A Framework to Support and Evaluate the Participation of Children with Autism in the Design of Technology

P.H.D.

2020

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DECLARATION

The work presented in this thesis is, except where otherwise stated, entirely that of the author and has not been submitted as an exercise for a degree at this or any other university.

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For Karen, Dearbhla & Ruadhán

ACKNOWLEDGEMENTS

ABSTRACT

As the availability of technology developed for children with autism has increased, an awareness of the benefits of designing technology with them has also improved. However, the intellectual, communication and social interaction deficits that characterize children with autism often see them overlooked as research or design participants.

The objective of this thesis is to examine how children with autism can participate in the design of technology and to evaluate their participation. To this end, a two-stage ethnographic body of research composed of fourteen exploratory case-studies, conducted with sixteen children with autism, in a special education centre in the State of Qatar was undertaken. The first stage involved developing a framework to support the participation of children with autism in all the phases of the design process: early, intermediate and final. Data collected comprised observation, field notes, video and audio recordings, the design artefacts generated by the children and the final output for each design cycle. Data analysis consisted of, coding, categorisation, pattern analysis and cross-case synthesis. The second stage involved the articulation of a framework to evaluate the participation of children with autism in the design process. To assert the influence, impact and agency children with autism had on the design of technology, data collected in the first stage was examined through the lens of the evaluation framework.

Findings illustrate the support framework facilitated the representation of the lived experience of children with autism in the designed output. Assisting children in the generation of creative content and evaluating design possibilities gave them a voice in guiding the direction of the design. The described framework ensured children with autism contributed to decision making thus guiding the eventual design outcome. The evaluation of their participation reveals their impact, influence and agency in a design process is linked with harnessing their unique abilities and valuing their contributions.

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Chapter 1: Introduction

Technology use by children in modern society is the subject of much debate with a focus in popular discourse of the dangers technology can pose in childhood. One constituent group however that have benefited greatly from developments in new technologies are children with autism.

Autism or autism spectrum disorder (ASD), refers to a broad range of conditions that are characterised by challenges with social interaction, language and communication skills and repetitive behaviours. Autism is a complex developmental condition and the extent to which it affects a child's day to day life and functioning is related to the severity of its symptoms. Children with autism can have trouble communicating with others, understanding what other people think and feel. As a 'spectrum disorder' each child with autism is likely to have a unique pattern of behaviour and level of severity (American Psychiatric Association, 2013). Because of this unique mixture of symptoms in each child, severity can sometimes be difficult to determine. The severity of the condition is generally based on the level of impairment and how the child's symptoms impact their ability to function. Computers, mobile devices and software have opened up a world of educational, therapeutic, employment and leisure opportunities for children with autism. Much of the development of new technology is guided by a desire to use it for learning or therapeutic outcomes. Applications focus on addressing key deficit areas for children with autism including improving communication skills (Bouck et al; 2014), empathy and emotion recognition (Fabri, Elzouki & Moore, 2007; Moore, Cheng, McGrath, & Powell, 2005), and social-interaction skills (Mesa-Gresa, Gil-Gómez, Lozano-Quilis & Gil-Gómez, 2018).

Designers of technology for children on the autism spectrum are challenged by several factors; 1) the heterogeneous nature and presentation of the condition, 2) the evolving, developmental nature of the disability (DiCicco-Bloom et al., 2006) and 3) the challenge presented by children with ASD in generalizing skills learnt using technology to naturalistic environments (Parsons, Guldberg, et al., 2011). An increased recognition of the benefits that can be accrued from well-designed, purposeful technology for people on the autism spectrum has led researchers and designers to explore the use of design methodologies that focus on reflecting inclusivity in their unique and individual needs in the eventual design outcome. In particular, there has been an increased recognition of the value of involving the child with ASD at the heart of the design process both in terms of the outcomes of design and provide children

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with a   feeling of ownership over the final product (Benton, Vasalou, Khaled, Johnson, & Gooch, 2014; Frauenberger, Good, & Keay-Bright, 2011; van Rijn & Stappers, 2008). A clear motivation for the active inclusion of children with autism in technology design is to ensure that the end-product of the process accurately reflects the expressed needs and requirements of the child. It is anticipated that the needs of the child participating in the design process is representative of a broader population of children with similar needs and thus the final design product will accurately reflect their collective needs. Including the proposed user of the eventual design outcome offers the opportunity to build a technology based on real needs rather than assumptions, thus ensuring a higher chance of producing a successful product. Human-centred design approaches share a common interest in the need to identify the end-user as central to the design process. The implications for ensuring the active inclusion of children with disabilities such as autism in the design of technology however, requires careful consideration and planning.

A recent review of relevant literature in this area has recommended the need to develop and adapt design methods to match the abilities and needs of groups such as children with autism (Börjesson, Barendregt, Eriksson, & Torgersson, 2015). Notwithstanding the benefits of including children with autism in the design, the methodologies employed to support their interaction, knowledge transfer and decision making in design rely heavily on a host of communication, social-interaction, creativity, problem solving and other executive functioning skills. Considering the fact that estimates suggest that 30% of children with ASD remain minimally verbal (Tager-Flusberg & Kasari, 2013), such design practices cannot be considered "inclusive" for those with the most significant limitations.

1.1 Research Objectives

The aim of this research was to examine ways in which children with autism[1], for whom the severity of their condition has the greatest impact, can participate in the design and production of new technology. The objectives were to develop and implement a framework to support the participation of children with autism in technology design and to evaluate the nature and level of that participation.

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[1]Henceforth in this thesis the term children with autism will be used to refer to children considered to be amongst those presenting with the severest symptoms and functional limitations associated with the condition.

This qualitative research proposes a framework to support the participation of children with autism through the early, intermediate and final phases of a technology design process. A framework differs from a model as it is considered to provide a practical perspective on the structures underlying a system, concept or phenomenon. The exploratory nature of this research suggests the need for a framework that informs how to operationalize the participation of children with autism using its composite methods and techniques. The framework comprises a range of techniques and methods that have not previously been configured or utilised as proposed in this thesis. In this research this framework is implemented using fourteen exploratory case-studies conducted with sixteen children in a special education centre over the course of one year to investigate.

How children with autism can participate in the design and production of new technology?

Arising from this investigation this thesis examines the following sub-questions:

- What factors affect the participation of children with autism in a design project?

- In what ways can adapted design techniques support children with autism to identify design requirements, contribute creative content and engage in the evaluation of design solutions?

- How can adults contribute to and support the participation of children with autism through the phases of a technology design process?

Additionally, this research conducts an evaluation of the nature of participation for children with autism in technology design. An evaluation tool is developed by the author and used as a lens by which to investigate:

- How can the nature and level of participation of children with autism in technology design be evaluated?

This thesis also examines these further sub-questions:

- What is the nature of participation for children with autism in a technology design process?

- What level of participation can be expected of children with complex intellectual and social-communication challenges?

- In what ways does the nature of the project impact the level of participation for children with autism?

1.2 Research Methods

An ethnographic approach was taken in the collection of rich data from the sources available in this research including children and adult participants, the context and this researcher as participant. Field study data collection included field-notes recorded by this researcher and by study participants, video and audio recordings of design workshops with children with autism. All field-notes, audio and video recordings were transcribed and made available for further investigation and analysis. In addition, design artefacts emerging from the workshops were collected including visual content generated by children with autism, design elements, low-fi prototypes, design documentation and completed design solutions. The process of data analysis included early stage coding, data segmentation and categorisation. This was followed by content and pattern analysis and finally cross-case comparison. This qualitative process was theory driven and emergent patterns and theories were considered relative to the existing literature.

1.3 Summary of Contributions

This thesis makes a significant contribution to the **understanding of participation** in design for children with autism by:

1. Advancing the understanding of how the dimensions of participation; impact, influence and agency can be refined to describe the experience of children with autism

2. Building on the previous understanding of role of the adult in supporting participation in design for children with autism

This thesis makes a significant contribution to the **opportunities for participation** for children with autism by:

1. Articulating a framework to support participation for children through the early, intermediate and final phases of a technology design process.

2. Describing methods and techniques to support designers in understanding and capturing the lived experience of children with autism and to reflect these in developed design solutions.

3. Describing methods by which children with autism can generate content that can be translated into tangible elements of a technology design

4. Describing methods by which children with autism can influence the outcome of a design project by making choices and decisions at key times in the process.

This thesis makes a significant contribution to the evaluation of participation for children with autism by:

1. Articulating an evaluation framework to support the examination and analysis of the experience of participation for children with autism.

2. Highlighting the applications of the evaluation framework in planning and ensuring participation practice in a design project.

1.4 Thesis Structure

This opening chapter of the thesis serves to provide a short introduction to the motivation for this study, a short outline of the context and an overview of the research objectives, questions and approach and a short summary of the contributions made. The remaining thesis is structured as follows.

CHAPTER 2: BACKGROUND

This chapter details the background to the subject of this research, namely; an examination of the participation of children with autism in technology design. In this way the chapter will explore the concept of participation detailing how it is perceived of as a right that should be extended to children in society and how it defines the nature and quality of our interaction with the physical and social worlds. The process of technology design is detailed as it applies to the typical process that can be seen in human-centred design processes and those concerned with the development of new technologies for children with disabilities. Finally, autism will be defined not only as a medical condition or pathology but will be contextualized in term of how it is experienced in a range of life contexts including education, community and family life. The heterogeneity of this spectrum condition will be discussed with a view to understanding the how the presentation of social, behavioural and cognitive symptoms combines to create unique array of challenges for each child in their everyday functioning.

Approaches to the treatment and remediation of its associated symptoms and functional implications will also be outlined as will the application of technology.

CHAPTER 3: LITERATURE REVIEW

Chapter three presents a detailed analysis of the literature reporting on previous studies examining the participation of children with autism in technology design. The chapter outlines some of the major approaches developed to support participation for children with autism and will describe their implementation across a range of technology design projects. Previous studies are examined regarding the challenges faced by the children involved; the nature of the participation opportunities available to children. The roles of children and other stakeholders is evaluated as is the contributions that can be made by children with autism and the benefits they accrue through participation. Furthermore, the chapter will examine in detail efforts to identify, adapt and modify design techniques to support participation of children with autism across the various phases of the design process. These techniques are evaluated in terms of the nature of the participation opportunities, or otherwise that they offer children with autism. The chapter goes on to describe the development of a range of design methods and techniques to facilitate the participation of children with autism across the early, middle and final phases of technology design. These methods and technology together form a proposed framework to support the participation of children with autism in design. Furthermore, this chapter concludes with the outline of a proposed framework by which a child with autism's participation in a design project may be examined and evaluated.

CHAPTER 4: RESEARCH METHODOLOGY

This chapter seeks to explore a range of research approaches, designs and methodologies with a view to identifying a comprehensive approach that can be used to frame and guide the two-stage research in this thesis. Following an examination of the standpoints that served to motivate this research a discussion of the qualitative and exploratory approaches is conducted. The associated data collection, treatment and analysis methods are outlined as are some of the additional challenges and considerations required when conducting research with a vulnerable group such as this. The chapter concludes with a short description of this two-stage research process and outlines the implementation and evaluation studies that follow.

This chapter will also describe the qualitative data gathering and analysis methods employed and will briefly address the ethical issues pertinent for working with vulnerable groups such as children with complex disabilities such as autism.

CHAPTER 5: RESEARCH METHODS, PROCEDURES AND CONTEXT

A detailed description of the context of this research is provided at the start of this chapter. This serves to orient the reader as to the unique cultural and social space within which this research took place. A detailed outline of the background to the project is described including participant details, the location and context in which the research took place and the procedures that guided the process. This chapter describes the implementation of this research as a two-stage research process by outlining the of fourteen exploratory case-studies examining the participation of children with autism at the early, intermediate and final phases of a design process. The case-studies relevant to each of the design phases are outlined and data collection and analysis procedures are described in detail.

CHAPTER 6: EXPLANATORY CASE-STUDIES

This chapter describes a series of three explanatory case studies which serve to illustrate the process of evaluation of the application of a framework of identified methods and techniques to support the participation of children with autism in early, intermediate and final design phases. In each of these case studies a 'thick description' is presented based on analysis of the data sources gathered during the series of case-studies described in Chapter 5. Each of the case studies contributes to an examination of the nature of the participation of children with autism through each of the phases of design focusing particularly on their contributions at each phase.

CHAPTER 7: FINDINGS & DISCUSSION

In chapter seven the framework to support the participation of children with autism that emerged from the design project described in detail. This is discussed in terms of how the methods and techniques that comprise the framework shaped and contributed to the nature of that participation. The final chapter of the thesis summarises the findings of this study in terms of their implications for current and future research that involve children with autism as an integral part of the design process. The chapter includes a review of the research questions

considering the findings outlined previously in the thesis and summarises the way the specifics of the research questions are addressed. A description of the contributions of this research are presented and elaborated upon. Finally, the scope and limitations of this study are described to contextualise the contributions of this thesis and to inform and guide future work.

CHAPTER 8: THESIS SUMMARY & CONCLUDING REMARKS

The final chapter provides a summary of the research and the findings emerging. A description of the contributions is provided showing how this research study furthered and built upon previous work describing efforts to ensure participation in technology design for children with autism. A reflection on the limitations of the research is outlined highlighting some of the areas for potential future research attention.

1.5 A Framework to Support and Evaluate the Participation of children with autism in technology design

A framework to support the participation of children with autism has been articulated by this author. The framework represents methods and techniques identified from the literature or adapted to support the participation of children through the entirety of the design process. The framework defines a series of design workshops that contribute to the participation of children with autism in the early, intermediate and final phases of technology design. The workshops in the early phase of design comprise a series of methods to facilitate designers in understanding, capturing and translating the lived experience of children with autism. These provide an early platform for children with autism to contribute to the design process. During the intermediate phase of design, the framework involves methods and techniques to support children's co-creation providing opportunities to develop and contribute design artefacts. In the final design phase, the framework offers structure and support enabling children to engage in decision making thus supporting their evaluation of potential design outcomes.
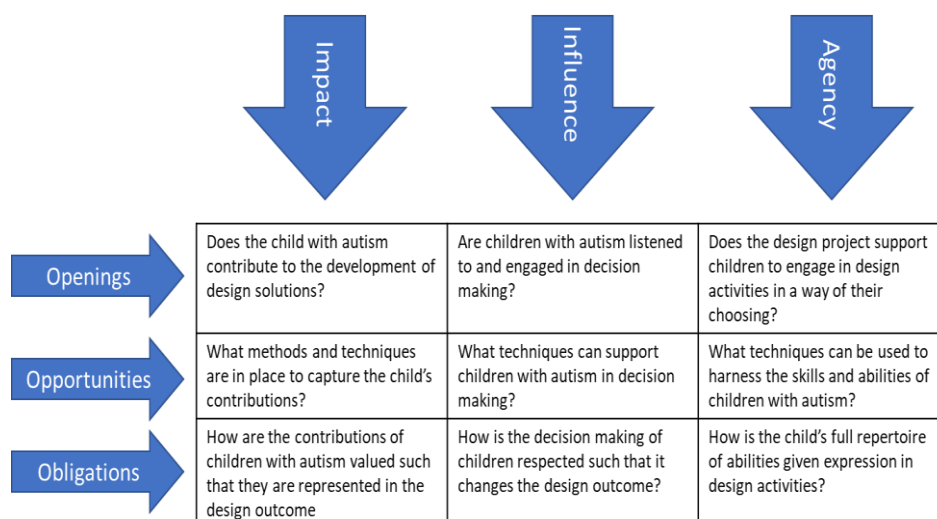
Figure 1: A framework for the evaluation of the participation of children with autism in technology design

In the absence of existing methodologies for examining the participation of children with autism in technology design the author has developed, evaluated and described an evaluation framework for this purpose (Figure 1). This evaluation framework provides a lens by which to examine the impact, influence and agency of children with autism in a design process. These three dimensions provide a measure of the level of participation offered to and experienced by children with autism in technology design. The framework also provides a mechanism for the analysis how the design process itself supported children's participation. By examining the commitments to participatory practice, the opportunities made available and the obligations through which they are realised we can establish a picture of the levels of participation potential in a design project.

Chapter 2: Background

This chapter aims to provide a broad overview of three key areas. Firstly, it will look at the concept of participation and how it is viewed as a fundamental right for all children; it will define what participation means for children and examine the importance of the role the adult plays in children's participation. Secondly this chapter will look at what is meant by a diagnosis of autism and how this impacts a child in their participation across all facets of their daily life. Finally, this chapter will also examine the processes that underpin and guide the design of new technology, focussing on human-centred design approaches.

This chapter will illustrate how the process of technology design for children with autism necessitates an appraisal and refinement of traditional technology design processes. This chapter will outline approaches taken in terms of the role of the eventual end-user in and mechanisms by which they can contribute to technology design. An examination of how the application of participatory processes in technology design projects can empower children with autism will be discussed. Finally, the chapter will conclude with an examination of why participatory design (PD) has become a dominant approach focussed on ensuring that an end-user can bring their own experience to bear of the outcome and process of technology design.

