathy?)	
	<b>Attention and focus</b> (what is this like? Are there certain activities this is stronger on?)	

		Present	Absent
Other abnormal responses	<b>Hyperactivity</b>		
	<b>Aggressive/destructive</b> (what behavior is displayed? Who is it directed towards?)		

Note if these occur at particular moments	<b>Anxiety</b> (does this easy? Does it keep returning? Are there obvious triggers?)		
Any additional notes			

## Appendix 10: participant information sheet (level 1 and 2)



To be shown/read by parent or carer

Hello. I would like you to take part in my study.



This study looks at autism diagnosis and drama.



This study will happen in the 'pod' (like a big tent)



Where you will play with puppets, other people and characters, like the snowman, in the arctic.



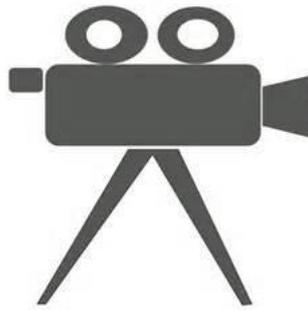
This will happen at the University of Kent.

University of  
**Kent**

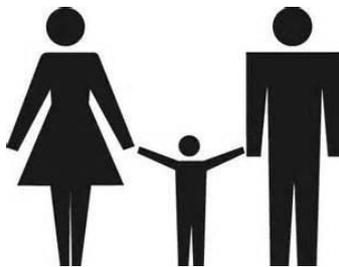
You will come and see me two times.

**2**

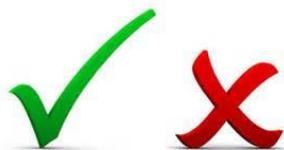
You will be filmed (the cameras are small though).



I have asked your Mum, Dad or Carer if it is ok.



But you can say yes or no to taking part. No one will be cross.



This is me, Hannah. I will be there at the University.



You will also meet and play with my friends Angela and Vicki.



Thank you for looking at this sheet. Goodbye!

To be shown and read by parent/carer if required

**Study Title**

Can playing in a drama environment help with diagnosing autism?

**Why is this study being done?**

I want to see if when children play in a drama environment, they behave differently to when they are playing with the clinician in their autism diagnosis session.

**What is the drama environment?**

This drama environment is called Imagining Autism. You can ask your mum, dad or carer to show you lots of photos on the website ([www.imaginingautism.org](http://www.imaginingautism.org)). We set up the 'pod' which is like a giant tent. Inside there are lots of coloured lights, different sounds, puppets, characters and some people to play with.



The 'pod' (like a giant tent).

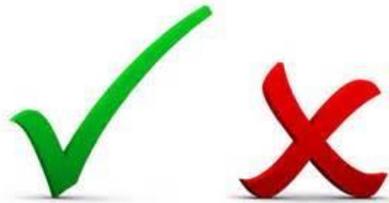
**Why me?**

You have been chosen because you have been tested for autism. I am asking about 20 other children to help me out.

**Do you have to take part?**

No! Your mum, dad or carer has received a sheet like this and you can decide

together whether you would like to take part. Your mum, dad or carer will fill out a form on your behalf. You can still change your mind later, even if you say yes now. If you don't want to take part, just say no.



### **What will happen?**

As well as the tests you had for autism, you will come to the University of Kent in Canterbury with your mum, dad or carer. They won't come and play with you but they will be nearby. Here you will meet myself (Hannah) and some of my friends.

This is me.



These are my friends Angela and Vicki.



You will come and play with my friends and I in the 'pod'. It is going to be set up like the arctic, so there will be a snowman there for you to play with.

You will play with us for half an hour and then you can leave. You will come and play with us twice within a week. After you have come and seen us twice, I will write up some notes about your time in the 'pod' and send this to your mum, dad or carer. There may be some photos and footage for you to look at

of you in the environment. There will be some cameras filming you during the session on the 'pod'. I will also carry around a little one.



The snowman playing with another child.

### **What happens when the study stops?**

I will collect all the information from all of the children and see if the drama environments do help with the diagnosis of autism.

### **What if something goes wrong?**

Your mum, dad or carer can speak to one of the team involved in the research and we can let them know what to do.

### **What if I don't want to be involved anymore?**

Just let your mum, dad, carer or Hannah at any time. Don't worry about it. No-one will be cross with you.

### **What will happen to the information?**

This will be kept safely and locked on computers that have passwords. People will not know that you joined in with the study, as I will not put your name on any of the work. When the study is finished I will get rid of the information that identifies you. I will keep anonymous information (stuff that no one knows who was involved).

### **I have a question...**

Please ask your mum, dad, carer or Hannah and they can help you out.



The snowman and his friends.

**Thank you for reading this. Hannah Newman.**

## Appendix 11: practitioner form

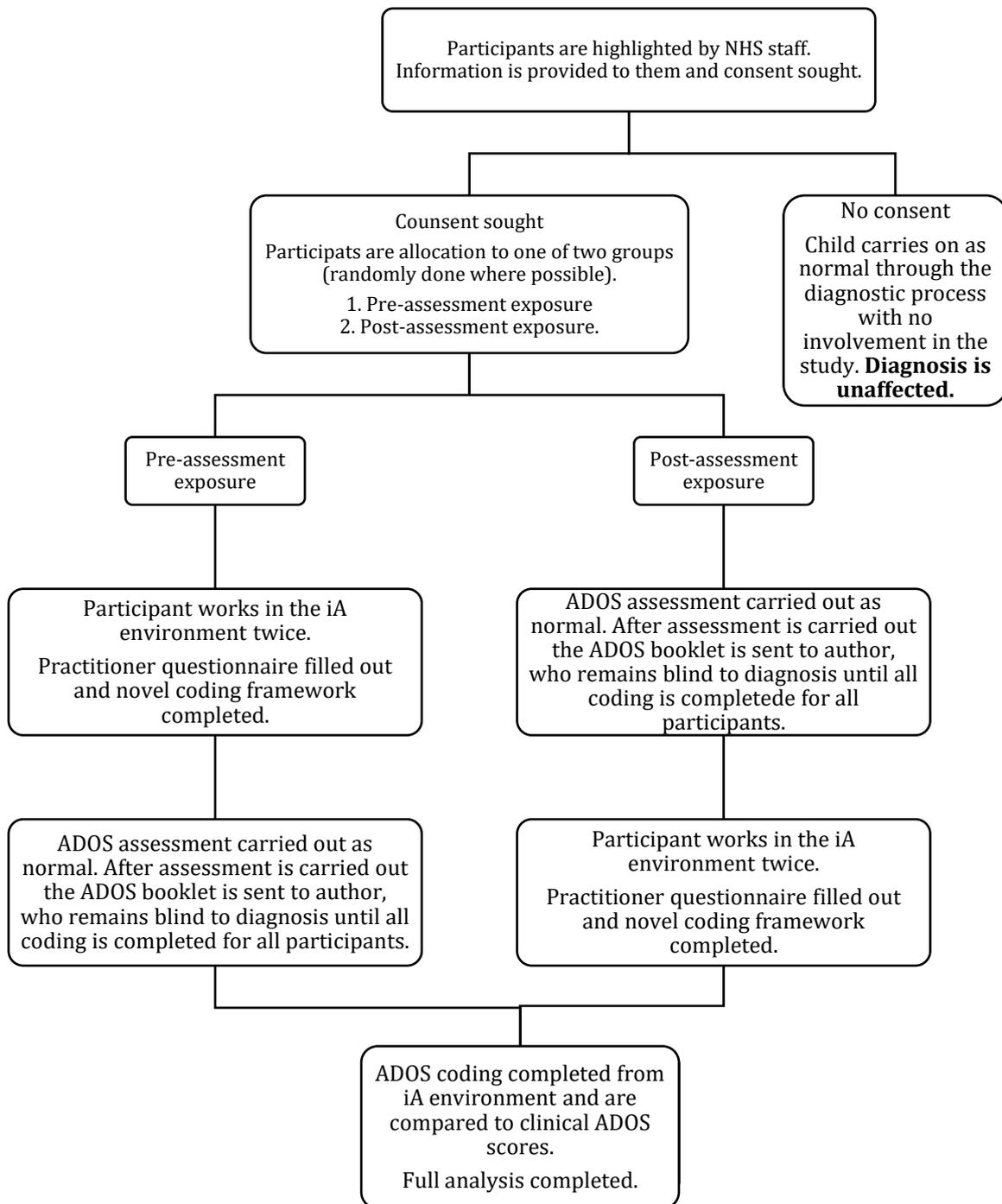
Name	
Name of child	
Date	

**Please only refer to the interaction that you had with the child, not any interaction you observed with others.**

Please describe the interaction that you had with the above child e.g. what kinds of activities did you do?	
How do you feel they interacted with you?	
What do you think they thought of the interaction?	
What was their eye contact like?	