2.1 Understanding Participation as a Right

Over the past number of decades, society has witnessed an increasing understanding of the importance of the perspectives of children and young people. The recognition of children as citizens in their own rights has resulted in acceptance that they should be consulted about many aspects of their lives and communities. This new way of thinking about children and childhood is influenced by progress in children's rights which has seen a reframing of the position of children and their standing in society (James & Prout, 1997; James, 2001). Children are now seen as having knowledge and experiences that differs from that of adults and as being competent social actors, who are actively responding to and shaping their social worlds (Hutchby, 2007). One of the drivers in this change has been an international recognition of children's rights through the United Nations Convention on the Rights of Children (UNCRC) and the rights of people with autism through the United Nations Convention on the Rights of People with Autism (UNCRPD). Both these international human rights treaties set out the civil, political, economic, social, health and cultural rights of children defining the concept of

participation for all children, those with and without autism. Both conventions have radically shifted the focus on outcomes in health and education services for those with impairments to their participation in life experiences over the course of their lifespan.

Article 12 of the UNCRC (1989, p. 12) states that "State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child". The UNCRC defines a 'child' as a person below the age of 18. The significance of Article 12 is such that it has been elevated to the status of general principle alongside Article 2 (non-discrimination), Article 3 (the best interest's principle), Article 6 (the right to life, survival and development (United Nations, 1991).

Article 7 of the United Nations Convention on the Rights for Persons with Autism (United Nations 2006, p 16) focuses specifically on children with autism, with Article 7 (3) echoing Article 12 of the CRC but adding that the children's views are "on an equal basis with other children", and that children with autism are to "be provided with autism and age appropriate assistance to realize that right".

2.1.1 Defining Participation for Children

The term participation covers a broad continuum of involvement and has many different interpretations (Cavet & Sloper, 2004). Clearly articulating a definition however has been complicated by the transactional and multi-dimensional nature of participation (Horgan, 2015, Hammel, 2013). The publication of the World Health Organisation's International Classification of Functioning, Autism and Health (ICF) provided a common framework for understanding health, disability and participation. The ICF defined participation as 'involvement in a life situation' (WHO 2007, p.9). This framework also recognised the role that a person's health condition and status, alongside their environment plays in the disablement process and on a person's capacity and/or opportunities to participate in their chosen or prescribed activities.

The ICF framework was subsequently refined in a specific version for children and young-people (ICF-CY) to address additional or unique concerns that require consideration such as the developmental nature of their emerging functional skills, capacities, activities and environments (WHO 2007). Beyond the domain of health, the importance of participation for children is increasingly seen in areas such as research, education (Burger K., 2019) and citizenship (Alkathani 2018).

Imms et al., (2015) described how participation can refer to being present (attendance) as well as being consulted (involvement) and has been used to refer to the 'involvement of children and young people in decision-making on issues that affect their lives" (Brady, Kennan, Forkan, Tierney, Jackson & Holloway. 2019, p22). Furthermore, there is an emphasis on recognising, understanding and capturing the perspectives of children's lives, recognising them as experts in their own right. The Committee on the Rights of the Child describes participation in the following terms;

"….is now widely used to describe ongoing processes, which include information sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are considered and shape the outcome of such processes" (UN Committee on the Rights of the Child 2009, p.3).

As such, participation is seen not only as recognising children, but also involving them by listening and including them in decision making.

There has been much focus placed on the competence of a child as it relates to their age (Mårtenson & Fagerskiold, 2007) with the competence of younger children involved in decision making being questioned. Alderson and Montgomery (2001) stated that children are presumed to be competent to participate in decision-making from five years old. However, in contention to this, the UNCRC Committee (2009) and the Council of Europe (2012) asserts that there is no age limit on the rights of the child to express their views and the right needs to be applied to younger children as well as older children (Twomey & Carroll, 2018). It is now understood that even very young children are commentators on their own lives and are competent enough to be involved in decision making (Clark & Moss, 2001). The General Comment on Article 12 (Committee on the Rights of the Child, 2009) stated that "children's levels of understanding are not uniformly linked to their biological age". The inclusion of children, including those with disabilities such as autism, in societies depends therefore on the degree to which they are listened to and the mechanisms by which they are included in decision making. Participation therefore cannot be seen as simply an either/or condition, rather it is characterised by degrees of participation or non-participation.

Those promoting participation emphasise the importance of maximising children's participation as the ideal, highlighting the moral, ethical and practical value in doing so (Horgan, 2015, Philips et al., 2013). An example is in areas such as health-care policy where, despite extensive efforts to engender participation research suggests that current participation activities offered to public participants provide little opportunity for substantive impact (Morrison &

Dearden 2013). If the participation of children is to have impact, then we must examine the extent to which their voices are heard, and they are engaged in decision making. The level or depth of individual or collective participation has been commonly characterised as a 'ladder of participation' (Arnstein 1969).
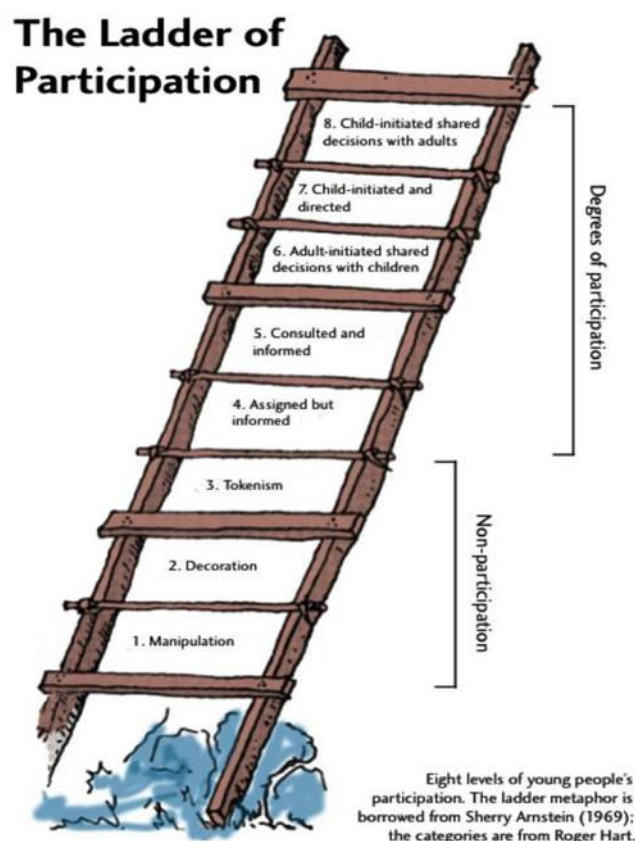
Figure 2: The Ladder of Participation guiding participation for children (Arnstein, 1969; Hart, 1992; Shier, 2001)

To further illustrate the levels of participation, particularly regarding children and young people the "Pathways to Participation" model was developed by Shier and his colleagues (Shier, 2001; Shier, Méndez, Centeno, Arróliga, & González, 2014). Such participation models have attracted their share of criticism, including the suggestion that the models highlight a hierarchy of 'participation' where the objective is to ensure that all efforts should focus on reaching the levels reflected by the top of each model. They argue that levels of decision making power vary dynamically across tasks and projects and that power opportunities do not always present sequentially (Kirby & Gibbs, 2006).

2.1.2 The Role of the Adult in Children's Participation

Drawing heavily on the influential work of Hart (1992) and Arnstein (1969), Shier's model articulates a continuum of non-participation through to meaningful participation. It mainly focuses on activities and processes that underpin participation eliminating any equivalence to the process of 'non-participation' such as 'manipulation', 'decoration' and 'tokenism' concepts included in previous models (Shier 2001). Shier's model articulates five levels of active participation:

1.   Children are listened to

2.   Children are supported in expressing their views

3.   Children's views are taken into account

4.   Children are involved in decision-making processes

5.   Children share power and responsibility for decision-making

These levels can also be viewed as a statement of values that ensure that children are supported adequately to participate to the greatest of their potential. Shier's model outlined above emphasises that listening to children and involving them in decision making are key components of participation. This model focuses more on the adult responsibilities rather than the status of children and frames participation as emerging from the collaborative activity of adults and children.

This model reflects participation as an interpretation of the behaviours of both children and adults, both with unique responsibilities. As such the importance of the role of the adult in ensuring participation for children cannot be understated. Adults play a key role in creating the conditions for participation. The Committee on the Rights of the Child (CRC, 2009) assert that for meaningful opportunities for the implementation of Article 12 to be achieved, adult assumptions about children's capacities must be challenged and the development of environments in which children can build and demonstrate capacities is encouraged (para. 135). Within Article 12, it is imperative a culture is created whereby the views of the child are heard and given due weight, as Noyes (2005) states "voices are nothing without hearers" (p. 536). Shier's model identifies three stages of commitment at each of the levels; openings, opportunities and obligations, each of which afford children greater degrees of participation.

This suggests that children's participation can differ based on their ability and focusses responsibility for the provision of participation opportunities not on the child, but on adults responsible for the construction of the activity, engagement or experience.

2.2 Autism Spectrum Disorder

ASD is not a single disorder, but a spectrum of closely related disorders that share a common, core set of symptoms. It is considered a lifelong, neurodevelopmental disability and is characterised by the presence of persistent deficits in three core areas of functioning; namely, social interaction, communication skills [2]and the presence of fixed or repetitive behaviours (Wing & Gould, 1979). Common symptoms include poor eye contact, poor "reading" of social cues, failure to develop peer relationships, lack of social or emotional reciprocity, delayed speech development, difficulty sustaining conversation, lack of imaginative play, repetitive motor mannerisms, and rigid adherence to routines. Symptoms are present before 3 years of age and there is no cure.

2.2.1 Presentation and Severity

Referred to as a "spectrum" disorder, autism as it manifests in a child's social-communication skills and behaviours is highly individualised and heterogeneous with symptoms presenting in a wide array of combinations and ranges of severity. It is recognised now that some of those diagnosed with ASD can successfully lead independent lives whereas for others the it can significantly impact their quality of life and that of their families and communities (Farley et al., 2009; Howlin, Moss, Savage, & Rutter, 2013). There is a high degree of variability between those diagnosed with symptoms presenting across a broad range of severity. A person characterised as "high-functioning autism" may have above-average cognitive and verbal abilities while those at the other end of the spectrum with so-called "low functioning autism" [3]may have profound deficits in behaviour, cognitive and language skills with the presence of

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[2] The core domain of social interaction and communication skills is derived from what was originally two separate domains of impairment in communication and social interaction (American Psychiatric Association 2013).

[3] There is considerable debate amongst families of children with autism and autism advocates to the use of 'low' and 'high' functioning as descriptors for the presentation of a child's condition. This is part of a broader debate concerning how best to refer to people with a diagnosis of autism. In a relatively recent study it was suggested that most adults prefer to be referred to as 'autistic people' whereas amongst health and education professionals the term most commonly used in 'children/people with autism' (Kenny, L., 2016). There is also a growing movement aiming to recognise autism as a human trait or characteristic equivalent to colour, ethnicity or sexual orientation. The 'neurodiversity movement' as it has been referred to aims to remove what is seen as 'medical model' labels that serve to differentiate people (Silverman 2015).

psychiatric and medical comorbidities impacting significantly on their functioning and participation. One such comorbid condition is Intellectual Disability (ID); defined as a disability, originating before the age of 18, characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills (Schalock et al., 2007). Classical Autism or Kanner's Autism falls on the more severe end of the autism spectrum. Children and adults diagnosed with this form of autism need more support to complete daily tasks and will struggle to communicate and manage their behaviours. They will generally share the same list of common difficulties including communication and social relations and regulating behaviours. They will however present with more severe deficits in these areas may also exhibit challenges with sensory processing, limitation in learning and intellectual disabilities.

Symptoms & Presentation associated with Severe or Low Functioning Autism	
Communication & Language	Children are typically non-verbal or minimally verbal and present with significant impairments of comprehension and expressive language (Tager-Flusberg & Kasari, 2013). It has been speculated that children with such disabilities do not have the skills to manage the level of abstraction required to develop language (Volkmar, Rogers, Paul, & Pelphrey, 2014).
Social Interaction	Social interactions for children with severe autism are often difficult and, in some cases, impossible. Some children will hit early milestones in social functioning and then experience a regression of social skills previously acquired between the ages of three and five whilst others will never develop the skills. Most children will present with a lack of social responsiveness, for example, exhibiting little no eye contact, not acknowledging others' presences (even parents or caretakers), and little to no smiling from a very early age. Social situations involving other children can also be particularly difficult for those with low functioning autism as they do not usually engage in communication, imaginative play or may have a rigid adherence to a narrow repertoire of behaviours (Lyons, Huber, Carter, Chen, & Asmus, 2016).
Behaviour Difficulties	As mentioned earlier, those diagnosed with ASD are likely to engage in a restricted repertoire of behaviours or may engage in repeated or stereotypical behaviours such as hand-flapping, rocking or flipping their fingers. People with severe autism are likely to have many such behaviors, and those behaviors can be extreme and uncontrollable (violent rocking, door slamming, moaning, etc.). Some of these behavioural difficulties can include aggression and non-compliance, which can result in a multitude of negative outcomes for the child and their family members such as physical injury, significant disruption to daily activities, and impaired quality of life (Maddox et al., 2017). The combination of symptoms coupled with the severity of these significantly impacts the person's day to day functioning and their prognosis for independent living into the future. Those diagnosed with LFA are more likely not to accrue the gains typically seen with early therapeutic intervention, are less likely to attend mainstream education, take up employment or live independently (Fusar-Poli et al., 2017; Howlin et al., 2004).
Cognitive Challenges	Approximately three quarters of those diagnosed with autism will have below-average IQ of less than 70 where scores of less than 70 indicate an

	ID (Joseph, Tager-Flusberg, & Lord, 2002). Recent findings by the Centre for Disease Control indicate that 38% of those diagnosed with ASD also have an ID (Christensen, Baio, et al., 2016). Children with an ID and autism have shown difficulties establishing or maintaining attention to daily tasks and activities (Freeman, Gray, Taffe, & Cornish, 2016). They demonstrate difficulty recognising objects (Dawson et al., 2004), categorising objects and patterns (Gastgeb & Strauss, 2012), concept formation and abstract reasoning (Minshew, Meyer, & Goldstein, 2002). Moreover, these challenges mean that traditional, mainstream learning environments do not have the appropriate supports for children with such difficulties.
Additional Medical Issues	Epilepsy affects up to a third of those with autism, this may lead to chronic sleep disorder or if untreated can result in permanent damage to the central nervous system. Research has also linked autism with psychiatric conditions such as bipolar disorder and schizophrenia. For children with an existing diagnosis of Cerebral Palsy there is a comorbidity prevalence of autism in 7 – 18% of cases (Christiansen et al, 2014).

Table 1: A description of autism as it presents for those experiencing the most severe form of the condition

Although the exact figures are widely debated, it is estimated that approximately 70% of those diagnosed with ASD will also have a diagnosis of ID (Fombonne, 2009; Matson & Shoemaker, 2009[4]). Children with autism presenting at the severe range of the spectrum can also be expected to have deficits of functional language and are often significant obstacles to social functioning and can have behaviours that impact upon every aspect of their functioning (American Psychiatric Association, 2013).

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[4]It has been proposed that the proportion of people with ASD who have a comorbid diagnosis of ID is decreasing and will continue to do so because of the recent trend to broaden the definition of Autism and Autism Spectrum Disorders. As individuals and groups with deficits in social functioning and/or idiosyncratic behaviours but with IQ greater than 70 increasingly come under the diagnostic umbrella then those with ID will become a smaller subset of the larger ASD family (Medical Research Council 2001)
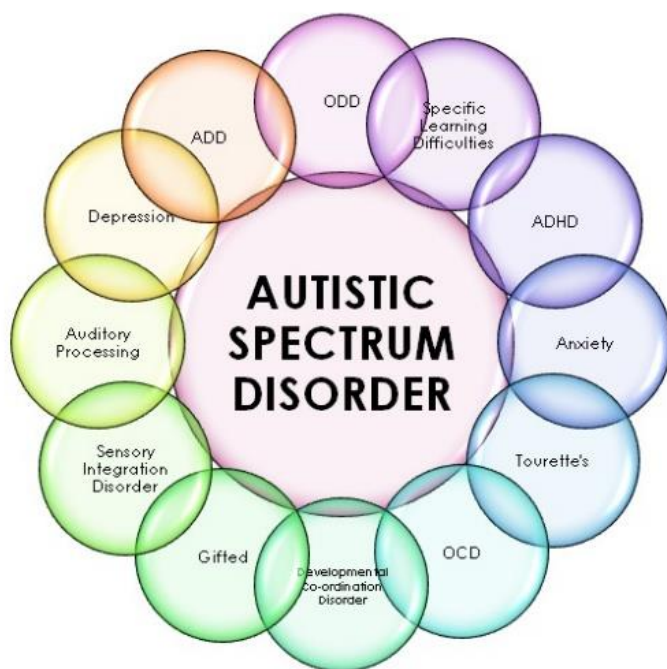
Figure 3: Co-morbidity & ASD[5]

Because of the unique mixture of symptoms in each child, severity can sometimes be difficult to determine. The severity of the condition is generally based on the level of impairment and how the child's symptoms impact their ability to function. This research focuses on those children for whom the severity of their symptoms has the greatest impact on their day to day functioning. Children with such severity of symptoms will typically have an ID impacting their cognitive skills such as attention, concentration, language comprehension and expression. Communication and social skills are impacted such that the child may not have a functional range of verbal or non-verbal skills to engage with others. Further symptoms seen in children include a lack of imaginative play a reluctance to engage reciprocally with others and extreme difficulty shifting their focus and attention either autonomously or on command.

The children at the heart of this research are often characterized and labelled as having non-verbal autism or 'low-functioning autism' as a way to describe the severity of their symptoms. Many autistic rights organisations, family groups and advocates however are critical of the characterization of people with severe autism suggesting that it creates a culture where low expectations are imposed upon them and ignores the impact that supports or accommodation can have in promoting their abilities (Chong-Ming, 2015). Labels such as 'low functioning autism' although in common use are often considered as pejorative and serve to

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[5] Reproduced from https://www.lanc.org.uk/related-conditions/autistic-spectrum-difficulties-asd-adhd/.

reinforce stigma in society for children with the condition[6]. As such, the phrase will be avoided throughout the course of this thesis, although it may occasionally be used when reporting the work of others. Henceforth in this thesis the term children with autism will be used to refer to children considered to be amongst those presenting with the severest symptoms and functional limitations as described above.

2.2.2 Theories of Autism

Since its early description in the mid-20th century many theories have been proposed in attempts to explain and understand autism. Many of these theories have reflected the "theoretical zeitgeist" of their time and have been influenced by dominant theories of their time from psychoanalytic theory through behaviourism to, the current, cognitive and neurodevelopmental models (Rajendran & Mitchell, 2007). Research since the 1980's has been dominated by several, often overlapping approaches seeking to explain the functional deficits displayed by those on the spectrum by identifying a pragmatic neurocognitive deficit or process that underpins the behaviour. These approaches are briefly outlined below.

Theory of Mind (ToM) refers to a person's capacity to understand the subjective, mental states of others. It describes the ability to understand another's thoughts, perspectives, beliefs, emotions and other cognitive processes and is, on occasion referred to as empathy (Baron-Cohen, 2005). This ability typically develops early in childhood but is significantly delayed or absent in children on the autism spectrum (Moran, Young et al 2011). It has been postulated that a child's ability to engage in pretend and peer/social play requires their ability to understand this process of meta-representation. Furthermore, this theory hypothesises that without a clear understanding of the mental states of others the consequence for the person with ASD is a significant difficulty in interpreting or inferring the emotions of others from their behaviours. Deficits of ToM are also used to explain the impairment of pragmatics of language that are evident in those on the autism spectrum with verbal skills (de Villiers, 2007). Development of ToM is typically identified by 'false belief tests' where a child's belief or representation about the world is examined in contrast with reality.

While this theory explains some of the social interaction difficulties and challenges faced by children on the autism spectrum and their parents, critics of ToM point to the fact that not

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[6] https://www.theatlantic.com/health/archive/2016/04/the-language-of-autism/476223/

all children with ASD fail the false-belief test[7.] Furthermore, it is also common for children with developmental disabilities, ID and impairment of normal language development to fail false-belief tests suggesting that deficits of ToM may not be universal to populations on the autism spectrum or indeed unique to them (Fenici, 2017).

Emerging from the work of Dr. Uta Frith, central coherence theory (CCT) suggests that many of the characteristics of autism may result from an inability to adequately process and interpret sensory information. Frith proposed that interaction with others and with our environment requires "central coherence", i.e., the ability to draw together, interpret, discard and codify a range of sensory information and to construct higher level meaning in context (Happe & Frith, 2006). According to the theory, those on the autism spectrum have weak central coherence. What is implied by this is that at people with ASD are good at picking out details but have a lot of trouble "figuring out the big picture". It also implies that they have problems filtering information due to an inability to discern which details are relevant and which aren't. Proponents of the theory of weak central coherence suggest that its key strength is that it explains some of the non-social, behavioural elements of the disorder such as attention tunnelling, repetitive or obsessive behaviours and adherence to rigid routines (Rajestran & Mitchell, 2007). It has also been used as a way of better understanding those on the spectrum who exhibit extraordinary, savant abilities in areas such as memory, music, art and mathematics while simultaneously experiencing significant challenges with social relations.

2.2.3 Approaches to Treatment and Education

Estimates suggest that over one in one hundred people in Ireland have a diagnosis of autism and although experts disagree on the most effective approach to teaching children with autism, they do agree on two things; the importance of early and intensive intervention (Howlin, Goode, Hutton, & Rutter, 2004; Howlin et al., 2013; Marchi, 2015). Since there is not yet anything close to a universal treatment for ASD, there is an urgent need to develop therapies and interventions that address the disorder's core symptoms (Damiano, Mazefsky, White, & Dichter, 2014). There is currently no consensus regarding a single cause for ASD, it is however generally accepted that the symptoms and behaviours that characterise the condition are caused by abnormal development of brain structure or function (Won, Mah, & Kim, 2013). Much of the research in this area has focussed on identifying a common cause at a genetic, environmental

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[7] In a study by Baron-Cohen and his colleagues, they found that 8/10 children with autism failed a commonly used False beliefs tests called the Sally-Ann test (Baron-Cohen et al 1985)

hereditary level, although a consensus is now emerging that autism does not have a single cause, rather it is a complex disorder that has a set of core characteristics that may have distinct causes (Happé, Ronald, & Plomin, 2006).

Over the past number of years' treatment and education approaches have been dominated by behavioural (Applied Behaviour Analysis – ABA) and cognitive-behavioural (CBT) intervention approaches. Techniques guided by the CBT approach are designed to help people become more aware of how they think and consequently act with techniques explored directly with the person to ensure that they can develop the correct behavioural response for particular situations or conditions (Wood et al., 2009). This approach, however, is typically only employed with children and adults who are characterised as having what is referred to as High Functioning Autism. The difficulties and deficits of language and social interaction tend to be considered "milder", impacting less on their overall functioning than those for example with more severe end of the autism spectrum. Many educational and treatment programs based on the principles of applied behaviour analysis (ABA) are popular because of the strong base of empirical evidence. This is shown by the fact that it has been endorsed as a treatment approach by the US Surgeon General (Rosenwasser & Axelrod, 2001). ABA intervention has been defined as the process of systematically applying interventions that draw upon principles of behavioural learning theory to improve socially significant behaviours as they are applied in functional settings (Capaldi, 2006). In this approach, the learning environment is highly structured and typically directed and controlled by a teacher or therapist. Targeted, desired behaviours are broken into a series of discrete sub-skills and presented in multiple, successive trials. Specific behaviours (e.g., eye gaze, object tracking, object orientation and turn taking) are selected by a teacher or therapist from actions that the child is not yet performing spontaneously. Acquisition of desired behaviour is facilitated using explicit prompting, prompt fading, and reinforcement (typically praise or access to a preferred toy or activity).

Strict ABA approaches to therapy and education however have attracted criticism as an intensive, one to one, adult centric approach. As such there is a lack of recognition as to how important the child's motivation is in ensuring therapeutic or educational success. More recently there has been increased attention on the ecology of children's social interactions in natural settings with a concurrent shift to models of social, peer and collaborative learning (Fletcher-Watson, McConnell, Manola, & McConachie, 2014; Rogers, 2000). Recognition of the limitations of traditional CBT and ABA approaches and the benefits of a developmental approach to skill development have led to Pivotal Response Training (PRT) or therapy emerging as a new framework for intervention for children on the autism spectrum. More

naturalistic, behavioural treatments such as PRT, have a similarly solid evidence base but have been designed to address the limitations of the traditional behavioural approach (Pierce & Schreibman, 1995). Pivotal Response Treatment (PRT) is an approach to the treatment and education of children on the ASD spectrum that has been derived from Applied Behaviour Analysis (ABA outlined in the section above). Where PRT differs from the ABA approach is that it targets key, "pivotal" areas of the child's development rather than targeting specific, individual behaviours. Typically these "pivotal" areas include motivation, self-management and joint attention (Koegel & Koegel, 2006). The PRT approach is underpinned by the belief that targeting change in these critical areas will produce a broad spectrum of collateral improvement in other, non-targeted social-communication behaviours. The success of this approach is attributed to the incorporation of behavioural techniques known to facilitate learning (i.e., multiple trials, explicit prompting and shaping, contingent reinforcement) with techniques known to facilitate early motivation and social-communication behaviour in typical children such as peer mediated and collaborative learning.

2.2.4 Technology for Children with Autism

Much has been made of the potential that technology can offer to support developmental, educational or therapeutic interventions for children on the spectrum. Researchers as well as parents, teachers and others involved in the education, treatment and care of children on the autism spectrum increasingly recognise the potential computer-technology offers as an effective and efficient tool in research, education and treatment (Ploog, Scharf, Nelson, & Brooks, 2013). Research highlights the value of technology in a myriad of areas including; communication (Logan, Iacono, & Trembath, 2017), sharing interests with others (Kamps et al., 2015), self-regulation (Picard, 2009), and developing a sense of personal competence. Technology has demonstrated beneficial outcomes for children with autism in better understanding and recognising emotions and feelings (Schuller et al., 2013), developing cognitive flexibility (Pascualvaca, Fantie, Papageorgiou, & Mirsky, 1998), expressive and receptive vocabulary (Ploog et al., 2013), and reducing repetitive behaviours (Boyd, McDonough, & Bodfish, 2012; Odom et al., 2003).

Technology for children on the autism spectrum has moved considerably beyond the use of desktop computers and seeks to exploit new opportunities offered by emergent technologies. The range of technology recognises that children, particularly those on the severe range of the autism spectrum may not have the cognitive perceptual and motor skills required

to use a keyboard and mouse. Several authors have pointed to the creative potential touchscreens promise in terms of harnessing some of the affinity demonstrated by children with autism to directly interact with and manipulate objects (Bauminger, 2007; Herrera et al., 2008). Such potential can also be seen in the rate of uptake of the iPad™ and other consumer products by children with autism and their families and the explosion of apps developed on handheld and touch pad devices specifically for people on the spectrum (Kagohara et al., 2013). Farr, Yuill and Raffle (2010), explore the potential of programmable objects or "tangible user interfaces" as a tool for children learning social interaction skills. The use of multi-touch and shared surface devices have been investigated in terms of their potential as collaborative learning solutions for children with autism (Gal et al., 2009; Goh, Chen, Trinh, Tan, & Shou, 2014; Piper et al., 2006; Silva, Raposo, & Suplino, 2014). The past decade has seen a growing interest in single user and collaborative technologies (Parsons & Cobb, 2011) and the use of social robotics for interventions such as imitation and modelling (Pennisi et al., 2016). The use of "serious games" as tools for learning and recreation for children and adults on the autism spectrum has similarly gained a foothold within the research community (Blum Dimaya et al., 2010; Zakari & Simmons, 2014). Across the literature, the area that attracts most research attention is that of the application of computer aided learning solutions for learning and practice of social and socio-emotional skills. In a review of literature however, Parsons and Cobb (2011) stated that the trend in published research in this area has emphasised the potential of the technology while often falling short on demonstrating its effectiveness.

As with many other areas of health and social care, professionals are looking to actively exploit the potential technology has to offer children facing the challenges posed by a disability such as autism to support education, development and participation.

2.2.5 Autism and Participation

A person's participation competence has been described as referring to their ability to execute a chosen activity according to an expected standard (Imms et al 2016). A person's ability to participate can therefore be seen in terms of the configuration of physical, sensory, cognitive and social skills and abilities that makes up that individual. A person's competence is usually defined as their ability to engage alongside the quality of their engagement in activities, for example using objects as they were designed or completing tasks independently without external support. While capacity and competence are at the fore of conversations around children's involvement in decision making, it is questionable whether they are useful concepts to guide the participation of children. Tisdall, (2018, p. 30) succinctly stated that "it is

increasingly realised that all people have evolving capacities and that competence is situational and relational rather intrinsic and individual". For children with autism, this suggests that children can engage to differing degrees of participation matched to their degree of ability and focusses responsibility for the provision of participation opportunities not on the child, but on those responsible for the construction of the activity, engagement or experience. For adults concerned with the child with autism realising their potential it is incumbent upon them to create the opportunities for participation, the conditions that support participation and the unique ways in which that child will demonstrate their participation.

Participation, or indeed non-participation, is no longer considered a consequence of a person's physical or psychological traits and characteristics but reflects the dynamic interdependence and transformation that emerges from the interplay between that person and their environment. A child with autism's participation in a chosen activity, therefore, cannot be defined in terms of his or her ability to perform tasks by themselves but must recognise the resources and supports that they require to participate to their potential.

2.3 Technology Design

The term 'design' is used interchangeably to describe the disciplines, practices, management, and theory that guides the creation of a product or service that has the intention of improving the human experience (Atkinson, 2017). Although the term design refers to a broad range of applications, for example, urban, graphic, interior and industrial design, in the context of this research it will refer to the processes required to create a new technology product for use by children with autism. The following section of this chapter focusses on defining and detailing the process of technology design as it applies to software that is intended for use by human operators. The typical phases a design project goes through are outlined as are the processes that occur during those phases. Each phase is described in terms of what its objective is and how this contributes to the eventual outcome of the process. It also describes what is expected of those involved in the design process including users and designers.

As the context of this study is an examination of technology design involving children with autism, careful attention will be given to user-centred design approaches that focus on the centrality of the human user in the design process. Particular attention will be paid to one such approach; PD and will detail how its collaborative processes have made it a popular choice of methodology for those designing with children with autism.

2.3.1 The Process of Design

Designing new technology is a process that involves 1) identifying a problem that needs to be addressed, 2) exploring ideas and developing a better understanding of the nature of the problem and potential solutions, 3) planning and development of possible solutions, 4) testing solutions, modifying and refining the solution before finally, 5) presenting the solution (Winograd 1996).

The design process is not a linear process, as some steps will be repeated, and some will overlap. During each of the above phases a designer will use a variety of tools and methods to progress to the next phase. In the UK, the Design Council[8] have articulated a four-step process to describe the process and methods of design. Often referred to as the "Double Diamond Approach" these four steps – Discover, Define, Develop and Deliver attempt to assimilate twenty-five different design methods to provide a simple, easy to understand map of the design process.
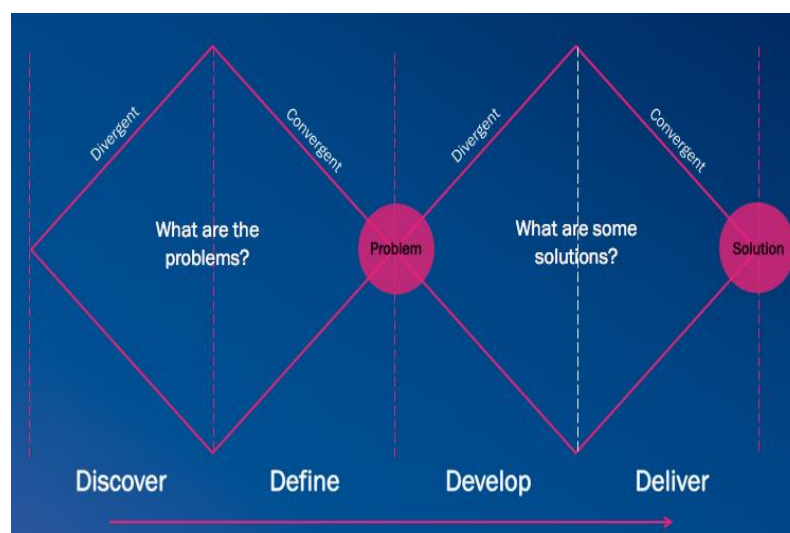
Figure 4: The Double Diamond Design Process[9]

Often characterised in terms of creative endeavour, design comprises two thinking processes; the designer must consider the breadth of possible ideas that will maximise their understanding ('divergent thinking') before refining and narrowing down to the best idea ('convergent thinking'). In the 'Double Diamond' approach the designer considers all possibilities and ideas before narrowing down to define the problem that requires attention.

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[8] www.designcouncil.org.uk
[9] Reproduced from: https://www.kaylaheffernan.com/blog/2015/8/21/designing-for-people-you-didnt-know-existed – last accessed September 2017

Similarly, once the problem has been identified the designer employs a range of techniques to help explore all possible solutions before focussing in on the most appropriate one.

The early phases of the design process often referred to as the "fuzzy front-end" or "front end of innovation" is characterised by the activities that take place between the time the opportunity is identified, and formal design activities commence.