**If you have any general comments that you would like to add or need to expand on any of the points, please do so on the back of this.**

## Appendix 12: original proposed procedure (pre- and post-assessment exposure)



## Appendix 13: module 1 observation tasks (or ‘presses’)

MODULE ONE (Pre-Verbal/Single Words)		
Task Number	Tasks	Focus of Observations
1	Free Play	<p>Does the child <i>spontaneously</i> seek engagement with the parent/caregiver?</p> <ul style="list-style-type: none"> <li>- If so, how does he or she do this?</li> <li>- Does it involve joint reference to objects, such as giving and showing, or is it limited to seeking affection or help?</li> <li>- How does the child communicate, if at all?</li> </ul> <p>Does the child direct affect to others?</p> <ul style="list-style-type: none"> <li>- How is it conveyed?</li> </ul> <p>Does the child explore materials, either symbolically or functionally?</p> <p>Does the child stay with activities, flit from object to object, or engage in repetitive actions?</p>
2	Response to Name	<p>Observe and evaluate the consistency of the child’s response to the hierarchy of presses.</p> <p>What sounds and actions must you or the parent/caregiver make to get the child’s attention?</p> <p>How does the child respond? Does the child...</p> <ul style="list-style-type: none"> <li>- Display eye contact?</li> <li>- Look at your face or in your general direction and/or look at the parent/caregiver’s face or in the parent/caregiver’s general direction?</li> <li>- Vocalize?</li> </ul>
3	Response to Joint Attention	<p>Does the child follow a shift in gaze alone or follow a shift in gaze when it is accompanied by pointing?</p> <p>Pay attention to the child’s behaviors when playing with the remote-controlled toy, including eye contact, vocalizations, requesting, shared enjoyment, initiations of joint attention, and pretend play (e.g. hugging or kissing the toy animal).</p>
4	Bubble Play	<p>Observe the child’s affect, initiation of joint attention, shared enjoyment, requesting, and motor behavior when the bubbles are present.</p> <p>Does the child display any unusual sensory behaviors or movements?</p>
5	Anticipation of a Routine With Objects	<p>Observe the child’s affect, initiation of joint attention, shared enjoyment, requesting, and motor responses, particularly repetitive mannerisms.</p>
6	Responsive Social Smile	<p>Evaluate the occurrence of the child’s smile in response to:</p> <ol style="list-style-type: none"> <li>(a) You smiling,</li> <li>(b) The parent/caregiver smiling,</li> <li>(c) The parent/caregiver smiling and making a familiar noise or calling in a way that implies physical contact but without actually touching the child (e.g., “I’m gonna get you!”), or</li> <li>(d) Being touched.</li> </ol>

7	Anticipation of a Social Routine	<p>Evaluate the child's affect and his or her attempts to initiate repetition of the routine.</p> <p>Pay particular attention to the social directedness of the child's behaviors and the extent to which he or she integrates gaze, facial expression, vocalization, and gesture in actions directed to you or the parent/caregiver, especially those behaviors that are indicative of shared enjoyment.</p>
8	Functional and Symbolic Imitation	<p>How does the child use miniature objects and a placeholder in imitation of familiar actions?</p> <p>Are these acts carried out with social awareness and shared enjoyment?</p>
9	Birthday Party	<p>Evaluate the child's interest and ability to join in the "script" of a doll's birthday part.</p> <p>Does the child treat the doll as a representation of an animate being?</p> <p>Does the child spontaneously contribute to the enactment of the party?</p> <ul style="list-style-type: none"> <li>- If not, does the child imitate your actions spontaneously or participate when asked or directed to do so?</li> </ul> <p>Pay attention to shared enjoyment, overtures, and reciprocity.</p>
10	Snack	<p>Does the child indicate a preference and request food?</p> <ul style="list-style-type: none"> <li>- If so, how does he or she do this?</li> </ul> <p>How does the child use gaze, gesture, reaching, facial expression, and vocalization to communicate requests to you and to make social overtures?</p> <p>Does the child show his or her snack to the parent/caregiver or try to feed and/or share with the adults in the room?</p>

## Appendix 14: module 1 codes

<b>MODULE ONE - Codes</b>	
<b>A – Language and Communication</b>	
A1	Overall Level of Non-Echoed Spoken Language
A2	Frequency of Spontaneous Vocalization Directed to Others
A3	Intonation of Vocalizations or Verbalizations
A4	Immediate Echolalia
A5	Stereotyped/Idiosyncratic Use of Words or Phrases
A6	Use of Another’s Body
A7	Pointing
A8	Gestures
<b>B – Reciprocal Social Interaction</b>	
B1	Unusual Eye Contact
B2	Responsive Social Smile
B3	Facial Expressions Directed to Others
B4	Integration of Gaze and Other Behaviors During Social Overtures
B5	Shared Enjoyment in Interaction
B6	Response to Name
B7	Requesting
B8	Giving
B9	Showing
B10	Spontaneous Initiation of Joint Attention
B11	Response to Joint Attention
B12	Quality of Social Overtures
B13a	Amount of Social Overtures/Maintenance of Attention: EXAMINER
B13b	Amount of Social Overtures/Maintenance of Attention: PARENT/CAREGIVER
B14	Quality of Social Response
B15	Level of Engagement
B16	Overall Quality of Rapport
<b>C - Play</b>	
C1	Functional Play with Objects
	Imagination/Creativity
<b>D – Stereotyped Behaviours and Restricted Interests</b>	
D1	Unusual Sensory Interest in Play Material/Person
D2	Hand and Finger and Other Complex Mannerisms
D3	Self-Injurious Behaviour
D4	Unusually Repetitive Interests or Stereotyped Behaviors
<b>E – Other Abnormal Behaviours</b>	
E1	Overactivity/Agitation
E2	Tantrums, Aggression, Negative or Disruptive Behaviour
E3	Anxiety

## Appendix 15: module 1 algorithms

<b>FEW TO NO WORDS</b>	
Social Affect (SA)	
<i>Communication</i>	
A-2	Frequency of Spontaneous Vocalization Directed to Others
A-8	Gestures
<i>Reciprocal Social Interaction</i>	
B-1	Unusual Eye Contact
B-3	Facial Expressions Directed to Others
B-4	Integration of Gaze and Other Behaviors During Social Overtures
B-5	Shared Enjoyment in Interaction
B-9	Showing
B-10	Spontaneous Initiation of Joint Attention
B-11	Response to Joint Attention
B11	Quality of Social Overtures
Restricted and Repetitive Behaviour (RRB)	
<i>Restricted and Repetitive Behaviours</i>	
A-3	Intonation of Vocalizations or Verbalizations
D-1	Unusual Sensory Interest in Play Material/Person
D-2	Hand and Finger and Other Complex Mannerisms
D-4	Unusually Repetitive Interests or Stereotyped Behaviors

<b>SOME WORDS</b>	
Social Affect (SA)	
<i>Communication</i>	
A-2	Frequency of Spontaneous Vocalization Directed to Others
A-7	Pointing
A-8	Gestures
<i>Reciprocal Social Interaction</i>	
B-1	Unusual Eye Contact
B-3	Facial Expressions Directed to Others
B-4	Integration of Gaze and Other Behaviors During Social Overtures
B-5	Shared Enjoyment in Interaction
B-9	Showing
B-10	Spontaneous Initiation of Joint Attention
B11	Quality of Social Overtures
Restricted and Repetitive Behaviour (RRB)	
<i>Restricted and Repetitive Behaviours</i>	
A-5	Stereotyped/Idiosyncratic Use of Words or Phrases
D-1	Unusual Sensory Interest in Play Material/Person
D-2	Hand and Finger and Other Complex Mannerisms
D-4	Unusually Repetitive Interests or Stereotyped Behaviors

## Appendix 16: module 3 observation tasks (or ‘presses’)

Task Number	Tasks	Focus of Observations
1	Construction Task	Does the participant indicate the need for more pieces? <ul style="list-style-type: none"> <li>- If so, how does he or she attempt to do so? (For example, does he or she reach over your arm? Does he or she vocalize, gesture, or make eye contact?)</li> </ul>
2	Make-Believe Play	To what extent does the participant produce imaginative sequences of actions that involve using materials beyond their most obvious intention? Does the participant cast the dolls and action figures as animate beings and pretend that they are interacting with each other? How? Does the participant display any repetitive or sensory interests in the materials? Observe social overtures, spontaneous language, facial expressions, gestures, and how the participant responds to you.
3	Joint Interactive Play	Observe the <i>reciprocity</i> and <i>shared enjoyment</i> shown by the participant in interactive play. <ul style="list-style-type: none"> <li>- The goal is for the participant (not you) to develop the interaction and to provide a novel initiative that goes beyond a direct response to your overtures.</li> </ul> Is the participant able to suggest ideas for the play? Is the participant able to follow or join in with your ideas about what could happen in the play sequence?
4	Demonstration Task	Does the participant represent familiar actions in gesture? <ul style="list-style-type: none"> <li>- If so, how does he or she do this?</li> <li>- Does the participant use his or her body to represent an object (e.g. a finger for a toothbrush) or mime the use of a pretend object?</li> </ul> Evaluate the participant’s report of a routine event and the pragmatics of teaching a sequence of actions.
5	Description of a Picture	Obtain a sample of the participant’s spontaneous language and communication, as well as a sense of what captures his or her interest.
6	Telling a Story From a Book	Obtain a sample of the participant’s spontaneous language and communication, as well as a sense of what captures his or her interest. Evaluate the participant’s response to conventional humor, his or her spontaneous comments about how the characters in the story are feeling, and the degree to which he or she can convey continuity in a story.
7	Cartoons	Observe the participant’s use of gesture and its coordination with speech, as well as his or her response to humor. Obtain an additional language sample from the participant and a sense of his or her degree of flexibility in adapting a narrative to the audience of the listener.

		Note any comments the participant makes about emotions and relationships.
8	Conversation and Reporting	To what extent does the participant build on your statements, elaborate on his or her own statements to provide leads for you, and take a full role in back-and-forth conversation, particularly about a topic outside of the immediate context? How does the participant report <i>routine</i> and <i>nonroutine events</i> , and how does he or she describe <i>relationships</i> and <i>emotions</i> ? Observe features of the participant's communication, including his or her use of gaze, facial expression, intonation, and gesture.
9	Emotions	Identify the events or objects that elicit different emotions in the participant, particularly whether they are social in nature or not. Observe how the participant describes his or her emotions. Does the participant exhibit facial expressions or creative uses of language in the context of describing his or her emotions and others' emotions? Does the participant display insight into typical social relationships that may cause some of these emotions?
10	Social Difficulties and Annoyance	Evaluate the participant's perception of social difficulties and his or her insight into the nature of these problems. - Has the participant made any attempt to change his or her own behaviour in order to fit in with others more smoothly? Pay attention to the participant's understanding of the appropriateness and implications of his or her feelings and behaviours.
11	Break	How does the participant occupy himself or herself during free time? - How does he or she respond to your withdrawal from and return to the interaction? Does the participant initiate and participate in an unstructured conversation or interaction with you at the end of the break? - If so, how does he or she do this?
12	Friends, Relationships, and Marriage	Evaluate how the participant understands the concepts of friendship, marriage, and other social relationships, and the nature of these relationships. Evaluate the participant's understanding of why a person might want to be involved in a long-term relationship and of his or her own possible role in such a relationship.
13	Loneliness	Does the participant understand the concept of loneliness? How does he or she feel it pertains to him or her or to other people?
14	Creating a Story	Observe and evaluate the participant's creative use of objects in telling a novel story or creating a newscast or commercial.

## Appendix 17: module 3 codes

<b>A – Language and Communication</b>	
A1	Overall Level of Non-Echoed Spoken Language
A2	Speech Abnormalities Associated With Autism (Intonation/Volume/Rhythm/Rate)
A3	Immediate Echolalia
A4	Stereotyped/Idiosyncratic Use of Words or Phrases
A5	Offers Information
A6	Asks for Information
A7	Reporting of Events
A8	Conversation
A9	Descriptive, Conventional, Instrumental or Informational Gestures
<b>B – Reciprocal Social Interaction</b>	
B1	Unusual Eye Contact
B2	Facial Expressions Directed to Examiner
B3	Language Production and Linked Nonverbal Communication
B4	Shared Enjoyment in Interaction
B5	Comments on Others' Emotions/Empathy
B6	Insight Into Typical Social Situations and Relationships
B7	Quality of Social Overtures
B8	Amount of Social Overtures/Maintenance of Attention
B9	Quality of Social Response
B10	Amount of Reciprocal Social Communication
B11	Overall Quality of Rapport
<b>C - Imagination</b>	
C1	Imagination/Creativity
<b>D – Stereotyped Behaviours and Restricted Interests</b>	
D1	Unusual Sensory Interest in Play Material/Person
D2	Hand and Finger and Other Complex Mannerisms
D3	Self-Injurious Behaviour
D4	Excessive Interest in or References to Unusual or Highly Specific Topics or Objects or Repetitive Behaviours
D5	Compulsions or Rituals
<b>E – Other Abnormal Behaviours</b>	
E1	Overactivity/Agitation
E2	Tantrums, Aggression, Negative or Disruptive Behaviour
E3	Anxiety

## Appendix 18: module 3 algorithms

<b>Social Affect (SA)</b>	
<i>Communication</i>	
A-7	Reporting of Events
A-8	Conversation
A-9	Descriptive, Conventional, Instrumental, or Informational Gestures
<i>Reciprocal Social Interaction</i>	
B-1	Unusual Eye Contact
B-2	Facial Expressions Directed to Examiner
B-4	Shared Enjoyment in Interaction
B-7	Quality of Social Overtures
B-9	Quality of Social response
B-10	Amount of Reciprocal Social Communication
B-11	Overall Quality of Rapport
<b>Restricted and Repetitive Behaviour (RRB)</b>	
<i>Restricted and Repetitive Behaviours</i>	
A-4	Stereotyped/Idiosyncratic Use of Words or Phrases
D-1	Unusual Sensory Interest in Play Material/Person
D-2	Hand and Finger and Other Complex Mannerisms
D-4	Excessive Interest in or References to Unusual or Highly Specific Topics or Objects or Repetitive Behaviours

## Appendix 19: minimal response descriptions with practitioners

### Ed – Minimal Response: Character

#### Session One:

He came into the pod and took a toy that the Inuit was playing with from her.

He smiled as the Snowman joined in with the “1, 2, 3 fly” game with Purdy on the second iteration. In this game, then counted to three and then on three Purdy would fly across the space.

He smiled at the Snowman when the Snowman offered the dog’s tail to Ed and pretended to tickle him. He then allowed the Snowman to tickle him.

He again smiled at the Snowman when he was joining in with Purdy on another iteration of the “1, 2, 3 fly” game, although this time the game was directed into the pod, rather than on the outside.

There was a very brief moment of interaction with the toy that the Inuit was playing with. A moment later he had a slightly longer interaction with the Snowman when he was operating the same toy.

#### Session Two:

Towards the end of the session, Ed showed some signs of being upset. His interaction became limited and we had to get his father to come in. It became apparent after talking to his father, that he wanted his cup and once he got that he was quite happy.

## Appendix 20: interactive response descriptions with practitioners

### Harriet – Interactive Response: Character

#### Session One:

She was initially shy and had to be invited in by the Inuit to help wake the Snowman up. Once he had woken up, she waved at him, after he waved at her. Harriet then followed the Inuit's lead to throw snow at him and then helped to bury him. After the Snowman had uncovered himself, he waved at Harriet, who waved back. The Snowman then gave her two of his buttons and after he had gestured, she took the rest of them off his costume and then put them back on.

She was offered the chance to dress up as a Snowman and accepted, then being helped by the Inuit and Snowman into the costume. She began to communicate verbally with them and indicated that she could not stick the snowball onto the Velcro on the costume. There was limited eye contact and interaction.

The practitioners invited her to play tug of war and used the tube. It was the Inuit and Harriet, against the Snowman.

She sat with the Inuit and the Snowman by the pond and they pretended to eat different fish.

She joined in with playing with the icicles, after she had seen the Snowman doing it. The Snowman and Inuit provided noises to accompany her actions.

The practitioners sat by the cave with Harriet. She played with a toy that was offered to her and then put on a hat, which she later swapped for a bear hat that the Snowman offered to her. A while later the Inuit and Harriet collected snow and threw it at the Snowman. The Inuit then told Harriet that the Snowman was ticklish, after the Inuit had tickled Harriet with the dog's tail. Harriet then tickled the Snowman, after the Inuit suggested it. She smiled whilst she was doing this.

Later she collected a large pile of snow with the Inuit. When she had collected it all, she said to the Inuit "help. I can't see", as the pile was so large. She then carried this over to the Snowman with help from the Inuit, and they both counted and threw it over him together.

#### Session Two:

She woke the Snowman up with the Inuit. She then was invited to wake the Penguin up. Once all the characters were awake, they threw around a snowball and Harriet joined in and applauded when the Penguin caught the ball.

She enjoyed watching the Penguin and the Snowman fight over who should get the ball that Purdy had hidden. Both characters tried to be the tallest and she selected the Penguin to collect the snowball, which she then watched.

She threw the Snowman's buttons at the Penguin, after she was invited to do so. She was then invited to speak down the tube to the Snowman, which she did.

She threw snow around after she saw the others doing this.

She laughed and smiled as she watched the Penguin and Snowman fool around with the snow. They put it on their heads and then pretended to walk on a catwalk. She declined the chance to do this when offered by the Inuit.

The Snowman got stuck in the tube and Harriet helped the Inuit pull him out.

She joined in with the game, after being asked, of telling the practitioners what the fish tasted like.

She went and hid in the cave during the storm with the practitioners. They sat close together and she suggested making a fire to keep them warm.

She worked with the practitioners to dress up as the penguin, then being shown how to become one.

After they had completed a circuit as penguins, she came back into the pod and high-fived the Snowman. The first time she tried to, he moved his hand and the second time, allowed her to hit it.

She then high-fived one of the penguin toys, that the Penguin operated.

She smiled as the Inuit put on a bear hat and then scared the other characters. They fell but she remained stood up.

She waved goodbye to the practitioners and helped tuck them into bed, after the Inuit encouraged her to do so.

William – Interactive Response: Character

Session One:

He went with the Inuit and William, and woke up the Penguin. Once the Penguin had woken up and waved at him, he said “I’m [William]”. Then when a practitioner asked what he thought the Penguin’s called, he responded “great”. A moment later he then said to the same practitioner that he had another name for the Penguin, Thomas (he was wearing a Thomas the Tank Engine top).

## Appendix 21: proactive response descriptions with practitioners

### Annabelle – Proactive Response: Character (part 1)

Session One:

#### *Inuit*

She engaged with the Inuit outside of the pod and responded to her questions.

She responded to the Inuit, when she asked Annabelle and AMY to help translate what the Snowman was saying.

She discovered the microphone and drew the Inuit's attention to it. She then worked with the Inuit on the microphone and looked at her own image in the live-feed. She held the microphone up to the Inuit and told her to scream down it, when the Inuit said she did not know what to do.

She jumped on the Inuit's back when she was bent over.

After the Inuit claimed that she was very hungry and would like some fish, Annabelle went and picked some fish up to give to her.

She threw snow over the Inuit.

#### *Snowman*

She found a snowball, which she threw at the Snowman to wake him up. As he began to wake up she waved at him. She helped get him up when he indicated that he was unable to do so.

She watched the Snowman throw snow at the Inuit and then threw snow at him, laughing as she did it.

They started playing hide and seek with the fish and she got very close to the Snowman's face (who was counting) and said loudly, "ten" to indicate the number that he should count to. When the Snowman was meant to be finding the fish, she picked up two snowballs and showed it to him.

She found a bear hat and showed it to the Snowman, whilst asking what it was. The Snowman then helped her put on another bear hat.

She picked up snow and threw it at the Snowman.

She expressed concern for the Snowman, and drew attention to it.

She came out of the cave with the bear hat on and tried to scare the Snowman.

She gave the Snowman a fish as a replacement nose.

She helped look for the Snowman's nose and his button.

She put the Snowman's buttons back onto his costume.

She put the dog's tail around the Snowman's neck and pulled it tight. She stopped and then put it on the other way, like a scarf.

She gave the Snowman back his nose.

She jumped on the Snowman's back and had to be supported by the Inuit, so she did not fall off.

She gave a fish to the Snowman.

She showed a penguin toy to the Snowman that she had found, and then went to show it to the Inuit.

She suggested that the Snowman should go into the water, so that he kept cool.

When the Snowman was tucked up, she suggested putting some fish next to him so that he could eat them.

#### *Group*

She worked with the Inuit and the Snowman when they were sat around the pond. She went fishing and then told them what the fish tasted like. She responded quickly when the Inuit asked her what her favourite things to eat were. They caught a bigger fish and handed it to the Snowman. The Snowman started a game of catch with the fish, that she joined in with.

She popped bubble wrap with everyone, after the Inuit invited her to do so and then they put it on the floor and jumped on it.

Continued on next page.

Annabelle – Proactive Response: Character (part 2)

*Group*

She worked with the Inuit and the Snowman when they were sat around the pond. She went fishing and then told them what the fish tasted like. She responded quickly when the Inuit asked her what her favourite things to eat were. They caught a bigger fish and handed it to the Snowman. The Snowman started a game of catch with the fish, that she joined in with.