These activities focus on 1) identifying and analysing opportunities, 2) generating and selecting ideas and 3) developing concepts (Koen et al., 2001; Wagner, Baureis, & Warschat, 2012). The early phases of a typical design process, referred to sometimes as the requirements phase or pre-development, involves gathering relevant information, translating this data into design ideas and conceptualisation. This process has been described in the Double Diamond model as a two stage process termed 1) Discover and 2) Define. The Discover step of the Double Diamond model requires designers to capture information about the user, the context, the nature of the problem and their inter-relatedness. Designers will use a range of tools and techniques to support this information gathering, including, observation, user diaries, brainstorming, surveys, questionnaires and secondary research. The Define step requires designers to try to make meaning of the information gathered during the previous stage and to create new understanding. Using techniques that include focus groups, concept testing and user mapping the designer refines their insights with a view to clearly articulating the problem that will be addressed. This step finishes once the designer has developed a clear brief that frames the design challenge.
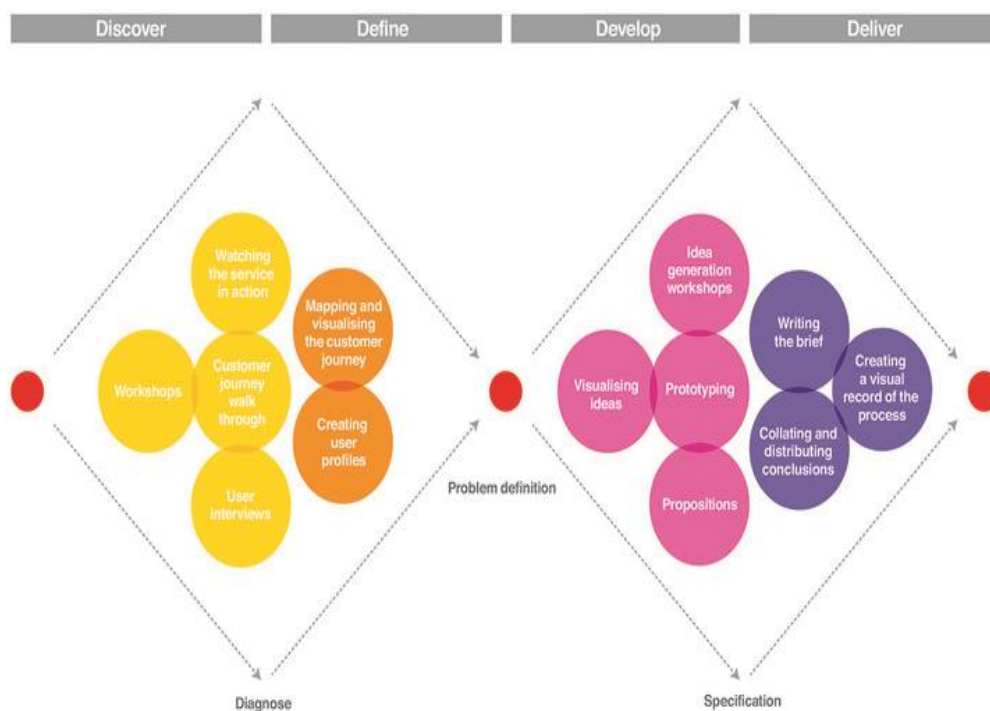
Figure 5: Double Diamond Design with illustrative design techniques and tools[10]

The intermediate phase of the design is characterised by the creative efforts to imagine what the proposed product or software looks, feels and acts like. In software design projects, it is during this phase that designers begin to assimilate all that they have learnt and understood about the problem in question, the imagined end-users and the context in which it will operate. Referred to in the model as 'Develop', intermediate design phase process is focussed on considering a range of potential solutions and developing a range or series of solutions for consideration. The Develop step also comprises a range of techniques that can be used to imagine the success of identified solutions, including character profiles or personas, imagined use scenarios and various prototyping techniques. It is only after this phase that these potential solutions can then be tested and evaluated during the final phase of design (Deliver) before a final outcome has been finalised and agreed. During the final phase of design various prototypes may undergo testing and evaluation. The product may also be tested against particular standards or regulations. The proposed design outcome may at this point be tested by users to determine how accurately it matches their requirements. Evaluation in the final design phase explicitly focuses on decision making. Many technology design projects can be characterised as a series of decision making events, deciding what, why and how to design. In

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[10] Reproduced from: https://www.designcouncil.org.uk/news-opinion/double-diamond-universally-accepted-depiction-design-process – last accessed January 2018.

many design projects decision-making is a complex process and decisions made have a critical impact on the direction and outcome of that project. Decision making is a key process during the final phases of a design project where the focus is on evaluating potential solutions. During the final phase of design, the designer may be faced with the question "what is the best design?". They may be asked to 'validate' a solution, "is this the best fit for the problem?". The evaluation of a solution that hasn't quite been resolved may require the designer to 'navigate and unify', insofar as they consider combining features to propose a better alternative. Eventually to propose a final design there is a need to simply 'decide' (Hansen and Andreasen 2004).

In simple terms, the early phases of design focusses on the process of understanding the problem, the intermediate phases involve the creation and visualisation of potential solutions and the final phases require evaluation and selection of a potential design outcome. Considering this in terms of the Double Diamond approach described here, we can see that the early and intermediate phases of design are characterised by 'divergent thinking' while the evaluation phases constitute 'convergent thinking'.

2.3.2 User Centred Design Approaches[11]

Thinking around design has evolved since the 1960's, with theorists such as Christopher Alexander and others suggesting that the design of artefacts for humans is best informed by those for whom the technology is being designed (Alexander et al., 1977).

User centred design (UCD) and human centred design (HCD) emerged as terms used to describe a range of processes that focus on creating more effective and efficient solutions and systems for people that will improve human well-being, satisfaction and minimises the risk of potential adverse effects that may be sustained through its use. This is achieved by incorporating the human users' perspective in the design of the technology to ensure that the resulting solution is usable by its intended user and that all of the person's usability requirements have been met. UCD and HCD[12] has its roots in fields such as ergonomics, computer science and artificial intelligence and claims to offer substantial economic and social benefits for users, employers and suppliers through its rigour in assuring a high degree of fit between a product and the user. Products and systems that employ UCD methods should be easier to understand and use, reduce discomfort and stress and can be used by people with a wider range of

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[11] Appendix – provides a fill glossary of terms.

[12] Although some attempts are made to clearly differentiate the terms UCD and HCD they are often reported interchangeably across design and research literature. Within studies examining design with cohorts of people with disabilities including autism, UCD is the more commonly used term, as such, in the interests of clarity this thesis will continue using this as the preferred term.

capabilities (Giacomin, 2015). User-centred design has been driven or guided by the international usability standard, ISO 9241-210:2010 (Human Centred Design Process for Interactive System[13]) which specifies the principles and activities that underpin UCD:

- The design is based upon an explicit understanding of users, tasks and environments

- Users are involved throughout design and development

- The design is driven and refined by user-centered evaluation

- The process is iterative

- The design addresses the whole user experience

- The design team includes multidisciplinary skills and perspectives. (ISO-921-210, p5)

The rise in prominence of UCD has coincided with the rapid development of modern consumer computer and electronic products and has influenced the related areas of Human Computer Interaction and Interaction Design (Preece, Sharp & Rogers, 2015). UCD approaches attempt to develop a product or service around how users can, want, or need to use it, rather than forcing the users to change their behaviour to accommodate the product or services requirements (Goodman-Deane, Langdon, & Clarkson, 2010).

The popularity of such approaches suggests a consensus that designers should draw upon the experiences of the people they design for. This can ensure that the outcome of the design process will match the desires, abilities, needs and preferences of the eventual end-user (Visser, 2009). The behaviours of users are understood as contextual, embedded in day to day activity and shaped by motivations and feelings (Schuler and Namioka 1993). Accessing the experience and expertise of the anticipated end-user of a new product or innovation is seen as a key predictor in its future success (Bano & Zowghi, 2015).

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[13] This standard was last revised in 2015 and remains the current confirmed version of this international standard - for more information see https://www.iso.org/standard/52075.html
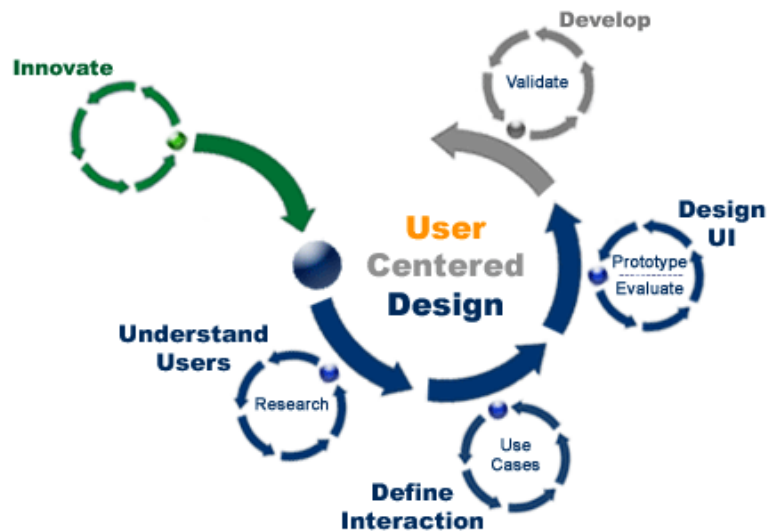
Figure 6: User Centred Design[14]

There has been criticism of this approach suggesting that the user is seen as the subject of the design and has minimal influence on the decision-making process (Sanders, 2002). This design approach has been said to relegate the role of the user to that of tester with a strong emphasis on gathering the opinions of users and implementing realistic testing at regular intervals throughout the design cycle (Chamberlain, Sharp, & Maiden, 2006; Salah, Paige, & Cairns, 2014). Furthermore, there has been criticism that a user-centred approach to design inevitably becomes "object-centric", focused exclusively on the product, ignoring the social, cultural and political milieu of the user and the range of other stakeholders that may be invested in the design (Donaldson, 2009; Janzer & Weinstein, 2014).

User-centred design has seen refinement of the model over recent years focusing on users and contexts with characteristics. In an education context, this approach is often referred to as Learner-centred design, where the 'user' is effectively replaced by a child as a learner and the context for the design is the classroom, school or place of learning (Parsons & Cobb, 2014). Another approach developed to guide design projects for people with disabilities is that of Ability Based Design, an approach that encourages designers to focus on users' abilities rather than disabilities.

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[14] Reproduced from https://www.designorate.com/ux-research-for-design-project/ - last accessed September 2018.
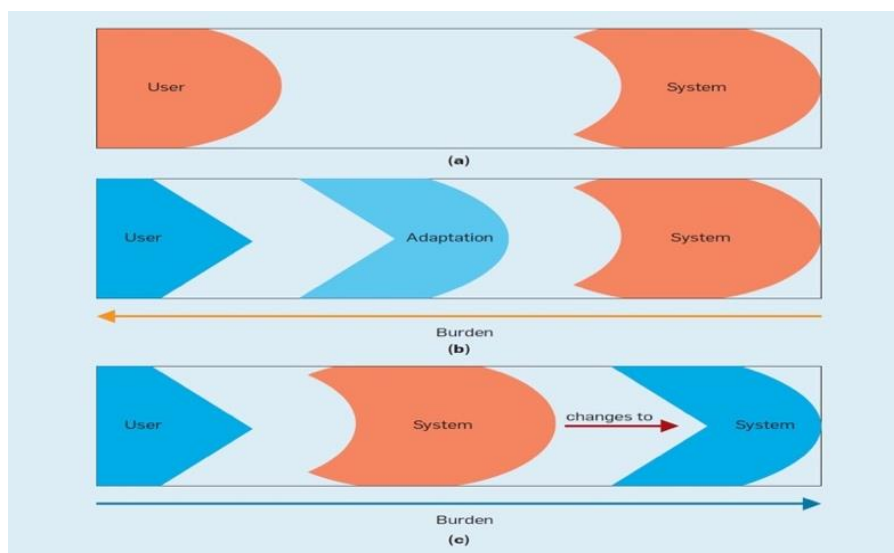
Figure 7: Abilities Based Design[15]

The aim is to build into the system efficient ways to make the system adaptive to their abilities. The system could adapt automatically, or, more commonly, the system has user-selectable options to make the system work effectively for a user's abilities (Wobbrock, Kane, Gajos, Harada, & Froehlich, 2011). This approach has been influential in the design of web-interfaces and assistive technologies for those with sensory disabilities. Similar approaches such as Design for All (DfA) and Inclusive Design aim to support the design such that the eventual product can be used by people with a disability (Keates, Clarkson, Harrison & Robinson 2000, Newell & Gregor 2000). The DfA approach differs from other design methodologies by extending the ambition of the design from one which focusses on the needs of a person with a disability to one which aims to develop products and services that can be used by as many people as possible without the need for adaptation (Stephanidis 1995). An Inclusive Design approach recognises that disability is a by-product of interaction with one's environment; as such, product design has the potential to 'enable' or 'disable' users. This approach stresses the need to design "a world that best matches the diversity present within a population" (Clarkson, & Coleman, 2013 pp 2).

A similar approach that has attracted increased interest in recent years is Universal Design, referring to a broad, ambitious and wide-reaching methodology that aims to produce buildings, products and environments that are inherently accessible to older people, people without disabilities, and those with disabilities.

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[15] Reproduced from https://cacm.acm.org/magazines/2018/6/228034-ability-based-design/fulltext – last accessed September 2018.
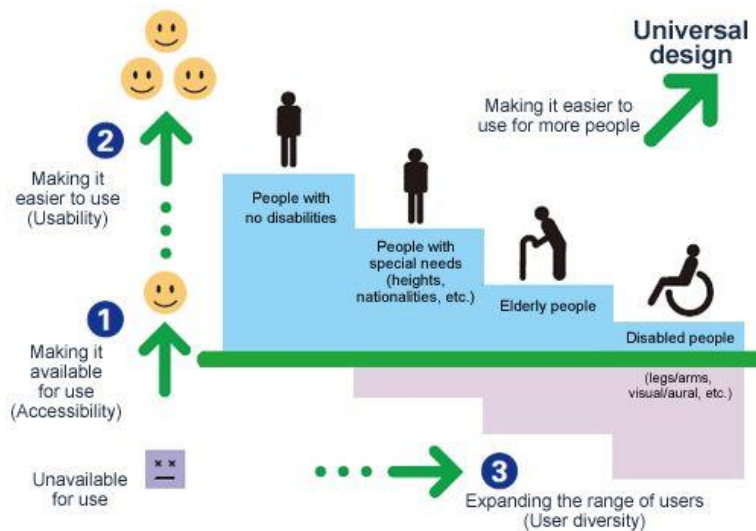
Figure 8: Universal Design[16]

In Ireland, this approach has been enshrined in the 2005 Disability Act where it is defined as; "the design and composition of an environment so that it may be accessed, understood and used, 1) to the greatest extent possible, 2) in the widest possible range of situations, 3) in the most independent manner possible and 4) without the need for adaptation, modifications or specialised solutions" (Government of Ireland, 2005, p. 46). Although lauded for its inclusive aspirations, this approach has been criticised as impractical offering scant recognition of the complexity of the design process or the unique needs of many people. It has also been criticised as an approach that is now bounded by concepts of accessibility, regulations and disability rights, rather than the intellectual challenges inherent in designing for the whole of the population (Bringolf, 2008). Furthermore, user-centred approaches to design are often criticised for being selective about the inclusion of people in the design of technology intended for their use.

An alternative approach which aims to assimilate end-users throughout the entirety of the design process is PD, also referred to as cooperative design or co-design, is characterised by its efforts to ensure the inclusion of numerous stakeholders including the end-user ranging in expertise, experience and ability. Most especially, PD aims to place the ultimate end-user of a design artefact at the heart of the design process and implicit in its outcome. PD, like UCD, constitutes a collection of methods and approaches rather than a single methodology. The difference between the two philosophies is summed up in the statement, user-centred design is design for users, PD is design with users (Sanders, 2002). PD practice aims to contextualise the design process by gathering and interpreting the real, lived experience of these stakeholders and

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[16] Reproduced from: http://access.ecs.soton.ac.uk/blog/training/universal-design/ - last accessed July 2018.

translating these into a set of characteristics that will ensure the future success of a new technology (Halskov & Hansen, 2015; Schuler & Namioka, 1993). Methods include design workshops, brainstorming, role-playing scenarios, prototype development, storyboards, and ethnographic techniques such as focus groups, interviews and observation. Sanders and her colleagues suggest organising such techniques into the following categories, 'talking, telling and explaining', 'acting, enacting and playing', and 'making tangible things', thus summarising the main purposes of the PD process. (Sanders, Brandt, & Binder, 2010). In emphasising democracy, mutual learning and empowerment as they key defining features of the approach, PD shifts the emphasis of design from the outcome to the process itself (Bossen, Dindler and Iversen 2016). As such, PD can be seen an evolution in thinking that considered moving from designing *for* users to designing *with* users.

2.3.3 Participatory Design

This section will outline the historical context of PD and elaborate on some of the processes that comprise this design approach. Attention will be paid to outlining how the emphasis on ensuring participation through the design process serves to make PD a popular choice amongst those seeking to include children with disabilities including autism in design projects.