She popped bubble wrap with everyone, after the Inuit invited her to do so and then they put it on the floor and jumped on it.

Session Two:

*Inuit*

She found the microphone and shared this with the Inuit and said that it was like last time.

The Inuit and Purdy worked together to guess the relationship between P3 and her toy bird.

She asked the Inuit to play hide and seek again.

She asked the Inuit to help her get into the penguin onesie at the end of the session, as she wanted to show her parents.

*Snowman*

She saw something, pointed and then drew the Snowman's attention to it.

After Amy said that they should make the Snowman sleep, P3 brought him over and playfully pushed him into his bed.

She suggested that they play hide and seek, which they all then did.

She was helped into the penguin onesie by the Snowman.

She blamed the Snowman for making a mess and then told him to tidy the house.

When the session was coming to an end, she asked the Snowman if they could play hide and seek.

She suggested throwing water at the Snowman to keep him cool.

*Group*

The Inuit brought P3 into the space and they spoke about the Snowman and where he was sleeping.

Once they found him they talked about ways to wake him up. She collected fish to give to the

Snowman to make him feel happy, after the Inuit said that he might feel grumpy after being woken up.

After they were dressed as penguins, she suggested that they play hide and seek, first telling the Snowman to hide and then the Inuit.

She explained how to do the Hokey Cokey to the Inuit and the Snowman.

Amy – Proactive Response: Character (part 1)

Session One:

*Inuit*

She was very responsive when she was outside of the pod and with the Inuit. She found humour in the name the Inuit had given herself and was very excited, shouting “yes” and fist pumping when the Inuit invited her in. She took the hand of the Inuit and went in, pressing the magic button to open the door. She responded to questions from the Inuit about the Snowman.

She jumped on the bubble wrap after the Inuit invited her to do so.

Amy declared to the Inuit that the bear was killed (referring to P3 who was wearing a bear hat).

She told the Inuit that the Snowman was upset by the storm and suggested to her that she could use some magic spells to stop it.

She described the snowman’s nose (which has been lost) to the Inuit.

She was delayed in leaving but responded when the Inuit called her and said “come with me”.

*Snowman*

She threw a snowball at the Snowman to wake him up. She helped to pull the Snowman up, once he had woken. Amy took a handful of snow from the Snowman and a moment later threw this at him. She then communicated with the Snowman.

She then looked for the Snowman’s nose and followed the Snowman’s gibberish vocals and gestures to where he last had it. She had a brief discussion with the Inuit about finding the nose.

When Purdy highlighted to the Snowman that he was missing a button (Amy and Purdy have hidden it), she went off to retrieve it for him and said, “I know where it is”. She then found it and gave it back to him. The Snowman gave her another button and she went off to hide it again. She drew attention to herself and said “right. He has another button missing. Can you find it?”

Amy continued to look for the nose and then apologised to the Snowman for not being able to find it.

She offered the Snowman a fish, after she had given one to Purdy.

She spotted that the Snowman’s nose had gone again and pointed at him – it was broken and had been removed from the environment.

She threw snow, over the snowman.

She suggested to the Snowman where he should sleep and then threw snow over him to keep him cool.

She waved goodbye to the Snowman.

*Group*

Afterwards, she went fishing with the Snowman and helped to catch a fish, which later she pretended to eat and described what it tasted like. She then joined in with the Inuit, Snowman and the other participant in a game of catch. The same fish used for catch was then hidden from the Snowman and the Inuit, by Amy. When the Inuit could not find it, she offered them a clue, drawing another practitioner into the game by saying it was hidden near her.

Amy made magic fingers with all the characters to bring the storm back

She announced to the group that Santa was coming in half an hour, as she had interpreted the bell sound effect as Santa.

Continued on next page.

Amy – Proactive Response: Character (part 2)

Session Two:

*Inuit*

When she entered the space, she highlighted to the Inuit, the differences within the environment from last time. She asked the Inuit where the person who did the electric was – referring to the technician.

*Snowman*

She spotted the Snowman, who was asleep in the cave and suggested throwing snow at him to wake him up. Her and Annabelle then threw a big ball of snow together at him. When the Snowman stirred, she said “let’s do some fishing”. She caught a fish and offered it to the Snowman. She then suggested to Annabelle that they make a bed for him.

She pointed out where the Snowman was when Annabelle was looking for him.

Over the microphone, she said “make the Snowman sleep”.

She offered solutions for when the Snowman was upset.

When they had decided to play hide and seek, she said to the Snowman, “how about we do that thing with the nose again”, referring to the work from the previous week.

She started to play hide and seek with the Snowman.

She offered the Snowman some fish, that she had caught.

She tried to help the Snowman, who had got stuck in the tunnel and said on the microphone, “make the Snowman not stuck”.

She denied making a mess of the house when the Inuit asked, instead she blamed it on the Snowman.

When the Snowman indicated that he was getting hot (the session was ending), she called for the storm to try and cool him down.

*Group*

When the Inuit and the Snowman found two penguin onesies, she suggested to the Inuit that they (her and Annabelle) could be the Penguins too. The Inuit then helped her into the onesie and they spoke to each other as they did this.

She counted on the microphone as they were playing hide and seek. The Inuit was counting with her and the Snowman and Annabelle were hiding.

She spoke on the microphone about tidying the house, which the Inuit and Snowman joined in with and started to create a song. She counted along to this.

She helped explain the rules of the Hokey Cokey to the Snowman and the Inuit and then joined in with them and Annabelle.

## William – Proactive Response: Character

### Session One:

#### *Inuit*

He spotted the sleeping Penguin and asked, “who’s that inside?”

When the Inuit asked, “what do you think of snow”, he responded “great”. When the Inuit showed them how they could play with the snow, he said “I want to do that too” and a moment later asked for some more snow from the Inuit. He then threw it over the technician. A few moments later, he directed the Inuit’s attention and pointed, then asking what something was.

He walked into the pod and went to the cave where the Inuit and William were. He said “excuse me. Can I do it?”

He fell into the pond and called for help. The Inuit helped to get him out.

#### *Penguin*

When the Penguin lightly tapped him on his side, he said “hey”.

He sat down by the bubble wrap with the Penguin. He did not pay much attention to the Penguin and seemed to be focused on the bubble wrap.

With Purdy’s help he threw a snowball at the Penguin, when she was not looking.

There was some interaction with the Penguin, who was blocking his way (sabotage technique) as he was trying to move around the outside of the pod. The Penguin was standing in his way and he tried to get through.

He walked around the pod with the Inuit following him.

He pretended to go to sleep in the cave with the Penguin, and he lay next to her.

#### *Group*

When the Inuit said to the Penguin, “come back Thomas” he said to a practitioner, “I’m Thomas”.

He helped to get the Penguin out of the tunnel, where she had got stuck with Purdy. He later got the Inuit into the tunnel and pretend to be stuck. He said, “I’ll help” and then pulled her out.

The Inuit directed William to tickle the belly of the Penguin, which he did.

### Session Two:

#### *Inuit*

He ran around the outside of the pod with the Inuit (and then the film operator) following him and said, “you can’t catch us”. When the Inuit asked if he was going to do this the whole time that they were there, he responded “yes”.

He spontaneously commented to the Inuit, “it’s actually really cold today” even though the session was occurring in the summer.

#### *Penguin*

He went into the cave and waved at the Penguin, then he sat next to her. She tried to put a bear hat on him, but he got up and went out of the cave, picked up a snowball and put it on his head.

He went into the pod and took the microphone off the Penguin and then coughed into it. He picked up several of the fish and then threw them at the Penguin.

He threw a snowball at the Penguin, as he was running around the perimeter of the pod.

He went into the cave and lay down with the Penguin, again in silence.

There was a little bit of interaction with the Penguin when they were working with a fish.

#### *Group*

The Inuit and Purdy helped him get into a snowman costume, although he did not get into this fully.

He went into the cave with all the practitioners, when the snowstorm was happening. There was some interaction with the practitioners in the cave.

He went into the cave, where all the other practitioners were sat and Megan was on the microphone.

William went outside the pod with the Penguin, and ran.

## Megan – Proactive Response: Character

### Session One:

#### *Inuit*

She responded to questions from the Inuit in the opening, “what do you think of my house” “Good”. She followed the Inuit’s action of throwing snow up in the air. She even suggested how you could improve it by altering the action.

She tucked the toy penguins into the tunnel, alongside the Inuit.

She said to the Inuit, “listen to this” and then made a tune on the icicles that were hanging down. She had just seen the Penguin do this.

She had put one of the penguin toys in a bear hat and was discussing what this animal would be called with the Inuit.

When the Inuit asked where the penguins were, she said that they are in the cave snoozing. She worked with the Inuit in the cave where she was wrapped up the penguins and gave them names. She shared this with the Inuit. She responded to questions from the Inuit and actively continued the conversation. When the Inuit asked if they should see what the others were up to outside, she did not respond, instead she told the Inuit the names of the penguin toys. A minute later, she then said that she thought they should see what the others were getting up to.

#### *Penguin*

She played with the Penguin. It looked like (although not entirely clear from the camera angle) that she was holding her hands up (she had the paw mittens on) and the Penguin was tapping them. She then tried to tickle the Penguin. Megan as laughing as she did this.

She tickled the Penguin.

She comforted the Penguin during the storm, when the Penguin was indicating that she was scared.

She repeated this a moment later, after she had been outside of the cave during the storm, to retrieve the penguin toys.

When the Penguin went to throw the toy penguins to count how many she had got, Megan caught them.

She animated the penguin toys, giving them voices to communicate and interact with the Penguin.

She guided the Penguin to the cave, when she realised it was time to go to sleep.

#### *Group*

She discovered the Penguin with the Inuit and they went to wake him up.

Once she had woken the Penguin up, she rubbed the Penguin’s head. When asked if she had a name for the Penguin, she offered “Pengy”.

She worked with the Inuit to throw snow over the Penguin. She laughed a lot as the Penguin reacted to her having snow thrown over her. She warned the Inuit when the Penguin was coming over with a snowball.

She fished with the Inuit and the Penguin. She understood the gestures that the Penguin used to indicate that she needed a fishing rod. She offered the Penguin a fish.

She worked with the Inuit and threw snowballs at the unsuspecting Penguin and denied her wrongdoing.

She worked with all the practitioners with the “help help” game set up by William and then set up her own comic interaction, working with the practitioners.

## Megan – Proactive Response: Character

Session Two:

### *Inuit*

She worked with the Inuit and tucked the penguin toys into the tunnel. They had collected snow to put around the toys. She suggested putting fish in the tunnel and she collected them from the pond whilst the Inuit watched.

She was helped into the Snowman outfit by the Inuit and Purdy.

She was with Inuit in the cave and Megan tried on different hats.

### *Penguin*

She put snow over the cave onto the sleeping Penguin. She watched the Penguin through the camouflage net.

She looked up to the Penguin, when the Penguin started to work on the microphone. She took the microphone from the Penguin, who indicated that she should through point. She spoke on the microphone to the Penguin and used similar sounds to what the Penguin had been making.

She gave a fish to the Penguin and dangled it in front of her face and threw it to her.

She tried to distract the Penguin by tickling her, when she was working with the other participant.

She dangled a fish in front of the Penguin's face to get her attention and then threw a snowball at her.

She threw snowballs at the Penguin but pretends that it was not her.

She indicated to the Penguin that she should turn around, by spinning her finger. Once the Penguin had done this, she threw a snowball at her.

She put snow around the Penguin's neck and the Inuit commented that it looked like a scarf.

She then went outside of the cave and made the Penguin jump, by pretending to be a bear. She did not initially acknowledge that the Penguin was scared, but then removed the hat to show the Penguin that it is was her dressed up.

When the Penguin was scared by the storm, Megan rubbed her head.

She called for the Penguin, when she was outside in the storm.

She gave another fish to the Penguin.

She directed a speech towards the Penguin and incorporated Purdy. The other practitioners listened. She presented the Penguin with a gift and said, "here's a little special gift from me". She then hugged her. There was a break between her talking on the microphone again and she dropped some snow on the Penguin's head, who was laid down.

When she went to seek cover from the storm (along with the others) she tried to get the Penguin to come along with her.

She told the Penguin she was silly, when the Penguin was trying to swim on the snow.

### *Group*

She used the dog's tail to tickle the Penguin with the help of the Inuit. The Penguin and Megan then moved around with the tail and both held an end. After a while, Megan took it off her and walked away with it wrapped around her neck.

She took a snowball from the Inuit and threw this at the Penguin.

She began to sing a song, which the rest of the practitioners (including Purdy) joined in with.

She started to tell a story, which incorporated the practitioners and involved her directing.

## Emma – Proactive Response: Character (part 1)

### Session One:

#### *Penguin*

They woke the Penguin up by throwing snow over her and then hid from her. They went out of the pod and ran away from her. Later they hid under some blankets in the cave. They woke the Penguin up by throwing snow over her and then hid from her. They went out of the pod and ran away from her. Later they hid under some blankets in the cave.

She suggested that they fix the home for the Penguin and went into help her. After they have fixed it, it broke again. Emma said “we’ll make it again” and helped to lift it up.

The Penguin caught Emma’s attention when she was on the microphone and Emma understood the Penguin who used non-verbal communication to suggest that they played hide and seek. They played hide and seek, hiding from the Penguin first. The Snowman joined them in their hiding spot.

There was some interaction with the Penguin, who imitated the sound that Emma was making on the microphone to call her cousin.

She gave the Penguin several high-fives, after they had managed to stop the snowstorm.

She told the Penguin off when he threw a snowball and then engaged in a snowball fight.

#### *Group*

She peered into the pod when the Penguin, Snowman and practitioner were fishing (used as a sabotaging technique). She tried to draw their attention towards her and picked up the microphone and said “hello”. She then said, “I’m here” after her cousin said it on the microphone. A moment later she independently went into the space (without her cousin) and watched what was happening. She watched the characters and the practitioner play the game where they guessed what the fish tasted like. She smiled at the correct guess of “sausages and mash”.

The practitioner, Penguin and Snowman all worked with Emma when she was on the microphone and called her cousin. She followed the point of the Penguin, when the cousin appeared. Emma then brought the Snowman over and pointed where she thought the cousin was hiding.

She threw some snow over the Penguin and the Snowman when the storm was happening.

She helped give the characters some blankets to keep them warm during the storm, after she saw her cousin do the same thing with hats and blankets.

She threw snowballs over the cave, when the Penguin and the Snowman were asleep in it.

As she was leaving, she copied the practitioner when she said “bye Penguin. Bye Snowman”.

### Session Two:

#### *Inuit*

The Inuit asked her what happened last time and who Emma met. She responded to the Penguin and nodded her head and said “yes” when the Inuit asked if she wanted to find them.

#### *Penguin*

She threw some snow at the Penguin, then pretended that it was not her.

#### *Snowman*

She picked up a fish and gave it to the Snowman.

She gave another fish to the Snowman.

Continue on next page.

## Emma – Proactive Response: Character (part 2)

### *Group*

She suggested that her and the Inuit call them to wake them up. This did not work and the Inuit suggested that they shake them which the Inuit did, whilst Emma watched. This did not work. Emma suggested covering them in snow. They both collected snow and threw this over the Penguin and the Snowman. When they had woken up, she waved at them, having seen that the Inuit had done this. She laughed as the Penguin threw snow at her.

She asked the camera operator and the Inuit “where did the Penguin go”, then pointed outside of the pod and suggested that the Penguin had left. The Inuit and Emma went to look for her and then Emma discovered that she was behind the light stand and pointed to her.

Emma took a snowball given to her by the Snowman and threw it at the Penguin. The Inuit joined in. The Inuit then gave her one of the fish and they both tried to lure the Penguin over by wiggling it. Emma then gave her the fish, and the Inuit threw a snowball at her. The Penguin started to cry and Emma went over and patted her on the back. The Penguin started to playfully fight the Snowman and Emma went in to break it up, after the Inuit drew her attention to it.

Emma played hide and seek and the Inuit helped to hide her. When she was found, the Penguin indicated non-verbally that it was Emma’s turn to count. The Inuit helped to translate this, as Emma was not clear on what the Penguin was suggesting. The Inuit and Emma counted together. They counted to five but when they turned around, the Snowman had not hidden. They turned back and counted to ten. They looked for the characters and Emma pretended that she had not found the Snowman. After she had found the Snowman, she spoke to the camera operator and said that she would go and find the Penguin. The Inuit and Emma tried to lure the Penguin out by tempting her with a fish. When she found the Penguin, she gave her a fish and said, “we found you”. She then gave one to the Snowman. She ran away from the Penguin, when she realised that the Penguin had a large pile of snow. Emma collected some and threw it over the Penguin, laughing.

The Penguin found a penguin onesie and offered it to Emma. She did not understand and the Inuit explained this. She declined the offer.

Emma was wearing a super girl costume and the characters all had a moment where they flew around the space and pretended to be super girl. It was suggested that they all should have capes, which they made from loose material. Once they all had one, they continued to fly around the pod.

Emma found a fish, which she gave to the Penguin. She found another one and gave it to the Snowman. They high-fived each other.

The Penguin set up the Snowman to walk past her, and then she hit her with the tube. Emma watched it happen and then went to pick up some snow to throw at the Penguin. She collected a handful of snowballs which she threw at her. The Inuit threw a snowball, which the Penguin batted back with the tube. The Inuit offered a snowball to Emma, who threw it at the Penguin, who then batted it back. They swapped over so that the characters threw the snowballs at Emma, who hit them back. When Emma hit them, the characters and practitioners cheered.

The Penguin offered her the microphone and she turned to the Inuit and said, “I don’t know what to say”. The Inuit responded “anything”. She did not say anything and so the Penguin made a noise, and then indicated that she should copy this. Emma did not understand this and so the Penguin and Inuit demonstrated. There were some technical issues with the microphone, so this interaction was not continued.

Emma put snow over the Penguin’s head, after she saw the Inuit do this.

When the storm happened Emma and all the characters went into the cave. Emma and the Inuit went out to collect the Penguin, who had got left behind.

She helped the Inuit tuck up the Penguin and the Snowman and waved goodbye to them.

Annabelle and Amy – Proactive Response: Character

In the first session, after the two participants had woken up the Snowman and had some interaction with him, the Inuit asked, “can you girls speak Snowman?” Annabelle shook her head. “Can you speak it? Because I’m very good. I can translate what he says” The Snowman then spoke in gibberish. At almost the same time as each other, the Inuit translated it as “hello” and Annabelle said “does that mean hello?” The Inuit verbally confirmed this and praised Annabelle. Amy then spontaneously spoke in gibberish and the Snowman replied to her. The Inuit asked what they thought the Snowman was trying to say and Amy responded, “I think he is saying goodbye”, which is confirmed by the Snowman and the Inuit.

## Appendix 22: peer interactions

### Annabelle and Amy – Peer Interaction

#### Session One:

They entered the space and remained near to each other.

When Annabelle found a snowball to throw at the Snowman, she immediately handed one to Amy.

Annabelle went to help the Snowman stand up and Amy took her hand and helped to pull.

Annabelle looked to Amy when the Snowman first started talking gibberish.

They went to collect the tube to use as a fishing rod together, after Amy spotted it. They worked together to catch several fish.

The fish that they were throwing around, fell into the pond and they went to get the tube back to fish for it.

They played hide and seek together, and hid the fish from the Inuit and the Snowman.

Annabelle found a bear hat and Amy said “oh no run”. Annabelle put a different bear hat on and went over to Amy. Amy playfully screamed and moved away from her, then picked up a snowball and threw it at her.

Annabelle suggested that they both look for the Snowman’s nose.

They both talked to Purdy about how old they were and then they tried to guess how old he was.

Annabelle fell into the pond and Amy helped to rescue her, after the practitioners failed to do so.