PD originated from the work of Kristen Nygaard and Olav-Terje Bergo with the Norwegian Iron and Metal Workers Union in the early 1970's where the focus of research and design shifted to emphasise the active collaboration between users and designers in the construction of technological alternatives with and for future users. The approach attracted significant attention outside of Scandinavia, particularly in North America (Bodker & Pekkola, 2010). Over the past four decades. recognition of the centrality of user participation to technology development has become the mainstay of design practice (Yankee Li 2008). PD has increased in popularity and breath across a range of research disciplines including human computer interaction, information systems and more recently the design of technology solutions for children with disabilities. It appears likely that the diversification in application of PD reflects recent, rapid technology developments across various domains and contexts (Halskov & Hansen, 2015). PD offers designers a methodology for accessing the experience, needs, tacit knowledge and preferences of participants and seeks to bring this to bear on the design process. Drawn from a similar theoretical and historical background as user-centred design, PD seeks to ensure that the prospective technology end-user is not just the focus of the

design process but also is an active contributor right through the process. PD grew out of an active tradition of directly involving people and professional designers collaboratively in the design of artefacts, environments and technology that shape their lives. This approach emphasises 'genuine' participation in terms of transforming the role of the technology user from informant to acknowledged contributors to the design process. Instead of merely answering questions or expressing opinion, users are seen as creative contributors who are empowered to sketch, draw, describe their own vision of a design outcome. Sometimes referred to as 'co-realisation', a PD approach puts great emphasis on collective involvement in design (Bratteteig, Bødker, Yvonne, Mogensen, & Simonsen, 2013). Collaborative workshops for designers and users have developed a range of techniques including mock-up's, prototyping and a variety of design games to create spaces that support participants in visualising, simulating, articulating and experimenting with envisioned, future technology.

A defining feature of PD is the collaborative nature of the process emphasising the mutual engagement of designers and end-users and a respect for shared decision making. Where the focus for user-centred design typically focuses on a single, model-user as the representative focus for design, PD seeks to capture the experiences of all stakeholders through all phases of design (Sanders, 2002). Furthermore, PD seeks to democratise decision making and design contributions throughout the process by providing participants with the appropriate tools with which to express themselves and empower them to be articulate and creative, facilitating the generation of new ideas and thinking (Wilkinson & De Angeli, 2014). In technology development using a PD approach there is an emphasis on the involvement of a broad group of stakeholders rather than a small number of user representatives. As with the related field of participatory research, PD practice is guided by several factors; 1) participants are responsible for problem definition, analysis and solving it, 2) inclusion of potential end-users provides an authenticity and greater accuracy to the design process, 3) participation should result in a greater understanding of the participant's own strengths, and, 4) the central objective of PD for people with a disability is to improve their quality of life (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998).

2.3.4 Participation in the Early Phase of Design

At the outset of a design project, PD concerns itself with understanding not only the eventual end-user of the technology in question but the context within which it will be used and the processes and practices therein (Robertson & Simonsen 2015). PD differs from other

UCD approaches in its concern for ensuring that the end-user is fully represented in defining the possible requirements of a design. In order to accurately represent the end-user in design requirements, it is incumbent upon the designer to fully understand the user from their own perspective. Often referred to as the person's 'lived experience', this construct is highly subjective and personal and as such cannot be directly accessed. It is a representation of the person's experiences, choices and other factors that contribute to their self-perception and actions (Barrow, 2017; DePape & Lindsay, 2016). When describing this within the context of design, Spinuzzi refers to a person's lived experiences as 'tacit knowledge' referring to the implicit, holistic knowledge that is often difficult for participants to articulate, but is of immense value in informing and guiding the design process (Spinuzzi, 2005).

PD depends upon the transfer of experience, expertise and tacit knowledge from the end-user to the professional designer and the translation of this data into design requirements that influence the design product. For participants who do not have a design background or expertise, PD offers opportunities for designers to similarly share their knowledge. Referred to by Bratteteig et al. (2013) as 'mutual learning', understanding the lived experience of the user is based on the premise that they know most about their own needs and preference and crucially the activities and context into which the system will be embedded. Such mutual learning helps to expand non-designers' vision of the potential applications and opportunities may offer (Simonsen & Robertson, 2012).

Developing an understanding of the user and their context requires the use of tools and techniques that help different participants to effectively express their needs and visions. Historically, PD projects have and continue to develop and evolve tools such as training programmes, paper based mock-ups, collaborative workshops, interviews and questionnaires etc., that support the expression and capture of user and context data that can inform the design process. The development and articulation of specifications of new technology is increasingly underpinned by rigorous ethnographic methods (Robertson & Simonsen 2013). Observation techniques such as user observation or field studies (Hussain, Sanders, & Steinert, 2012), narrative or discursive techniques such as storytelling (Bedir Erişti, 2016; Nielsen & Madsen, 2006) structured interviewing (Luck, 2003) and focus groups (Langford & McDonagh, 2003) and reflective techniques such as using diaries or journals (Franqueira, Gomes, & Gonçalves, 2013) , have all been used, modified or developed in previous design projects.

2.3.5 Participation in the Intermediate Phase of Design

The intermediate phase of design is characterised by the creative efforts to imagine what the proposed product or software looks, feels and acts like. In typical software design projects, it is during this phase that designers begin to assimilate all that they have learnt and understood about the problem in question, the imagined end-users and the context in which it will operate. In co-design projects, this is an opportunity for designers and non-designers to collaborate and communicate with creative purpose, with a view to finding and negotiating a solution and creating a shared understanding of how the outcome might look like and function. The creative expressions of non-designers can be incorporated into various elements of the final software interface or may support interaction. Capturing and translating their creative contributions is a significant way of demonstrating their impact on the design process but also contributes to their sense of ownership and agency in the project. Capturing the creative contributions of non-designers and incorporating these with those of professional designers is referred to as co-creation.

Co-creation refers to any act of collective creativity, i.e. creativity that is shared by two or more people. The practice of collective creativity in design has been a constituent of PD since it emerged as an approach to design practice in the 1970's. It seeks to provide participants with the appropriate tools with which to express themselves and empower them to be articulate and creative, facilitating the generation of new ideas and thinking (Wilkinson & De Angeli, 2014). In many instances the use of the terms co-creation, co-design and even (PD) are used synonymously. Drawing on historical sources over the past 40 years Sanders and Strappers (2008), suggest that the term co-design refers to the all collective creative processes as applied across the entirety of the design process. As such, for the purposes of this work, co-creation will be how the creative generation of artefacts that contribute to the design outcome will be referred to. Embracing co-creativity infers a belief in the intrinsic creative abilities of all people. Historically, within design processes expressions of creativity were considered the domain of professional designers with other stakeholders relegated to the role of informant or evaluator. Democratising power relations in a design team requires that the person(s) identified as a potential end-user of a design solution must be given the tools to develop and articulate ideas about possible technology designs and to concretise these ideas through sketching or prototyping (Bratteteig & Wagner, 2012). Researchers have developed and adapted traditional brainstorming techniques to support the creative expressions of novice designers such as through the use of video supported brainstorming workshops (Mackay & Fayard, 1999) and

using comics to scaffold idea generation and elaboration. Collaboratively working on developing a prototype app interface provided the platform for design and entrepreneurship students to work and learn together drawing together technical knowledge with an understanding of market and retail conditions thus ensuring a better final product (Kang, Choo, & Watters, 2015).

2.3.6 Participation in the Final Phase of Design

In the latter phase of technology development, designers will often seek the experiences and opinions of others to gather further information as the capacity of their proposed system to meet its intended purpose. The value of seeking the opinions and experiences of others prior to finalising a design came to prominence in user-centred design processes as a way of identifying potential problems and rectifying these. Commonly referred to as usability testing or user-testing, designers will in some instances seek the opinions of experts (usability inspections) or will seek people who best represent the intended audience for the proposed product or system. User-testing involving the potential users of a system is not limited to seeking the opinions of those who may eventually use it, rather it is a methodology for determining the ease of use of the system, the consequences of its use and to identify potential problems that may emerge under different conditions of use. In gathering this level and detail of information, designers will often seek to use a range of techniques to gather users' opinions and experiences. User-testing includes systematic observation of the person using the product or system under highly controlled conditions. Designers will often engage users in detailed interviews or focus groups to gather further opinions or interpretations. The gathered data is then considered with a view to making further decisions that will inform their immediate and future course of action as they proceed to their goal of producing a successful outcome (Unger, 2012).

Considering the 'empowerment of participants' as another key cornerstone of PD, there is a need to examine how such empowerment translates into design practice. The empowerment of participants in PD refers to a disposition and a willingness to share power with others, especially with prospective 'users', and to 'let go' of control. As such empowerment can be seen to reflect the extent to which decision-making is devolved or transferred from designer to participant (Steen, 2013). Furthermore, PD aims to 'democratise' the process of design, as such the devolution of decision making must be seen as meaningful, providing participants with true power to influence the direction in which the design process takes and

the final realisation of the design outcome (Björgvinsson, Ehn, & Hillgren, 2010; Shapiro & Euchner, 2016).

2.3.7 Degrees of Participation in design

As mentioned at the outset of this chapter participation as a construct refers not only to a child being in attendance but also refers to the degree to which the child is involved. This is often predicated on the extent to which a child's voice is listened to and their decision making is respected. Participation in the context of a design process has been more difficult to define and poses questions such as 'how democratic is decision making' and 'how much empowerment suggests adequate participation'? Attempts to measure the degree to which a person 'participates' are rare and remain challenging due to the bespoke nature of PD projects (Bossen, Dindler & Iversen 2016). In refining the construct of participation as it is manifest in a design project, Segalowitz describes three dimensions; 1) impact, 2) influence and 3) agency. These three expressions merit further examination with a view to understanding the degree to which participation is experienced in a design project.

In her framework, *impact* as a component of participation is viewed as the quality and use of user information. Participants are said to 'impact' the direction of a design project through their contributions. In her elaboration of the concept of impact as a constituent of participation, Segalowitz suggests that although the contribution of knowledge and creative content to design could be seen as a measure of the person's participation in the design process, that this was limited and a further measure was required, i.e., an appreciation of the quality of the contribution. That is to gain an appreciation of a user's impact in a design project, then we must examine the quantity of their contributions and how those contributions were used. The concept of impact underpins two elements of PD; that of the transfer of tacit knowledge (Spinuzzi, 2005) and the democratisation of creativity in design (Björgvinsson et al., 2010). As such, this impact that a user has on the design process requires firstly that the design team adequately capture the needs, preferences and use features from the child, and that secondly, the contribution of creative, design ideas may be seen as the active transfer of tacit knowledge from the user to the designer. Finally, impact also requires that this information is of sufficient quality to allow the designer to transform it to an element of the design.

Influence refers to a measure of the amount of power that a participant brings to bear on the project that they participate in. In traditional PD processes, such influence can be seen in

a range of associated behaviours, for example participants will influence the course of a design project through informal conversation, evaluation, informal meetings and elaboration of reasons for decision. In outlining influence as a dimension of participation, Segalowitz states that influence does not describe the power endowed on a participated through their professional background, their pre-assigned role, or other external influences, rather it is about the participant's ability to wilfully direct the nature and course of a project. She continues to describe the process of decision making in the context of a design project as a manifestation of a person's influence. *Agency* refers to a person's capacity to effectuate their decisions and have these decisions accepted. In this understanding of agency as a constituent component of participation, then agency represents the social context that enables a participant to act. Agency differs from both impact and influence by its focus on the social capacity the participant brings enabling them to affect change within the project (Segalowitz, 2012).

2.4 Summary

Despite rights enshrined in international legislation, children with autism often remain excluded from participating in decision making that directly impact on their lives, including consultation regarding policymaking and service design and delivery (Sinclair, 2004; Morrow, 1999). This research focuses on one specific representation of participation for children with autism, namely; participation in the technology design processes that aim to create new technologies to support their education, therapy and their vocational and leisure choices. This chapter provides an overview of 1) what is understood as participation, 2) what is meant by a diagnosis of autism and how this impacts a child in their day to day life and 3) the human-centred processes by which technology is designed. The chapter discusses a range of design approaches that focus on the participation of the end-user including, abilities based design, user-centred design and universal design. These approaches emphasise the involvement, to varying degrees, for technology end-users through the early, intermediate and final phases of the process of design. This chapter concludes with an examination of how another user-centred approach, PD, emphasises the involvement of technology end-users in a manner that ensures they can contribute not only to the design outcome but also a key role in determining the nature and direction of the entire design process. Such an approach differs from other user-centred approaches by ensuring the provision of opportunities for participation of the end-user across the entirety of the design process.

The degree of participation experienced in a design project is of relevance when examining the roles of children with autism in technology design. Frequently side-lined from such activities due to the limitations inherent with their condition they risk inclusion by manipulation or tokenism (Krieger et al., 2018). The following chapter will provide a detailed examination of the participation of children with autism in the process of technology design.

Chapter 3: Literature Review

The merits of inclusive design of technologies is increasing but often people who have physical and intellectual disabilities associated with conditions such as autism are still excluded from technology use and design due to their unique physical, cognitive and sensory needs (Harris, 2010). Designing with children with autism is not a straightforward process by any means. Typical design processes involve identifying the needs; demands and opinions of users and often depend on interviews and discussion. The underlying assumption is that the representative user is both willing and able to communicate freely and transfer knowledge and opinion (Herriott, 2015). The combination of a lack of clarity regarding their role, unequal power relationships, difficulty in communicating ideas, and dealing with adults in a largely unfamiliar context presents a range of challenges requiring a balanced and empathetic approach (Frauenberger et al., 2011).

Nonetheless, there are benefits to placing the child with autism at the centre of the design process, in terms of an improvement in the design outcome (Fletcher-Watson, 2014), mutual learning and empowerment (Bell & Davis, 2016). It has been reported that involving end-users in the design of technology can improve the quality or speed of the design process, produce a better match between a product or system and its end-user and can positively influence user satisfaction and buy-in (Kujala, 2003). In spite of the clear challenges faced when designing technology with children with autism, it is often this group that stand to benefit the most from their active inclusion and contribution (Frauenberger et al., 2011).

This chapter will examine the participation of children with autism in the design of technology. This will be done by 1) examining the literature that reports on previous studies that described the participation of children with autism in design, 2) outlining a series of methods and techniques to support those children with the most complex presentation of autism, and 3) presenting a mechanism by which the experience for these children's participation can be examined.

3.1 Participation in Design for Children with Autism: Examples from Literature

The inclusion of children of children in the design of technology has attracted increased attention over the past number of years. A comprehensive analysis of this literature provides

insights as to the roles children play in the design process, the opportunities offered to them across the different phases of the process and some of the methods and techniques used to support their participation. This section provides an analysis of this literature, examining the methods used or adapted to suit the varying needs of children with autism as design participants.

3.1.1 Role of Children with Autism in Design

When examining the participation of children with autism in a design process it is important to understand the roles that they can potentially play in such a process, notwithstanding the nature and severity of the disability as it presents and the availability and intensity of the support available. To understand the roles children with autism and other disabilities might play in design, Mona Leigh Guha and her colleagues developed an Inclusionary Model of Designing with and for Children with special needs by combining best practices in inclusive education with information from previous design work with children (Guha, Druin, & Fails, 2008). This model draws heavily on Druin's work on designing with children and from her work on levels of involvement (Druin, 2002). In articulating this model, Guha and colleagues suggest different levels of involvement relative to the disability of the child. These roles include 1) informant, 2) design partner, 3) tester and 4) user. This aligns somewhat with the objectives of typical design process where early phases depend on gathering information about the user and their context, an intermediate phase characterised by articulating creative solutions and the final phase which focusses on evaluation of those potential solutions. The inclusionary model suggests different levels of involvement relative to the severity of the child's autism and the availability of supports. For example, the suggested role that children on the autism spectrum consider is that of 'tester'. This is based on the role identified for children with autism in the work conducted by Pares and colleagues (Parés et al., 2005). In other studies, we also see children with autism take on the role of 'tester' providing a valuable role in the evaluation of potential prototypes. Guha's inclusionary model however goes on to suggest that careful use of appropriate supports can extend the role of the child beyond simply evaluation. This is borne out in the literature where the role children with autism play in the design of technology is not restricted to evaluation but can be seen across the various design phases including that of "informants" in design (Avramides et al., 2012; Frauenberger, Good, & Keay-Bright, 2011; Millen, Edlin-White, & Cobb, 2010) and as "design partners", contributing their creative potential to the process. As such although the nature and severity of a child's autism must be considered in terms of the role they might play in a design process, so too must the potential opportunities that can be provided and the availability of the

required supports[17]. The risk when isolating the role of a child with autism in this manner is that it potentially limits or restricts their opportunities to engage and participate in the broad range of processes that comprise a design process. For example, considering the child as an informant risks that their contribution is limited to the early phases of design and minimises their influence on the evaluation of solutions and its eventual outcome. For children with more complex presentations of autism, identifying discrete participatory roles in this manner may be more problematic. Difficulties in communication and intellectual ability for example will impact whether they are considered a 'tester'. In such circumstances, the role of 'key-informant' has been suggested to describe contributions made by children with autism throughout the design process that shape and impact the process while leaving the responsibility for decision-making with adults (Keay Bright 2007a, 2007b).

3.1.2 Approaches that Support Participation

Recognising the limited experience designers might have working directly with children with autism, Van Rijn and Stappers (2008) developed a series of guidelines to assist in understanding the preferences of children in their environments. Developed from their understanding of children with autism the guidelines are not a list of prescriptive techniques but rather act as a series of statements that ensure that their specific needs are addressed so that they can actively participate in design activities. These guidelines include (but are not limited to) the following; 1) give children a sense of being in control, 2) provide a structured situation, 3) make use of their special interests, 4) let them use their whole body (van Rijn & Stappers, 2008).