#### Session Two:

Amy showed Annabelle where the Snowman was sleeping. They then got a large pile of snow, and held it together and then brought it over to where the Snowman was sleeping, and then throw it over him. They independently got piles of snow to throw at him. After they had woken him up they fed him fish and then Amy suggested to Annabelle that they made a bed for him.

They tried to bring the storm back and Annabelle suggested saying “abracadabra”, which Amy said on the microphone.

Annabelle suggested that they played hide and seek and then looked at Amy and said, “like we did outside”.

They both got into penguin onesies, with the help of the practitioners. Annabelle took a penguin toy from the Snowman and then another one that the Inuit found, which she gave to Amy and said, “you can hold that”.

They played hide and seek together with Annabelle hiding and Amy seeking. Amy called out for Annabelle on the microphone, when they played hide and seek. She returned to the microphone and called her character name, when she was unable to find her.

Annabelle pretended to get stuck in the tunnel, after the Snowman had done this, Amy helped her out.

They both did the Hokey Cokey with the Snowman and the Inuit.

When Annabelle says that she did not want to be a penguin anymore and started to take off her onesie, Amy copied.

When Amy was filming on the Flip Cam, Annabelle ran up to her and playfully screamed in the camera.

Annabelle was wearing a hat and found another one. She said to Amy “you can be this” and put the hat on her head.

### William and Megan – Peer Interaction

#### Session One:

William and Megan woke the Penguin up, with the help of the Inuit.

Megan was sat by the pond with the Inuit and they were fishing for the Penguin. William went up to Megan and said, “give that to me” and took the fish she was holding and then gave it to the Penguin. Megan then asked if he wanted another fish and she helped him to collect it. She then said, “well done” to him.

When the storm started and Megan realised the potential danger of this, she guided William into the cave by the arm.

William followed Megan out of the cave when there was a storm happening. She had gone to rescue the penguin toys and he said, “I will come to” and went out to collect them with her.

William collected some snow and re-entered the pod. He went up to Megan and said “surprise”, and then threw the snow over her.

Megan helped to pull out William when he got “stuck” in the tunnel. She was then directed by William to get stuck in the tunnel.

He interrupted the comic interaction that Megan had set up, to continue with his game. William pretended to fall into the pond and Megan helped to get him out.

#### Session Two:

William tried to get Megan to come outside of the pod, to engage in the running around that he has been doing. He said he wanted her to come outside to play in the snow. He took her by the arm and pulled her outside. She then went outside and ran around the pod with him and the Inuit. She stopped after a short period and he called for her again.

The Penguin looked like they were trying to initiate a game of tug of war with a fish with William, but Megan took the fish from the Penguin to give to William.

William called for Megan, saying “come on [her name]” but did not indicate what he wanted her to do. After William had blown a raspberry on the microphone, he said “your turn [her name]” and then after she had blown one, he said “say something”. Once she had sung “hello”, he said “now say something else”. They then went on to share the microphone.

William copied what Megan said when she was talking on the microphone to the Penguin, “you silly little penguin”.

Megan was rustling the silver foil and William came into the cave and joined in with this.

After Purdy has asked if William made the storm come, he responded “no” and then William asked Megan if she did it. After this, there was some sharing of the microphone. William blew a raspberry on the microphone and then said, “your turn” and gave it to Megan.

Later they took turns of roaring on the microphone, as part of Megan’s story.

Further into the story, Megan said that they wanted someone else to play and William offered himself up.

When he was in the cave and had invited others in, he then said, “come on [Megan]” to invite her in.

When she did not come in, he went out to get her.

Megan told William to come along, when it was time to leave and he was outside of the pod.

## Emma – Peer Interaction

### Session One:

When the practitioner asked if they knew any snow related songs they both said, 'Let it go'. Emma responded to her cousin, when she tried to encourage her to sing on the microphone. She indicated that she was embarrassed by this. A minute later she indicated that she would sing on the microphone with her cousin, and went to take it. Then she decided against it. She then danced as her cousin sang. Emma pointed and said "[her name] look there's a penguin asleep". They collected snow together to throw on the Penguin, to wake her up. They counted to three and then threw it on her. They both went and hid from the Penguin under the bubble wrap and silver foil.

She called for her cousin when she encountered the Penguin outside of the pod, and then ran away. They both hid in the cave under some blankets from the Penguin. There was lots of laughter and physical contact between the two.

After they had been running away from the Penguin, they both stood on the edge of the pod. A practitioner commented on the fact that the Penguin's home had been messed up. Emma turned to her cousin and said, "do you want to fix the home?"

Emma drew her cousins attention over to the microphone by saying her name and then pointing to the microphone. They both worked on the microphone and Emma said (after her cousin said and then the practitioner repeated) "we just finished the house". Emma went to fix it again and her cousin said on the microphone, "what should we do". Emma went to the microphone and said, "build it again". Her cousin said, "team work" and put her arm around Emma who then said, "team work" on the microphone.

They hid together under the blankets. They then moved and hid in the curtains that surround the studio.

When she was interacting with the practitioners around the pond, she called for her cousin on the microphone.

When the storm occurred, Emma called for her cousin, "[her name]. There's a storm. Come on!"

They sang on the microphone "hush now, quiet now, it's time to lay your sleepy head. Hush now quiet now, it's time to go to sleep", when the storm was occurring and they had left the Penguin and the Snowman in the cave, wrapped up. A practitioner suggested that they tried to make the storm go away and her cousin suggested that they altered the words to "rain, rain, go away come back another day" and replaced the rain with storm. They both said this on the microphone, increasing in volume. They cheered the storm stopped. Her cousin said, "I did it", which Emma then repeated back. Her cousin said, "I did it" again and Emma offered a compromise and said, "we both did it". This was repeated once more.

She initiated the singing of "Let it go" on the microphone and invited her cousin to join in.

When Purdy entered, they both went to look at him from the outside of the pod. Her cousin said that she did not like birds and Emma copied this.

They ran away from Purdy together, when they were playing hide and seek.

They repeated "hush now" after the cousin said to the Penguin "you're going to go to bed".

She followed her cousin's lead of singing on the microphone.

## Appendix 23: interaction with Purdy

### David – Purdy Interaction

#### *Session One*

When Purdy entered, David watched him for a moment and then held out his Thomas the Tank Engine (TtTE) toy to him.

A little while later, he held the toy out to Purdy, which Purdy pretended to sniff and then made sounds which indicated disgust. David laughed at this and offered it back to Purdy.

Purdy returned and David looked at him and smiled.

He smiled at Purdy when he returned wearing a hat. He declined the offer from the practitioner to wear it.

He later offered the TtTE toy to Purdy, unprompted, when Purdy was perched on the edge of the pod. He allowed Purdy to come close to him and stroke his hair and peck him on his nose. He offered the toy back to him and laughed as Purdy tried to hold it in his mouth. He later allowed him to sit on his shoulder. He offered the TtTE toy to Purdy, when he called David's name. He put it in Purdy's mouth, who pretended to eat it.

He let Purdy sit on his head initially turning around so that Purdy moved off it. He then walked away and Purdy landed on his head and went with him.

He came into the pod (once the TtTE theme tune was played) and had Purdy next to him, who was singing along to the theme tune.

He pushed Purdy away, after he was sat down with the practitioner, who had her arm around him.

#### *Session Two*

David was outside holding a TtTE book. Purdy pecked it and David smiled.

He laughed at Purdy, who had placed himself between David and his book. He pushed him away and then held out his book. Purdy grabbed it with his beak and David laughed.

He laughed at Purdy, who blew a raspberry towards him.

He interacted with Purdy, when he lent over his book.

Purdy flew off with his book and put it in the camouflage netting, out of reach. David followed him.

He interacted with Purdy outside of the pod, when he read the book to him.

### Ed – Purdy Interaction

#### *Session One:*

He gave the toy that he had brought in to Purdy, making no attempt to interact.

He ignored Purdy when he asked if he could have a go with his snowball.

He laughed and had some eye contact with Purdy when they were playing the "1, 2, 3 fly" game.

#### *Session Two:*

He looked at Purdy when they were both outside and Purdy was trying to interact with him, by talking about the snowball. He allowed Purdy to peck him, whilst Purdy said "peck, peck, peck". After a couple of times of saying that, Ed imitated this back saying "peck, peck, peck".

There was some limited interaction with Purdy, when they were both outside. Ed was playing with some paper and Purdy swapped it over.

Ed allowed Purdy to work in proximity of him when he was outside, but had little interaction with him.

He was lying down outside of the pod and Purdy was stroking his cheek and said "peck, peck" softly.

He pushed him away and got up to leave.

### Harriet – Purdy Interaction

#### *Session One:*

She put a bear hat onto Purdy after he requested this. When he said that he could not see, she adjusted the hat.

She tickled Purdy, after this was guided by the Inuit. She then let him tickle her back.

Purdy landed on her head and she looked up at him and smiled.

She went to give Purdy a fish but then hit him with it – she laughed. Then she went to give it to him again, but quickly moved it from him, before he could get to it. She then gave it to him. She retrieved another fish from him, at his request, and then fed it to him.

Purdy asked Harriet where he should go to bed and she directed him to a spot.

#### *Session Two:*

Purdy stole the snowball that the practitioners were throwing around and put it out of reach. Harriet followed but after a moment.

### Annabelle – Purdy Interaction

#### *Session One:*

When Purdy entered after the storm, Annabelle looked immediately at him and said “hello”.

Purdy drew her attention over and suggested that she used a fish as a replacement nose for the Snowman (he had lost his).

Purdy entered the space as he had found the Snowman’s nose. She went up to him and took it.

She spoke to Purdy about how old she was and tried to guess his age.

There was a very brief discussion with Purdy who appeared to be eating something.

#### *Session Two:*

She responded to questions after Purdy found here e.g. her name. She introduced the penguin toy she had, to Purdy. Purdy asked if he can introduce himself to the two birds and she said yes and introduced them again.

Purdy later introduced Annabelle to the Inuit.

### Amy – Purdy Interaction (Part One)

#### *Session One:*

When Purdy entered the space during the storm and was blown around, she offered him a cloud to help him.

She responded to Purdy when he asked her about whether she could control the storm.

She high-fived Purdy after he requested this.

Amy described the Snowman’s nose to Purdy, after the Inuit told her to.

When Purdy tried to convince her that he had found the Snowman’s nose, she pointed out that it was a fish.

She gave Purdy a fish that she had caught, when he asked for one.

She spoke to Purdy about how old she was and tried to guess his age.

She attempted to feed Purdy a fish and later offered him another one.

She worked with Purdy and they hid one of the Snowman’s buttons that he had given to her.

Continued on next page.

### Amy – Purdy Interaction (Part Two)

#### *Session Two:*

She responded to Purdy's questions when she was working on the microphone. She introduced herself as "[Annabelle] the Penguin" and shook Purdy's wing. She asked if Purdy knew where her friend was and gave the microphone to him when he requested this. He drew her attention to the Snowman, who was hiding. She said that it was "our friend Snowman".

After Purdy suggested doing the special Penguin call to find her friend, she shouted P3's name at the top of her voice. Purdy found P3 and directed Amy over to her.

When she had control of the hand-held camera, she filmed Purdy.

When Purdy said to her "hello Mr Snowman" (she was wearing a nose), she corrected him and said, "I'm Mrs Snowman".

### William – Purdy Interaction

#### *Session One:*

Purdy helped explain to him, how he could sneak up on the Penguin and throw a snowball at her without her realising. Purdy explained this and then William carried it out.

He went around the outside of the pod with Purdy.

When William laid down in the cave, after he had been running around the pod, Purdy asked him if he was tired. He responded, "still not tired", got up and ran off again.

Purdy helped to get him into the tunnel to initiate the game where he got stuck and asked for help.

After Megan had her go at getting stuck, William told Purdy that it was his go. Once Purdy had got into the tunnel, William said "now me" and got in the tunnel with Purdy. They both then called for help.

Purdy called him into the pod to try to get William to find him. He was hidden under some bubble wrap. He said, "I bet you can't find me" and William responded "I can. There you are" and pointed to the practitioner who was operating Purdy. William then worked with Purdy to help get the Penguin out of the tunnel (she had got stuck).

#### *Session Two:*

Purdy tried to interact with him whilst he was working on the microphone. He gave some eye contact and had a small amount of verbal communication. He walked away when Purdy called him. He came back a moment later and Purdy told him to say on the microphone "hello my name is Thomas", which he did. A minute later he said to Purdy, "I want to be a Snowman".

Purdy asked him where they should go to get shelter (the storm was coming) and William was focused on his image in the live-feed and said, "too scary".

When Purdy asked, "how we can get warm", he responded saying "I don't know". He then stroked Purdy to help warm him up.

William commented on the storm and Purdy said that he could control it by saying "go away Mr Storm", which William then did.

William said "T-hom-as, Thomas" on the microphone, which Purdy tried to copy. William said to him "not like that". When William was working on the microphone, Purdy suggested that he made a raspberry sound over the microphone, which he did.

Later he spontaneously said to Purdy, "it's really cold outside".

### Megan – Purdy Interaction

#### *Session One:*

She worked with Purdy to set up the comic interaction.

She blamed Purdy for throwing the snowballs.

#### *Session Two:*

Purdy translated to Megan what the Penguin said on the microphone. He asked, “shall I tell you what that means” and she nodded.

After she had spoken ‘penguin’ on the microphone, Purdy took the microphone off her and did the same. He then handed it back to her and she made a noise into it.

She worked with Purdy when they were throwing snowballs at the Penguin.

Purdy helped her into the Snowman outfit, with the help of the Inuit, after Purdy drew her attention to the outfit.

Purdy translated what the Penguin was saying to Megan, who as dressed up as a Snowman.

She blamed Purdy for throwing the snowball at the Penguin, after the storm.

She told Purdy off and took a fish from him.

She dedicated part of her speech that she did on the microphone to Purdy.

She imitated Purdy’s Australian accent (the puppeteer had accidentally gone into an Australian accent and commented on it in the moment).

### Emma – Purdy Interaction

#### *Session One:*

She was outside of the pod when Purdy entered and then came to the edge of the pod when she heard him talking on the microphone.

She asked Purdy if he would like to play hide and seek.

She jumped out on Purdy, which made him jump, after she had seen her cousin do it.

Purdy had a snowball and he said to Emma tell me when to throw it (at the Penguin). She then said now.

#### *Session Two:*

Purdy was not in this session.

## Appendix 24: performing as 'other'

### Harriet – Performing as 'other'

#### *Costume*

In the first session, Harriet put on a snowman outfit. She did not embody the character, instead she focused on the buttons (which were detachable). The transformation into the snowman was not encouraged by the practitioners, or spontaneously displayed by the participant. Quickly after she put on the outfit, she was distracted and directed over to the pond by the characters.

In the second session, Harriet was offered the opportunity to wear the penguin onesie. She was shy initially and gave only a slight nod at the invitation from the Inuit, but then willingly got into the outfit with the help of some of the characters, smiling once the costume was on. The Inuit then asked the Penguin to help Harriet learn how to be a penguin. The Penguin indicated that both of her hands needed to be flat, which was reinforced by verbal confirmation from the Inuit, which Harriet did. The Penguin then showed that the feet needed to be turned out, again supported by verbal confirmation, and Harriet copied. She then spontaneously began to move from side to side, which was verified by the Penguin who did it almost immediately after, and the Inuit who verbally confirmed. The characters then lined up (Penguin, Harriet, Inuit and Snowman) and followed the Penguin, all waddling across and around the pod.

#### *Penguin Toys*

In the first session, Harriet was sat around the pond with the Inuit and the Snowman fishing. It was suggested that the toy penguin she was holding, might like to eat a fish. Harriet selected one and held it up to the toy's mouth (the Snowman made some noises to indicate that the penguin was eating it). After a while, she threw the fish back into the pond, which indicated that the toy did not like that fish. The Inuit then pointed out another fish. Harriet picked it up and held it to the toy's mouth (eating noises were made by the Snowman and the Inuit). This time the fish was kept there, which indicated that the penguin liked that one. A few minutes later, the Snowman offered another fish to Harriet, who again held it up to the penguin's mouth, then threw it away, indicating a dislike for this one. This happened once more.

### Annabelle – Performing as 'other'

#### *Costume*

In the first session, Annabelle found a bear hat which she put on and went towards the other participant (P5) with her hands held up like claws and attempted to make her jump. In the second session Annabelle put a different hat on and pretended to be a monkey outside of the pod. Although this was not caught on camera, she was heard making the sound effects.

In the second session, Annabelle put on a penguin onesie (with P5). She did not embody the way that the Penguin moved, although she did pretend to be called Lucy and carried around a penguin toy, which she called Lucy Whoop.

### Amy – Performing as 'other'

#### *Penguin Toys*

In the second session, when Amy dressed up as a penguin and held a penguin toy, she declared it was her boyfriend and said to the Inuit and Annabelle, "leave my boyfriend alone".

## Megan – Performing as ‘other’

### *Costume*

In the second session, Megan dressed up as a Snowman, after discovering the costume and choosing to wear it, when offered a choice between that outfit and the dog mask by a practitioner. She was helped into the costume by the Inuit and Purdy, and once the outfit and nose were on, the Penguin was invited over to see the new “friend”. The participant went on to spontaneously waddle like a snowman and collect a fish, which she pretended to eat, before returning to the practitioners. Within this session, she also found the bear hat, put it on and crept up on the Penguin and made her jump. She then stomped in front of the Penguin, smiled, and growled at her, and then raised her hands up like claws. The Penguin indicated that she was scared by this and after Megan looked between the Inuit and the Penguin, she jumped forward again growling and then stepped back laughing. She removed the hat, said “hello” and waved at the Penguin.

### *Penguin Toys*

In the first session, Megan created a den for the penguin toys in a tunnel. She shared this with others and said, “I made a little den for the penguins” then patted it. The Inuit gave her another penguin and said “shall we put the other one in there as well? Like a little family”. Megan then pointed out that one of the toys was the Mum and one was the Dad. She found a third toy and put it in with the others. A while later, there was a storm and Megan went out to collect the penguin toys and brought them into the cave, to shelter them.

Later in that session, Megan worked with the Inuit in the cave where she had tucked the penguin toys under some material. She suggested that they put some snow in between the penguins so it “is like their home a little bit because they are not use to having the warmth”. After she had tucked them up she named them: Luna, Jake and Pengu. When asked by the Inuit their age, she said they were 57, 57 and 2.

Near the beginning of the second session, Megan tucked the penguin toys into the tunnel, along with some snow, and left them some fish.

She took this further and later animated the penguin toys. She held them up to the Penguin and shook them, whilst making a high-pitched sound. A few moments later when the Penguin was holding up one of the tubes and talking down it, Megan offered one of the penguin toys to her and made it make sounds down the tube to the Penguin. She returned that penguin to the cave and brought over the other one. Purdy asked, “do the other ones talk?” She nodded and made that penguin toy talk into the tube, making a different sound to the first. Purdy asked where the penguin was from and Megan responded “South”. Purdy and the Penguin discussed where the Penguin was from (Purdy translated the sounds as the Penguin is non-verbal). The Penguin made another sound down the tube, which Megan copied with the toy, suggesting that that penguin too was from the North.

## Appendix 25: humour production

### Megan – Humour Production

Everyone had been playing a game, where they got stuck in the tunnel and had to request help to be saved. After several iterations of this, Megan said “now we need to make sure this never comes out again” and attempted to cover up the tunnel with the support of Purdy and the Inuit. William then lay on the tunnel. The Inuit and Megan sprinkled some of the shredded paper over him. He got out of the tunnel and Megan said “let’s get the netting back up” and attempted to cover the tunnel again. She then said “we don’t want anyone to find it. So it doesn’t \*indistinguishable\*”. Purdy then commented, “oh so we are camouflaging it” and then a moment later declared this to the others. After they have covered it, Purdy said that no one will fall in it. Megan picked up a cardboard fish and then whistled, attempting to get the Penguin’s attention. Purdy helped to draw the Penguin’s attention (only at this moment was it realised by the practitioners what was happening). Megan smiled, whilst wiggling the fish, then put it down on top of the covered tunnel and a moment later pointed at it. At this moment, the camera moved away and focused on William who had “fallen” into the pond and was asking for help. Megan stopped what she was doing and went to help him out. She collected more fish from the pond to put on top of the tunnel. William called for attention and eventually managed to get her to pretend to fall into the pond, which he then rescued her from with the help of the Inuit. The Penguin was then encouraged to go and retrieve the fish, which she did, then falling into the tunnel [this moment is not caught on camera as William has again fallen into the pond]. Megan smiled at this, looked to the camera and then applauded.