Recognising the heterogeneity of symptoms presented in different children with autism these guidelines emphasise the importance of creating a context for the design process that matches with the specific needs of participating children. This is something that Benton's IDEAS (An Interface Design Experience for the Autism Spectrum) method clearly articulates when ensuring that design approaches are informed not only by the presentation of children's symptoms

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[17] Guha and colleagues makes the point that if appropriate adult support is available to children with more profound disabilities their involvement could be maximised. Additionally, the model considers varying the child's involvement at different stages of development depending on the child's ability and a realistic assessment of their potential to add value to parts of the design process. The importance of this level of analysis and deliberation in terms of the child with a disability's role in the design process helps to guide the balance of power in decision making and results in a fair expectation of the child's contributions based on their abilities (Guha et al., 2008).

but also by what she refers to as the culture of autism (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012b). This model is fully outlined later in this section of this chapter.

During the development of an educational, collaborative, virtual environment entitled CoSpatial, the associated, multidisciplinary researchers sought to adapt PD methodologies to allow the involvement of children with autism and their teachers (Cobb, 2010; Laura Millen, Cobb, & Patel, 2011a; Parsons, Millen, Garib-Penna, & Cobb, 2011). Recognising that children with autism may have; 1) limited language and communication skills, 2) poor imaginative skills, 3) rigidity of thought process, 4) 'theory of mind' challenges and 5) learning difficulties, the design team, following consultation with teachers, structured prototype evaluation workshops that were focussed and supported by tools such as visual feedback sheets. This was further developed into a six-step process to support children with autism in a 'design a game' task. The method, tools and materials supported children, participating in design focus groups, to represent their thoughts regarding a proposed game both verbally and through drawings (Laura Millen, Cobb, & Patel, 2011b). The workshops that underpinned the design of the CoSpatial virtual environment comprised a broad range of stakeholders including teachers, autism experts, computer scientists, designers alongside children with autism and typically developing children. The process focussed on drawing upon individual stakeholder expertise at varying times across the design and development of the system. The collaboration of children with autism was actively structured by focussing activities thus reducing the demand on their imaginative skills. Furthermore, social communication challenges were addressed using supports that prompted and facilitated verbal communication amongst participants and provided alternatives such as drawing. These behaviours do however require a degree of cognitive and developmental skills that is often beyond the abilities of children with more complex presentations of autism including those with intellectual disabilities.

Guided by the TEACCH[18] programme for children with autism and traditional PD methods, the IDEAS method was devised to support the participation of children with high-functioning autism in technology design (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012a; Benton et al., 2012b). This method is built around a series of structures and supports to be used by designers to facilitate collaborative participation for children with autism.

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[18] TEACCH (Treatment and Education of Autistic and Communication related handicapped CHildren) is an evidence-based service, training, and research program for individuals of all ages and skill levels with autism. Established in the early 1970s by Eric Schopler and colleagues with a view to improving the quality of life of people with autism and their families (Mesibov et al., 2004).

IDEAS

Organisation of Physical Environment	Predictable Sequence of Activities	Visual Schedules	Routines + Flexibility	Structured Work/ Activity Systems	Visually Structured Activities
Quiet/Familiar environment	Explanation of activities/goal setting at start	Visual schedule of design activities	Consistent routine of checking off activities	Visual/verbal explanation of activities	Visual activities
1:1 adult support for sensitivities	Sequence of activities displayed throughout	Child checks off completed activities	1:1 adult support to tailor session structure to child's needs	Track progress through checking off activities	Visual recap of previous session
1:1 adult support for engagement	Recap at start + summary/intro to next session at end	Includes date, time, team name, participants + rules	Structured design templates	Discussion activity	Transfer ideas quickly to computer-based prototype
	Consistent structure across sessions	Schedule used by adults to reengage children	Consistent session + activity-level structure	Demonstration of existing technology	Visual templates
	Sessions weekly + same time/place		Multiple modes of expression	Themed to hobbies and interests	
			Staged idea generation	Content appropriate for children's ability	
				1:1 adult support for ideas + collaboration	

Figure 9: The IDEAS Method for children with high-functioning autism[19]

The authors of this work have developed this framework further and examined its application in supporting participation for children with autism and typically developing children. Used as a framework for the PD of game based mathematics software this method showed inconsistent benefits across different groups of children with some requiring more support than others, highlighting the need to develop a broad range of tools and techniques that could potentially comprise a 'toolbox' for designers to match with the needs of specific children (Benton & Johnson, 2014). In part recognising that children with autism only represent a small proportion of what is increasingly becoming known as the 'neurodiversity[20]' community, the IDEAS method has evolved further to address the broader design participation needs of this community. The D4D, or 'Design for Diversity' model aims not only to build support for 'neurodiverse' children

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[19] (from https://laurajbenton.wordpress.com/the-ideas-method/ - reprinted with permission)

[20] Neurodiversity is concept and movement that is concerned with recognising the diversity of neurological presentations. The concept emerged in the 1990's as a challenge to what was seen as the prevailing medical model view of disabilities such as autism, attention deficit hyperactivity disorder (ADHD), Asperger's Syndrome, Dyspraxia and Intellectual Disabilities. One of the main objectives for the movement that has grown up around the concept is to see the presentation of such conditions not as a disability but rather as a broad spectrum of the human condition in the same manner as ethnicity or sexual orientation.

but also draws on their particular strengths and abilities (Benton, Vasalou, Khaled, Johnson, & Gooch, 2014a).

The D4D Framework and the IDEAS Method are based on the TEACCH principles and suggest that the designer should; 1) understand the culture of the user (in this case the child with autism), 2) tailor the process to the skills, aptitudes and interests of the child, 3) structure the environment to support a child's understanding and learning and 4) provide supports for each child (Benton et al., 2014a). Both, these approaches have been used in projects with children with high-functioning autism, dyslexia and attention deficit hyperactivity disorder (ADHD) and have successfully established a range of techniques and methods that foster greater collaboration and communication between the child with autism and adult designers. With these methods there remains a high level of verbal interaction between participating children and adult designers with little evidence of their application with children with more complex presentation of autism such as those with limited communication skills or intellectual disabilities.

Over the past number of years' studies have reported on a broad range of approaches, methods and techniques that have focussed on developing or adapting methods from traditional PD practice to facilitate design participation for children with autism. Drawing upon the philosophical traditions of phenomenology it is suggested that PD practices with children with autism should be concerned more with the user's experience rather than the eventual design outcome. Furthermore, they have stressed the importance of understanding and valuing the user's context and their existing interactions with the objects they use. Within their work on the ECHOES project[21] this team utilised such a stance to inform not only the process of understanding the end user but also as a mechanism by which to better interpret the creative input of participating children with autism (Frauenberger, Good, & Keay-Bright, 2010). Researchers on the ECHOES project developed a multidisciplinary design methodology combining Action Research for Education, PD methods and Artificial Intelligence to guide the development of a technology enhanced learning environment (Porayska-Pomsta et al., 2010). An emphasis on the need for building relationships between adult participants and children with autism in design projects and finding creative and flexible mechanisms to support communication are highlighted as factors in ensuring successful participation (Frauenberger, Good, & Alcorn, 2012).

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[21] The ECHOES project was an Economic and Social Research Council (UK) funded project which aimed to develop a multimodal virtual environment to address social interaction skills for children on the autism spectrum - https://www.ucl.ac.uk/ioe/research-projects/2018/oct/echoes-project

Successive projects have demonstrated a value in modifying traditional PD techniques and tools and when required further adapting and re-interpreting these to match the characteristics of the child with autism. Frauenberger and his colleagues illustrate the selection of an appropriate repertoire of tools and techniques using a case-study of an 8-year-old girl with autism. Furthermore, the authors describe how selected processes were tailored on a continuous and iterative basis throughout their design work together. This highlighted the value of understanding the user in terms of her abilities and her interests. This understanding was facilitated first through contextual interviews with her family, teacher and mentor but also through careful and deliberate observation (Frauenberger, Makhaeva, & Spiel, 2017). This further emphasis on drawing upon a child with autism's strengths, abilities and preferences highlights the importance of developing a full appreciation of the user and their context in the early phase of design.

Drawing from PD traditions, Malinverni's 'inclusive design approach' employed in the development of a Kinect™ game for building social skills for children with autism sought to incorporate the expertise of clinicians, the creative contributions of children and the experience of designers. In designing the game, the participation of children with high-functioning autism focussed on techniques to identify their interests and preferences, their opinions regarding the mechanics of the game and their evaluation of outcomes. As with similar projects, the researchers focussed on using resources such as 'scene cards' to elicit narrative contributions from children with autism regarding narrative elements and game mechanics. Further techniques identified children's likes and preferences (to contribute to the game's reward system), and evaluated which elements of the game design contributed to a higher level of motivation and engagement (Malinverni et al., 2017).

Although the model described here has been developed specifically to support the inclusion of children with autism in design, its application across the spectrum of children with autism is limited by its reliance on the use of narrative to gather an understanding of the child's likes and preferences and to capture their creative contributions. Supporting narrative participation alongside adults may be an inclusive approach for some children with autism but remains restricted in its application to a narrow cohort of the overall autism population (Mora Guiard et al., 2014).

Studies involving children with more complex impairments of communication and intellectual functioning are significantly rarer (Börjesson, Barendregt, Eriksson, & Torgersson, 2015). This may be because of the perceived challenges that the nature and severity of disability presents designers in terms of integrating them within a design process and maximising their

potential contribution. Examples of work with children with such challenges are by no means absent and can inform us as to potential mechanisms for involving children in design without relying on traditional methods based solely on narrative discourse.

The Reactive Colours Model was developed to enable the participation and collaboration of children with autism in the design of the ReacTickles software and comprises a four-stage iterative cycle, namely; 1) research, 2) inspire, 3) listen and 4) develop. This four-stage cycle was applied across the various phases of the development of this software aimed at supporting play activities for children with autism. The development on this project describes the importance of understanding the context and the value of spending time with children in their classrooms naturally engaged in activities that might inform the design project. For example, an early phase of the design involved observing children in free-play and using computers in their school classrooms as part of the process of establishing a design concept for the project and informing the process of developing early, low-fi prototypes for consideration. This project emphasised a 'tangible' approach to the participation of children with autism in cycles of prototype testing where observation by adult members of the research team could quickly identify successes and areas for change (Keay-Bright, 2007).

Within the literature this work is one of the first examples that demonstrates that the participation of children with more complex presentations of autism are included in technology design projects despite the challenges that the paucity of social communication skills poses for adult designers. This contrasts with earlier efforts to utilise children with high-functioning autism in technology development projects as proxies for those with more severe symptoms (Parés et al., 2006). We see two important ingredients that work for designers to ensure participation of children presenting with symptoms right across the autism spectrum; 1) contact with children in their own context as a means of achieving empathic understanding, and 2) guidelines on an operational level to help them translate that understanding into design ideas and concepts. This is of relevance to the processes in early phase design which are centred on identifying the correct user requirements for the envisioned system. This will be discussed in some further detail in the next section of this chapter when we examine techniques and tools for supporting the participation of children with autism through the early phases of a design process.

3.1.3 Techniques to Support the Participation of Children with Autism in Design

In the previous section we examined a range of PD methods and approaches that aim to facilitate designers and researchers wishing to include children with autism in their technology

design projects. What will now follow is a more in-depth consideration of the participatory techniques reported in the literature. These techniques will be examined as to how they assist designers to engage in collaborative, participatory practices with children with autism through the early (requirements gathering), intermediate (design) and final (evaluation) phases of the design process. Table 2, below summarises these findings, outlining the authors of the study, the design objectives of the study and a summary of the techniques used across the various phases of the reported design process. A full examination and discussion of these techniques will be provided in the forthcoming sections.

Table 2: Summary of literature describing the participation of children with autism in technology design projects

Author	Design Objective	Role attributed to child participants	Methods & Techniques for Early Phase Design	Methods and Techniques for Intermediate Phase Design	Methods and Techniques for Final Phase Design
Argawal, Sampath, Indurkhya, (2013)	Kinect™ Interaction	Tester	x	x	Usability Study, System trial
Bai, Blackwell, & Coulouris, (2015)	Augmented Reality App	Tester	x	x	Observation[22] Video Analysis
Bartoli, Garzotto, Gelsomini, Oliveto, & Valoriani, (2014)	Kinect™ Games	Informant Tester	Observation	x	Prototype Testing
Benton et al., (2012a)	Education software	User Informant Design Partner Tester	Observation Ideas generation workshops	Lo-fi prototyping Creative workshops	Prototype testing
Benton, Vasalou, Khaled, Johnson, & Gooch, (2014b)	Mathematics/Education software	User Informant Design Partner Tester	Observation Ideas generation workshops	Lo-fi prototyping Creative workshop sessions	Collaborative, iterative evaluation Observation Discussion
Bossavit & Pina, (2013)	Educational Software	Tester	x	x	User testing
Boster & McCarthy, (2018)	Communication app	User Tester	Observation Adult Focus Group (Proxy)[23]	x	Prototype Testing[24]
Boyle & Arnedillo-Sanchez, (2016)	Kinect™ Games	Tester	Expert interview	x	Prototype Testing Observation[25] Expert Review Proxy Reporting

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[22] No changes made based on user-feedback
[23] Speech and Language Therapists and parents of children with autism participated in user requirements workshops.
[24] No changes made based on user feedback
[25] Iterative design process to support design development following prototype testing

Christiansen, Brooks, Petersson Brooks, & Rosenørn, (2014)	Virtual Dressing Room	Informant Tester	Questionnaires	x	User testing
Cooper & Ireland, (2018)	Communication software for non-verbal children	Informant Tester	Observation Expert consultation	x	x
Constantin, Johnson, Smith, Lengyel, & Brosnan, (2017)	Software reward system	Tester	x	x	User-testing
Escobedo, Ibarra, Hernandez, Alvelais, & Tentori, (2014)	Smart objects	Informant Tester	Observation in class	x	Video recording
Fabri, Elzouki, & Moore, (2007)	Emotion Recognition Learning App	Tester	x	x	Questionnaire Research/Evaluation Tools
Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, (2016)	iPad app for Social Skills	Tester	x	x	Observation User-testing
Foss et al., (2013)	Browser based computer game	Design Partner	x	Co-design workshops with adult support	x
Frauenberger, Makhaeva & Spiel, (2017)	Smart Object	User Informant Design Partner Tester	Reports on adaptations to collaborative methods	Reports on adaptations to collaborative methods	Reports on adaptations to collaborative methods
Guldberg, Parsons, Porayska-Pomsta, & Keay-Bright, (2017)	Collaborative Virtual Environment	Informant	Digital stories	x	x
Hamidi, Baljko & Gomez, (2017)	Digital living media system	Tester	Adult proxies used to inform requirements identification[26]	x	Prototype testing[27]
Hong et al., (2010)	Organiser software app	Informant	Video Diaries	x	x
Keay-Bright, (2007)	Play based software apps	Informant Design Partner	Observation in context (extended)	Child informed the direction of the project, but adults remained responsible for decision making	x

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[26] Adult proxies included Speech and Language Therapists and parents of children with autism
[27] Three prototypes used as design probes to support iterative design

Meter & Hasirci, (2018)	Trampoline	Informant	Observation Questionnaires Interviews	x	x
Malinverni, Mora-Guiard, & Pares, (2016)	Kinect™ motion-based game	Design Partner	x	Scene Cards Cliffhangers Paper based props[28] Storyboarding	x
Malinverni et al., (2017)	Therapeutic games	Informant Design Partner Tester			
Millen et al., (2011a)	Collaborative Virtual Environment	Design Partner Tester	x	Scenario Design Personas	Prototype testing
Munoz, Morales, Villarroel, Á, & Albuquerque, (2019)	'Theory of Mind' software app	Tester	x	x	User Testing
Parsons, Millen, Garb-Pen & Cobb (2012)	Collaborative virtual environment	User Informant Design Partner Tester	Multi-stakeholder collaborative workshops	x	Prototype Testing[29] Observation Verbal Feedback
Parsons, Guldberg, Porayska-Pomsta, & Lee, (2015a)	Collaborative virtual environment	Design Partner Tester	x	Creative workshops[30]	User testing Observation
Piper et al., (2006)	Tabletop social skills game	Informant Design Partner Tester	Structured Observation using technology Individual Interviews Group Interviews	Lo fi prototyping Brainstorming Group interview	Prototype Testing Observation Post-test questionnaire
Poroyska-Pomsta et al., (2012)	Technology enhanced learning environment	Informant Design Partner Tester	Sensory Exploration Idea Generation Knowledge Elicitation Workshop (with experts)	Storyboarding (with experts) Role Play (with experts)	Interaction testing

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[28] Used as tools to support children's expressions to capture a game narrative
[29] Prototype testing inferring changes made based on feedback from children
[30] Collaborative workshops with a broad range of stakeholders

Ringland et al., (2014)	Therapeutic (sensory integration) software	Tester	Expert consultation	x	User testing
Tang, Jheng, Chien, Lin, & Chen, (2013)	Educational software	Tester	x	x	User Testing
Van Rijn & Stappers (2008)	Educational technology	Informant Tester	Observation		Prototype testing
Weiss et al., (2011)	Social skills training app	Tester	x	x	Usability testing[31] Expert Review

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[31] No change to design solution based on user/expert feedback

3.1.4 Supporting Participation in the Early Phases of Design

In human-centred design projects the designer is tasked with the responsibility of developing a series of requirements that will inform the development and testing phases of the process and will ultimately determine the outcome of the project. In the case of technology design projects, these requirements pertain to the user and his or her context of use. In so doing, the designer aims to align the eventual outcome with the needs and preferences of the user and the conditions and requirements of the context in which the technology will operate.

In the case of PD projects involving children with autism a range of methods and techniques have been developed and, in some instances, modified or adapted to match their needs. A broad range of techniques and accompanying tools are detailed alongside how they benefit the designer in better understanding the child with autism and the nature of context they are in. The use of questionnaires (Christiansen et al., 2014), video diaries (Hong et al., 2010) and user-requirements interviews (Piper et al., 2006) are often commonly seen in PD projects with different user groups and may certainly be appropriate mechanisms for collecting data from children of high abilities. These are however challenging mechanisms for children with more significant social-communication and cognitive challenges.

Across the literature reporting on these techniques, observation of the child is one of the most commonly identified (Börjesson, Barendregt, Eriksson, & Torgersson, 2015). Some studies use what could be termed as 'naturalistic' observation of the child at their home or (more commonly) in their classroom (Escobedo et al., 2014; Fabri et al., 2007; Keay-Bright, 2007; Piper et al., 2006). In other studies, researchers and designers set up technologies, activities and scenarios by which to observe children with autism regarding how they act and react to objects or situations (Constantin et al., 2017; Ringland et al., 2014). This can be seen in a somewhat similar light to using cultural probes as a mechanism for gaining further insight as would be used in ethnographic research.

In such circumstances the importance of contextualising observations to gain a deeper understanding of the child is required. As with the Reactive Colours Model the importance of spending time in the child's context, examining his/her relationship with the objects and activities therein and building a rapport and relationship becomes crucial to gaining a meaningful understanding of the experience of the child (Keay-Bright, 2007, 2012). Many of the techniques highlighted here are not reliant solely on the observation skills of the researcher or designer, in many instances these are augmented via techniques that support narrative

feedback from children. In circumstances where the focus of the design or research is on children who are non-verbal or have minimal communication skills observation requires more sophisticated techniques such as iterative interpretation supported by adult proxies (Boster & McCarthy, 2018; Boyle & Arnedillo-Sánchez, 2016; Cooper & Ireland, 2018). A further challenge for designers working with children with diminished capacity to represent their needs and preferences is the ability to translate observed phenomena into meaningful and actionable design requirements. Working with children with limitations of communication skills often involves a complex process of decoding and interpretation (Frauenberger, Good & Alcorn 2010). Many designers at this phase of the design would engage children through dialogue in reflexive processes to confirm or challenge their observations or assumptions. For children who do not possess the skills required to engage in this way designers must ensure that they are not introducing their own interpretations and bias to the design.

A further challenge that emerges from the literature is that children with autism may not possess the skills to communicate their preferences or experiences in ways that are easily understood by designers and may not have the skills to articulate their preferences when evaluating potential solutions. As children cannot be expected to assume the role of designers themselves content and communications generated by children with autism will require interpretation. This has been referred to as mindful interpretation and requires that designers use methods to incorporate the expression of children in design while remaining true to their intentions (Keay-Bright 2010). Several studies have examined mechanisms for co-construction of knowledge using digital stories, a technique borrowed from research in the Arts (Guldberg et al., 2017; Parsons, Guldberg, Porayska-Pomsta, & Lee, 2015b). In describing the process adopted in the ECHOES project it is suggested that designers avoid practices that are based on problem solving or technical-requirements dominated approaches (Frauenberger, Good, Keay-Bright and Pain, 2012). Involving children more actively in prototyping and other 'making' activities may certainly provide a mechanism for eliminating the need to develop a discrete design plan but requires that children have the requisite skills to engage in this way.

Methods and techniques that support the translation of a designer's accumulated understanding of the child and their context into specific design requirements remains somewhat vague and light on specificity.

3.1.5 Supporting Participation in the Intermediate Phase of Design

Once a detailed understanding of the user and their context has been established, the intermediate phases of a design process often comprise the creative design practices typically associated with making the design solution tangible. Through this phase the design team will endeavour to imagine the outcome of the process or elements thereof. Typically, in PD projects there is a high degree of collaboration through this phase with designers and users working together to collectively develop design solutions. This collaboration can be referred to as co-design.

Projects involving children with autism have employed a range of techniques to facilitate their participation through this phase of the design process, including brainstorming (Piper et al., 2006), using design personas (Laura Millen et al., 2011b) and using role play and story cards to facilitate discussion (Malinverni et al., 2016).

Engaging children with autism in creative expression and workshops focussed on harnessing their creativity to produce prototypes of varying types is typically restricted to projects involving children with a degree of verbal ability and age-equivalent cognitive functioning (Benton et al., 2012a, 2012b; Benton et al., 2014b; Fletcher-Watson et al., 2016; Parsons et al., 2011). In some instances, children with more limited abilities interact only with the design prototypes by way of evaluation. Designers may engage the child with various prototypes in order to observe their use of these or to gather other evaluation data such as usability data that will assist in refining further prototypes (Bartoli et al., 2014; Garzotto, Valoriani, & Bartoli, 2014). Other studies have taken an iterative approach, using a well-established multidisciplinary team with considerable experience with the children with autism to build prototypes systematically based on the observed and interpreted experiences of children(Keay-Bright, 2007; Keay-Bright & Howarth, 2012).

Although there are examples of efforts to support active participation for children with autism, there is a paucity of examples where children presenting with complex social communication and cognitive challenges are encouraged to engage creatively in the process or where their creative contributions are encouraged, captured and incorporated into the development of prototypes or indeed the final design product.

3.1.6 Supporting Participation in the Final Phase of Design

The final phases of a technology design process typically involve a design team engaging in a series of evaluations both formal and informal of the potential design solutions. Evaluation for PD projects however is a multi-lateral process with a strong emphasis on comprehensively engaging the user through this phase and ensuring that their opinions and experience will contribute meaningfully to the design outcome. As such, evaluation in the context of PD requires not only consideration of a prototype or proposed design but that a decision or series of decisions are made to accept, reject or reconsider the solution in question. Actively engaging design participants in making decisions and acting upon these is considered a defining characteristic of PD ensuring that the power that usually resides with the design professionals is devolved to others thus empowering them through their participation.

The most commonly reported mechanism for engaging children with autism in evaluation of prototypes or design solutions is through 'user-testing'. User-testing is commonly used as a mechanism for the designers to observe how their proposed system operates under realistic usage conditions. It also works to allow potential users to consider the proposed solution prior to delivering their opinions or thoughts.

User-testing however, depending on how it is set-up and executed can involve varying levels of decision making on the part of the child. For example, user-testing in a study of a series of therapeutic games for children with autism involved the researchers gathering specific information regarding children's performance across a series of targeted skill domains including; 1) selective and sustained attention, 2) visual perception and 3) motor skills. Testing procedures involved several children with autism testing the game under experimental conditions (Bartoli et al., 2014). Opportunities for children with autism in such user-testing conditions to actively express opinions, inform designers as to their preferences and engage in decision making are very limited. User-testing or evaluation procedures that do not seek to capture the views of children with autism cannot be viewed as participatory as the opportunity to make decisions about the design are not made available. Other studies employing user-testing in experimental conditions supplement observation data by seeking the feedback of children with autism and their parents but do not necessarily act on the opinions or experiences gathered (Bai et al., 2015). In some studies researchers and designers seek multiple mechanisms to capture the opinions and experiences of using prototypes or potential design solutions including; post-test interviews, focus groups and questionnaires (Piper et al., 2006; Ringland et al., 2014; Weiss et al., 2011). Taking on board and acting upon the feedback of children with autism is seen more

often in design projects that engage in multiple iterative design steps seeking to improve the quality of their solution by incorporating such feedback with each iteration (Munoz et al., 2019; Tang et al., 2013).

Capturing the opinions and experiences of children with autism who present with more complex social-communication challenges is more difficult, consequently we see less examples across the literature of such children being actively engaged in the design evaluation. In the examples that are reported the process of engaging children in active decision making is challenging and requires designers to seek multiple ways by which the child with autism can express themselves. In some instances children with autism are provided with alternative communication methods to verbal engagement such as technology or visual supports (Sampath, Indurkhya, & Sivaswamy, 2012). Using adults as communication partners to support the interpretation of limited verbal and non-verbal communication can assist the designer in capturing and decoding the opinions of children with autism (Boyle & Arnedillo-Sanchez, 2016). Capturing and decoding the opinions and expressions of children with autism does not however reflect participation as defined in PD processes but requires that designers act upon these and use these to effect change to the proposed design in line with the understood expressions of the child. For children with autism for whom capturing their opinions and expressions is most challenging, evidence of their opinions and decisions resulting in action and change is seen across projects that engage in deliberate iterative improvement through this phase of the project (Keay-Bright & Howarth, 2012)

Participation in design evaluation for children with autism is evidenced in three ways, 1) in testing the fidelity of a proposed system but not sharing their opinions, 2) testing the proposed system, providing feedback and opinions on it but no changes made to the design based on these and 3) testing, providing feedback that causes a change to the proposed system. Considering the importance of sharing power PD projects, only evaluation processes aligning with the third condition can be considered as supporting true participation for children with autism.

In a study documenting the experience of developing a Kinect™ based game with children with autism the point was well made that the highly engaged nature of such research makes it difficult to unpick how and why certain design decisions are made (Malinverni et al., 2017). Some studies have focussed on adapting evaluation tools such as questionnaires or ranking scales to better match the cognitive and communication skills that those with autism and/or intellectual disabilities present with. Of note, are efforts to decrease the cognitive load

that decision making demands by using visual tools such as "smileyometer" scales (Benton & Johnson, 2013; Millen, Cobb, Patel, & Glover, 2014). In studies involving children with autism and other neurodevelopmental conditions, adults familiar with participating children are used to support the decision-making process (Boyd-Graber et al., 2006; Boyle & Arnedillo-Sánchez, 2016; Shen et al., 2016). In describing the IDEAS approach to designing with children with autism, decisions-making activities during the ideas generation phase, such as selecting between a range of proposed alternatives are supported by adults (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012). In a design project with children with more significant communication challenges feedback is actively sought from parents during evaluation activities, consequently, design decisions were then made and acted upon on the basis of such feedback (Keay-Bright, 2007).

3.2 Methods and Techniques for Designing with the Child with Autism

The preceding sections of this chapter have outlined a review of past technology design studies involving children with autism and examined the various approaches, methods and techniques employed to facilitate their participation. This review has highlighted inconsistencies in participation throughout the design process and in much of the research the technology design studies employed techniques that relied on the child having adequate social communication skills to engage in dialogue with designers.

One of the objectives of this research is to identify and evaluate a range of techniques that support the participation of children with a complex presentation of autism. The challenges associated with such a complex presentation of autism are described in detail in section 2.4.1 of the previous chapter. Many of the techniques previously described across the literature are not suitable for use with children with such complex challenges or require modification or adaptation to meet their specific needs.

The following section identifies and describes a range of methods and techniques to support the participation of children with such complex challenges in 1) the early phases of design, which focus on increasing understanding of the user and context, 2) through intermediate phases where focus is on co-creation and realising potential solutions and finally 3) late phase design where the focus is on evaluation of potential solutions and democratised decision making.

3.2.1 Participation Across All Design Phases

As with participation[32] in its traditional sense the success of a child's participation in a design project depends on the degree to which they are included and involved in the process. Frauenberger, Good and Alcorn (2012) adapted Arnstein's Ladder of Citizen Participation to define three levels by which a child with autism participation in design could be viewed at three levels; 1) 'non-participation', 2) 'participation by proxy' and 3) 'full 'participation'. The degree to which a child with autism participated therefore predicates the degree to which their voice is listened to, power is conferred to them and their decisions are acted upon. These authors go on to conclude that because work of this nature is specific both to the context and those involved that fewer design frameworks have been developed to guide designers (ibid.). The forthcoming section will elaborate on previous work conducted to develop such guidelines and will examine further mechanisms by which the voice of the child with autism and their decision making can ensure their participation in design projects.

Equalising power relations involves the deliberate effort to provide a voice for those who are normally not heard. For children with reduced means for communicating their needs and preference providing them with a voice and a mechanism for expression in this context has an ethical and moral dimension. This means that the designers learn from the users' knowledge and experience with their daily practices and the users learn about the potentials of the technologies from the designers. Users and designers try to create a shared understanding of the problem space and discuss potential solutions in ways that everybody understands. Designers need to learn from the users because they have expert knowledge of the context that the technology will become part of (Bratteteig & Wagner, 2012). By involving users with autism as partners in the design process it is possible to access and use their tacit knowledge, which is hard or almost impossible to access taking a user as research object approach since this knowledge is often difficult to share in interviews and might be missed in observation. Providing participants with autism with the opportunities outlined here requires that they be involved through the design process. Early engagement in the design exploration phase provides children with autism a chance to assert their own preferences and direct what aspect of their lives the envisioned technology will impact. Adopting practices and techniques that support children's creative expression (within the framework of technology design) gives direct opportunity for children to concretise their choices and bring these to life. Finally, inclusion of

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[32] Participation has been defined earlier in Chapter 2 as '*involvement in a life situation*' (WHO 2007, p.9).

the child with autism in evaluation of prototypes and the final design ensures that opportunities for active choice making are present through the entire design cycle.

3.2.2 Early Phase of Design: Capturing the Lived Experience of Children with Autism

PD differs from traditional technology design in a number of ways: 1) the end users are in the best place to suggest how to improve the work processes and should be considered "real experts" in the design process rather than the designers/developers, 2) the user's perceptions of and feelings towards the technology are regarded as important in what the final technology can actually do, 3) the software and technology are viewed as processes in the context of the environment they will eventually be used in rather than as products in isolation (Schuler & Namioka 1993). From this it can be inferred that the "user", in this instance the child with autism provides designers with all the relevant resources to create meaningful, authentic and usable technology solutions.

3.2.2.1 Observation in context

Efforts to capture and understand the lived experience of children with autism presents the designer with a unique set of challenges. Designers with limited experience of working with children with autism will face challenges in gathering such data due to their substantial difficulties with thorough processes and communication. Similarly, traditional methods, tools and techniques for such user research are redundant because these tools and techniques rely heavily on verbal communication and higher order cognitive skills to engage with identified end-users. The complex and highly personal nature of observing the experiences of children with autism in a special classroom or therapy setting challenges conventional observation techniques.

Participant observers may find themselves overwhelmed by the novelty of the experience and may not achieve the required depth of understanding required to inform design activities (Riekhoff & Markopoulos, 2008). In such circumstances, conventional user research will often employ cultural probes as a support in collecting and understanding the phenomena observed. Considering the challenges faced by children with autism in social interactions, cultural probes can further support a designer by structuring the initiating interaction between them and the users they encounter, and scaffolding participation in the exchange of information. Consequently, the use of cultural probes in early design phase data gathering ensures that users such as children with autism are conferred with a degree of agency that simple

conventional observation would not allow. In conventional user research, cultural probes are used as tools to support self-reporting by participants. Tools, techniques and artefacts are designed to structure a participant's self-reporting and their thoughts and reflections. For children with autism however, such self-reporting and self-reflection is not within their scope of abilities. Cultural probes however, can still serve a function in structuring the reporting and reflections of designers previously unfamiliar with or lacking experience of such a group of users.

3.2.2.2 Storytelling: Extending the role of the adult

Storytelling techniques as described in the literature are often inadequate or inappropriate when used with children who have limited communication skills or have challenges understanding and reflecting on their own lived experiences. Accessing this rich vein of design information requires developing and applying storytelling techniques adapted specifically to meet the additional challenges faced when designing with and for children with autism. Children with communication impairments face some of the following challenges:

1. They depend on the interpretations of others to be understood;

2. They often have a low sense of awareness as to their own intentions, or these may be difficult to determine;

3. Their comprehension ability is often low or difficult to ascertain;

4. They present with limited independent ability to use forma linguistic code and tend not to have a repertoire of speech, signs or symbols required to communicate effectively;

5. They tend to acquiesce to the suggestions of others and do not contradict or correct misrepresentation (Grove, Bunning, Porter, & Olsson, 1999)

Considering the above limitations, the onus is often on parents, therapists, teachers, carers and advocates to interpret and represent their wishes and desires. Such carers and professionals must rely on their own judgement of what the behaviour of a person with a communication impairment might mean. For those working with and alongside children who have limited communications skills their day-to-day interaction is characterised by a process of ascribing meaning to children's behaviour. These interpretive judgements are guided by the professional or carer's experiences in different communication situations with children with such challenges. Reliance on such a process raises clear questions about the validity of the

interpretations of caregivers, how much it reflects their own bias and who exactly the message 'belongs' to. The validity of the interpretations of the intent and meaning of children with disabilities' communication has attracted attention from the research community. A consensus has emerged that such communication is a continuous, dynamic experience that involves a process of intent and meaning co-construction by the stakeholders involved (Fogel, 1993). Enhancing the validity of such communication interpretations is greatly improved by the values and experience in successful interaction with children with limitations of speech and expression (Dennis, 2002). For children with restrictions in intellectual ability, many of their day-to-day participation experiences require the active support of adult caregivers or professionals. As such, a child with autism's understanding of their lived experiences can be considered co-constructed with the adults that support their participation. Caregiver stories, therefore, are communicating 'co-constructed experiences' and provide insight and understanding of the lived experiences of children with autism. Such use of 'proxy reporting' of the experiences of children with autism has been criticised in terms of its validity and the disenfranchising of the child's 'power' within the design process. However, when such proxy reporting is used to gather information rather than interpreting the decision making of children this additional data may be considered 'generative' and contribute to further understanding of their lived experience. Although designers should be cognisant of the limitations of using proxies, concerns regarding their use have led to design paralysis. In circumstances where there are such challenges accessing and understanding a user's lived experience, the contribution that can be made by data that is reported by proxies is too valuable to ignore (Herriott, 2015). In the context of working with children with such challenges in effectively communicating their lived experiences and bringing this to bear on a design project, Caregiver Stories must be viewed as a way of generating artefacts that can serve as an additional mechanism for increasing designers' understanding.