## Appendix 26: authorship

### Megan – Authorship example 1

In the second session, William and Annabelle were working on the microphone, with the other practitioners sat and listening to what they were saying.

**ANNABELLE:** To my best friend Purdy, who's the Penguin. \*reaction from Purdy and the Penguin\* Here's a little special gift from me [she picked up a toy Penguin].

**WILLIAM:** Me now.

**ANNABELLE:** Catch [threw the toy penguin at the Penguin].

**PURDY:** Ahh that's lovely.

**WILLIAM:** And here's a special gift from me too.

**PURDY:** What's your special gift?

**WILLIAM:** I \*indistinguishable\* you Thomas.

**PURDY:** Your special gift is Thomas? Fantastic.

**ANNABELLE:** I've got another special gift for Purdy.

**WILLIAM:** I know what it is.

\*Brief conversation off-camera between Purdy and the Penguin. Annabelle had mistakenly called the Penguin, Purdy. The Penguin decided her name was "who who who who" (said in a particular tone)\* [She then gives the Penguin a hug].

**ANNABELLE:** I've got a little song for Purdy and who who who who [said in the same intonation as the Penguin had said].

\*Sings\* *This is a special little song. For a Penguin and a little birdie. He can play a tune and tap dance and Purdy can do an Australian" ....*

\*Purdy responds\* [In session one, for a brief moment Purdy's accent had gone Australian, which the operator commented on in the moment].

\*In an Australian accent\* G'Day Mate. I'm Australian...Wanna go swimming...

\*Brief interaction between Purdy and the Penguin\*

\*Sings\* *There's a lot of fish in the pond. There's a lot of fish in the pond. There's a lot of fish in the pond. Lot of fish in the pond. Lot of...* \*thunder happens\* *There's a lot of lizards in the cold. There's a lot of lizards at the cold.*

**PURDY:** Where shall we go?

**ANNABELLE:** Umm.

**PURDY:** Can you sing us to where we should go to seek cover?

**ANNABELLE:** *Let's go in the bear cave. Let's go in the bear cave to get some warm.*

[The participants and practitioners go and hide in the bear cave, except for the Penguin].

Pengy if you can hear this. This is my special song for you. Hurry up! Quickly!...

\*Sings\* *If you want some fish hurry up* [other practitioners join in]. *If you want some fish hurry up. If you want some fish, want some fish, want some fish then hurry up...*

You silly little Penguin.

Megan – Authorship example 2

In the second session, William and Annabelle were sat in the bear cave with the practitioners. They were playing on the microphone, making different sounds into it and putting the material on it, to make it rustle. Annabelle then spontaneously began telling a story

**ANNABELLE:** “Purdy wanted some fish one day but then gave it to Penguin but who who who who [the name of the Penguin] needs somewhere to stay so

**PURDY:** Where could she stay?

**ANNABELLE:** She came into a bear cave.

**PURDY:** We’re the bear cave. Where’s the bear?

**WILLIAM:** It is a bit wet.

**ANNABELLE:** \*roars\*

[William took the microphone from her and Annabelle put on a bear hat]

**WILLIAM:** \*roars\*

**ANNABELLE:** \*roars\*

**WILLIAM:** I want to do that too \*roar\*

**ANNABELLE:** So they all had to run out of the cave.

**PURDY:** Quick! Run!

**ANNABELLE:** While the bear was still in the cave.

**PURDY:** [to the Penguin] You can’t run, you’ve got to roll there.

**ANNABELLE:** \*roars\*

**PURDY:** I think we should go and hide by the pond.

**ANNABELLE:** and the bear stopped [removed hat] and said \*indistinguishable sounds\* [left the bear cave] and then as Purdy had a cave with [William], there was lots of snow coming outside. Pitter patter. Pitter patter. Pitter patter. I think... I think Pengy is trying to swim on the snow.

**PURDY:** What a silly penguin.

**INUIT:** A very silly penguin.

**ANNABELLE:** But then, this little Penguin said [picked up a toy penguin and held it to the microphone] “who he, who he, who he”.

**PURDY:** What does that mean?

**ANNABELLE:** That means, I want Purdy. I want Purdy

**PURDY:** Ok. I’ve got to go [William’s name]. The Penguin’s calling me. [Annabelle threw the toy at Purdy] Oh, he came to me. Hello Penguin.

**ANNABELLE:** Then Penguin wanted somewhere, someone else to play with him, so...

**WILLIAM:** Me.

**ANNABELLE:** I think. I think [William’s name] wanted to play with Pengy.

\*All cheer\*.

**WILLIAM:** That means yes.

**PURDY:** That means yes. Good.

**WILLIAM:** Come on.

**ANNABELLE:** And then he started to run... and run. And while they were running this happened \*pats microphone\*.

**PURDY:** Ooh. What’s that?

**ANNABELLE:** It sounded like a bear [storm is instigated by the technician].

**PURDY:** It sounded like a bear?

**ANNABELLE:** \*pats microphone again\* but it was just Pur... it was just Pengy’s best friend playing a trick. Where did he go?

**PURDY:** Who are you looking for?

**ANNABELLE:** Pengy. \*blows on microphone\*.

**PURDY:** And the wind’s howling.

**ANNABELLE:** \*makes a howling sound and then barks. Then she drops the microphone and gets up\*.

### Amy – Authorship

After the storm had occurred in the first session and Amy has seen that the Snowman was upset by it, she suggested that a magic spell was used to stop it. The Inuit followed this up and asked her what magic spells she could do. She said, “make the storm flash and go” at which point Purdy asked for clarification as to whether she wanted it to start or stop. She confirmed that she wanted it to stop. Purdy asked if she could do a magic spell to start it. She said, “make the storm start” whilst she threw a handful of snow up into the air. The storm then started. She engaged in the performance of the storm and moved around like she was being blown by the wind and threw paper. She then said, “make the storm go away” and raised her hands up, which caused the storm to stop. Later she called the storm back with a poem, “make the storm back, so it was, going it and a flash, flash, flash!” She did this whilst rolling her hands in front of her. This time she was using the storm to help find the Snowman’s nose, which had gone missing. Later in the session, she wanted to bring the storm back and used magic hands (as suggested by the Inuit) and said “abracadabra. Make the storm come back”. Towards the end of the session she tried to call the storm back, as the sun was rising, meaning that the characters had to go back to bed. She wanted the environment to cool down, so that her interaction could continue.

### William - Authorship

After the Penguin had got stuck in the tunnel and Purdy and William had made several attempts to get her out finally being successful, William said “me now” and was helped into the tunnel. Once in he said “help help” and rolled over onto his side. The characters all responded to this and Purdy asked if they had to pull him out, to which he responded yes. Once he was rescued, he told Annabelle to get into the tunnel and then told her what to say, “help help. I’m actually stuck”, which he said in a higher pitched voice. He then rescued her and told Purdy that it was his go. William got into the tunnel with Purdy and the puppeteer. Both William and Purdy then called for help, and William was rescued by the Penguin. It was then the Inuit’s turn and William informed her of what to say. He then helped her out.

## Appendix 28: acknowledgement of artificiality

### Emma – Acknowledging the Artificiality

In the second session, the characters started to play hide and seek. Emma spotted where the Snowman was hidden and turned back to look at the practitioners. She put her fingers to her lips to indicate that they had to be quiet. She then pulled the material off the Snowman, who made a slight noise, but she was not revealed. Emma then looked back at the practitioners and said, “I wonder, she’s not here” and again raised her finger to her lips. She then took the second bit of material off the Snowman, who was then revealed.

In the same session, the Snowman handed Emma a snowball and she threw it at the Penguin, with a look of delight on her face. She looked at the Inuit and then pointed to the Snowman, to blame her. The Inuit and Emma then both threw one. When the Penguin turned around, so did the Inuit and Emma looked like she had not done anything and then pointed at the Snowman. They threw another snowball and this time Emma looked at the camouflage material that was hung down from the ceiling, and then stroked it. She threw another one and followed the Inuit who moved away and went behind the camouflage material. She threw another snowball and then hid behind the material with the Inuit, quickly turned away and pretended she was not up to anything.

### Megan – Acknowledging the Artificiality

The Inuit and Megan conspired together to throw two snowballs at the Penguin, who was sat down and had her back to them. Once they threw them at her, they both backed away and Megan and the Inuit giggled. The Inuit whispered something inaudible to Megan and they both pointed at Purdy, who was further away. There was a short exchange between the Inuit and Purdy, in which the Inuit was attempting to put the blame on him. Purdy blamed the fish (who were in the pond) and Megan and the Inuit agreed with him verbally, and pointed out which fish they thought it was. The Penguin turned back around and the Inuit picked up a snowball and handed it to Megan, who threw it at the Penguin. When the Penguin turned around, Megan quickly put her hands behind her back and then pretended to be playing with some icicles that were hanging down. She stopped and then pointed at the fish (the Inuit was already pointing at them), which suggested that she was again blaming them for throwing the snowballs.

### Annabelle and Amy – Acknowledging the Artificiality

In the second session, both the participants had made a mess of the pod. The Inuit commented on this and asked who had made it. Amy said “not me”, and put her arms out to the side to indicate that she was not sure. She then blamed the Snowman, “the naughty...ohhh... ahh... \*Annabelle screamed on the microphone\* Snowman. Not me”. Annabelle backed this up and pointed at the Snowman and said, “naughty Snowman”. Amy confirmed this by nodding and saying, “it is”. The Inuit probed and said, “was it really the Snowman?” Amy nodded and Annabelle said “yes it was”.