3.2.2.3 Context Mapping: Using photography to ensure depth of understanding

Context mapping is a generative technique used in the early phase of design to allow designers to further their understanding of users in their contexts. This methodology was developed by design researchers at Delft University of Technology and encompasses the use of ethnographic research techniques to provide users with ways of representing their world, their feeling about it and their aspirations (Visser 2009). The various techniques used in context mapping are often referred to as 'probes' and are chosen to suit the needs of the user and aim to easily capture factual, descriptive information about their context with a view to sharing and

analysing this with others. As seen in a range of studies detailed above drawing is a technique commonly used to engage children with autism in such 'context-mapping' either in the early phase of design or in low-fi prototyping. Drawing can be a problematic task that challenges children with autism who have impaired imagination skills and intellectual abilities. Other research projects have used photography as an alternative that compensates for the intellectual challenges that come with drawing (Danker, Strnadová & Cumming 2017, Cheak-Zamora, 2018). Providing children with tools to take and contribute their photo reflections has been referred to in research as 'photovoice' and describes a participatory research approach that is engaging and accessible as it eliminates the need for verbal skills or other forms of communicative expression. In some research studies where photographs have been used as a data source, photos are selected by either participant or researchers. In the photovoice approach however, only photos taken by participants or users are used. This approach has been previously used in studies with children and adults with intellectual disabilities, limited communication and other challenging needs (Povee, Bishop, & Roberts, 2014). Empowering children with autism with opportunities to take photographs representing their lived experiences not only provides designers with new perspectives but also enables children to exert control, make decisions and develop new skills.

3.2.2.4 Intermediate Phase of Design: Capturing the Creative Expressions of Children with Autism

The intermediate phases of design are characterised by the creative efforts to imagine what the proposed product or software looks, feels and acts like. In typical software design projects, it is during this phase that designers begin to assimilate all that they have learnt and understood about the problem in question, the imagined end-users and the context in which it will operate. In co-design projects, this is an opportunity for designers and non-designers to collaborate and communicate with creative purpose, with a view to finding and negotiating a solution and creating a shared understanding of how the outcome might look like and function. The creative expressions of non-designers can be incorporated into various elements of the final software interface or may support interaction.

For children with a disability the most common form of involvement for them in design projects focusses on evaluation of potential design options. This limits the impact that the child with autism can have on the outcome of design and fails to allow them to bring their creativity to bear (Frauenberger et al., 2011). Studies attempting to bridge this gap have used a range of low-fi tools and techniques to give children with autism a chance to draw, fabricate, generate

and record ideas. These techniques serve to simplify the process of co-creation and provide children with a degree of agency in the process by providing opportunities to create and contribute elements to the design process. These techniques remove some of the technical, knowledge barriers often associated with design and value the creation of paper-based and other lo-fi artefacts that can be translated later into a final system. These techniques have been modified and refined for use with children in other context (Guha et al., 2004), including children with high functioning autism (Benton & Johnson, 2014; Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012a). Many of these techniques however are bespoke and have evolved in specific contexts with specific groups of children. Many of the studies described here used low-tech paper based tools to support children's creative expressions with few using software or other such technology enhanced tools.

In seeking to incorporate the creative expression of children with high-functioning autism they adapted, modified and supported the creative open-ended activities to match the children's needs (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012b).

From these studies, it appears that the key to providing children with disabilities with opportunities to generate creative content in a design project requires three steps:

1) identifying the correct tools to support children's creative expression,

2) creating structured activities that support their creativity, and

3), analysing and interrogating children's creative artefacts to uncover and understand the meaning of these.

3.2.2.5 Structuring Workshops for Children with autism

The practice of co-creation allows children or non-designers to become an active part of the creative development of a product by interacting directly with design and research teams. It is grounded in the belief that all people are creative and that users, as experts of their own experiences, bring different points of view that inform design and innovation direction. There is a continuity through a typical software design process with co-creation workshops providing opportunities to build on data gathered in earlier phases of the process. The knowledge and understanding that a designer accrues can serve as inspiration for the actual co-design sessions, kick-starting and guiding the conversation, or helping participants dig deeper into specific areas.

Based on the premise that creativity is both an individual and a social-cultural activity, many design projects will use workshops providing a space for interaction, collaboration and

the sharing of ideas. These workshops are constructed around techniques and tools that support the creative expression of all participants and ensuring they have a method for representing their own work and their work as a collective (Amabile, 1983). Insights from ethnographic fieldwork in design practice suggests that creativity in design depends on four factors; 1) a multiplicity of perspectives, 2) openness, 3) availability of a diverse range of resources and 4) a desire to enrich the design space (Bratteteig & Wagner, 2012). Previous work with people with disabilities recommends structuring design workshops and activities around the strengths and weaknesses of children with autism (Benton & Johnson, 2014; Gaudion, Hall, Myerson, & Pellicano, 2015). In the IDEAS model, Benton and her colleagues (2012b), recommend that workshops integrate the appropriate supports and strategies to help increase a child's skills. They suggest ensuring that workshops provide a safe, supportive and quiet environment. Activities should be structured to support children's affinity for routine and predictability and that activities have a strong visual component.

3.2.2.6 Co-Creation with Children on the autism spectrum

Although co-creating technology with children with autism is considered challenging, it is often this group that stand to benefit the most from their active inclusion and contribution to the outcome of design (Frauenberger, Good, & Keay-Bright, 2011). Limitations of verbal communication skills and a perception that people with a disability have impaired creative abilities mean that designers shy away from engaging them directly in co-design activities. Involving those with disabilities more directly in co-creation activities and incorporating these into the software design is likely to have the greatest impact on the design, but is difficult to implement (Frauenberger et al., 2011). Providing a platform for design participants to create both visual and auditory content that is successfully incorporated into the design of software provides a tangible, authentic demonstration of their impact on design. For children with a disability the most common form of involvement for them in design projects focusses on evaluation of potential design options. This limits the impact that the child with autism can have on the outcome of design and fails to allow them to bring their creativity to bear (Frauenberger et al., 2011). Studies attempting to bridge this gap have used a range of low-fi tools and techniques to give children with autism a chance to draw, fabricate, generate and record ideas. These techniques serve to simplify the process of co-creation and provide children with a degree of agency in the process by providing opportunities to create and contribute elements to the design process. These techniques remove some of the technical, knowledge barriers often associated with design and value the creation of paper-based and other lo-fi

artefacts that can be translated later into a final system. These techniques have been modified and refined for use with children in other context (Guha et al., 2004), including children with high functioning autism (Benton & Johnson, 2014; Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012a). Many of these techniques however are bespoke and have evolved in specific contexts with specific groups of children. In seeking to incorporate the creative expression of children with high-functioning autism they adapted, modified and scaffolded the creative open-ended activities to match the children's needs (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012b). From these studies, it appears that the key to providing children with disabilities with opportunities to generate creative content in a design project requires three steps. 1) identifying the correct tools to support children's creative expression, 2) creating structured activities that support their creativity and 3) analysis and interrogation of children's creative artefacts to understand the meaning of these

Malinverni and her colleagues employed a PD approach to support the creative contributions of children with ASD in the development of a Kinect™ , motion based game for the development of social initiation skills (Malinverni et al., 2014). A key element of authentic participation is the opportunities that children with autism should impact the outcome of the design. Capturing and translating their creative contributions is one, significant way of demonstrating their impact on the design process but also contributes to their sense of ownership and agency in the project. This work however is unclear as to how the ideas were generated and as with the experience of the ECHOES team, describe the challenges of translating children's ideas into concrete design proposals.

3.2.2.7 Assistive Technology to Support Creative Expression

For children who present with limitations of motor, sensory or intellectual functioning, professionals often look to select Assistive Technology that compensates for such deficits. Children use Assistive Technology to compensate for the impairments they experience and to allow them to engage in chosen activities. Assistive Technology (AT) has been defined as any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customised, that is used to increase, maintain, or improve the functional capabilities of children with disabilities (Cook, Polgar, Cook, & Hussey, 2008). Examples of AT for children with autism include;

Electronic communication technology known as Alternative and Augmentative Communication (AAC) devices assist children who are non-verbal or minimally verbal to communicate.

In many instances teachers or other professionals will recommend the use of AT to enable children to perform certain tasks. For example, drawing using conventional tools such as pens/pencils and paper may be physically or intellectually too challenging for children with autism, however, they may be able to draw or colour a picture using an iPad with a drawing app. The appropriate selection and use of AT can increase a child's autonomy in performing activities such as drawing and decrease their dependence on the support and intervention of adults. The process of assessment to identify the correct AT that best matches a child's needs and the activity they wish to participate in is a deliberate, complex process usually undertaken by a professional in collaboration with the child. A typical assessment should include an evaluation of the child's abilities and limitations alongside other factors such as the child's preferences, the environments encountered, and potential changes in the child's situation. These factors all need to be considered during an assessment to result in a good person-technology match.

3.2.2.8 Final Design Phase: Supporting evaluation and decision making

The final phase of the design process is characterised by collaborative engagement in decision making. Such decision making ranges from offering opinions on elements of the design, suggesting alterations to prototypes and selecting the design outcome.

In PD practices democratic practice in design requires that responsibility for decision making is decentralised from the adult designers and shared amongst participant stakeholders. For children with limited communication and social interaction skills putting these mechanisms in place may be particularly challenging. It has been argued that choice making within design practice requires that participants are provided with opportunities to; 1) create choices, 2) select and make decisions about preferred choices, 3) concretise choices and 4) evaluate the choices as they impact the design outcome (Bratteteig & Wagner, 2012). Providing children with autism with the opportunities to participate fully in the design of technology requires that they be involved in decision making throughout the design process. In practical terms, the demand for decision making will ebb and flow as the process plays out and must be established as a cultural practice in design projects. Nonetheless, the evaluation process that is typical of the final phase of design requires that the child with autism engages in a series of decision-making events to

express their judgement as to the suitability or otherwise of a design solution prior to agreement on a final product. Therefore, ensuring the participation of the child with significant social communication skills deficits in such activities does require a series of appropriate supports.

3.2.2.9 Shared Decision Making

It is often not enough to identify design activities and tasks that match the child's skills and aptitudes. In many instances the child will also require modification to the task to decrease the demands upon their attention, cognitive ability, creativity and social functioning skills. For such a heterogenous group of potential participants, modification is often required to simplify the performance and execution of certain tasks such as choosing between design elements or indicating preferences. Furthermore, a predictable sequence for activities should be put in place thus reducing the amount of change the child with autism is faced with in participating in the design process. A useful framework for devolving decision making between adults and children with ASD and/or intellectual disabilities is Shared Decision Making (SDM). To restore parity of power in decision making situations, Shogren and Wehmeyer (2015), suggested that to understand and apply the supports required for a child to make decisions there is a need to understand (a) the relevant contextual factors, (b) the environmental demands on the child and the activity, and (c) the supports and resources needed to make those decisions. From this, all decision-making processes, for example, selection of visual interface elements or evaluation of alternative paper-prototypes were adapted to simplify the process. The role of adults as communication partners for children with autism is key to accurately interpreting the range of verbal and non-verbal decision-making communication. Furthermore, decision making should be further supported through using visual presentation and should be careful not to rely on providing information that is abstract or in a format that is not accessible to the child[33].

Using an SDM approach facilitates the participation in decision making for children who are non-verbal or minimally verbal by changing the nature of the decision making process and incorporating a range of supports that they can use.

The above can be summarised with the following points:

    a) Remove the need for spontaneous communication by identifying decision-making behaviours in in the planning of design workshops

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[33] The processes followed in this project were adapted from the National Disability Authority of Ireland's guideline, available in their Accessibility Toolkit - http://nda.ie/Resources/Accessibility-toolkit/Make-your-information-more-accessible/

b) Structure and timetable decision-making events during design workshops

c) Where possible remove the cognitive complexity in decision making (reduce choice making to selecting from two options, engage the child in indicating single preferences)

d) Support non-verbal decision making & the use of Alternative and Augmentative Communication systems or other resources required by the child.

In the application of SDM in a workshop scenario for example, a teacher, therapist or researcher will typically script the anticipated decision making events, sequence them in an easy to follow order and will make available a list of instructions to guide decision making by participants. Ample time is given to each decision making event and the necessary supports are available to allow the child to make choices or indicate their assent or otherwise.

3.2.2.10 Design decision-making for children with autism: Adult Proxies

In many situations, designers will depend on 'proxy participation' relying on the knowledge and authority of other adults such as parents, teachers or other personnel (Boyd-Graber et al., 2006; Shen et al., 2016). Although the use of proxies may offer much to designers in terms of convenience, devolving decision making to an adult proxy is certainly problematic in terms of ensuring that there is a somewhat equitable distribution of power across the design team.

In studies involving children with autism, adults familiar with participating children are often looked to support the decision making processes (Boyd-Graber et al., 2006; Boyle & Arnedillo-Sánchez, 2016; Shen et al., 2016). When designing with young children from populations where communication disabilities are common (e.g., autism), it is perhaps to be expected that designers will rely on feedback from proxies, such as parents, teachers, and care workers. Sampath, Agarwal & Indurkhya (2012) worked closely with a non-verbal autistic child and his mother during the development of an assistive communication app. Here, it is arguable that the mother plays both the role of proxy and user, as is often the case in such situations (Herriott, 2015). Several changes to the software were made based on the mother's feedback, and, in a subsequent very small-scale usability test of the resulting software, no usability issues were reported. The advantage of such an approach is that a suitable proxy with sufficient knowledge of the child will be well-placed to both recognise and convey the child's unique requirements. However, we would suggest that designers take care when selecting proxies. While a body of research has shown agreement between proxy and self-responses in a research

setting (e.g., Schmidt et al., 2010), it is important to remember that the aims of PD are not those of a quantitative research project. Boyd-Graber et al. (2006) provide a detailed discussion of issues that may inform the decision to use, and how to select, proxies in a PD context. For example, the authors suggest that advocates with the same disability (in this case, aphasia) are better suited to acting as proxies than carers and family members who, although they may be more familiar with the users, may not be able to convey the lived experience of the disability to the same extent as an advocate. It is generally more common for PD researchers to consult with carers and family members preferring proxies who have most familiarity with the participants, even if this does come at the cost of specialist scientific knowledge of the participants' disability (Robb et al., 2017). A third approach, and the one adopted by Boyd-Graber et al. in their work, involves using experts (e.g., speech-language therapists) as proxies, due in part to their familiarity with the child and his/her condition but also because of their understanding of the potential power imbalance that can result from this practice.

3.2.3 Summary

This section outlines a series of techniques that can be used to support the participation of children with autism through the early, intermediate and final phases of a technology design process. Capturing a child with autism's lived experience provides a rich and detailed understanding of the child and their context upon which a designer can construct some detailed requirements plan to support the development of potential design solutions. It is suggested that this can be achieved through immersive observation of the child in the context in which they use technology and through the stories that are shared by those working most closely with the children. Further depth of understanding can be achieved by providing children with the tools to 'show' designers their world.

Furthermore, it is suggested that children with autism can participate in co-creation activities and in creatively generating content that can be incorporated into design elements, prototypes and ultimately the final design solution. This can be achieved through carefully structuring workshops that provide processes and supports that reflect the child's abilities and through the provision of individualised AT selected to match each child's composition of needs.

Recognising that listening to the child's voice is only one component of participation in design there is a need to ensure the democratisation of decision making. To support a child with autism's ability to participate in evaluation in the final phases of design, it is proposed that SDM is used to simplify and support decision making processes and that professionals familiar

with the child be utilised in supporting the interpretation of children's decision making and as adult proxies.

3.3 Evaluating Participation in Design

We must remain mindful that participation must be seen not only as attending but is also characterised by the involvement of the child with autism. Involvement as a dimension of participation is understood as the degree to which the child's voice is listened to and their decision making is respected. As efforts to ensure and support the participation of different cohorts of citizens increases across a broad range of societal sectors the risk of contrived, limited or participation of convenience has emerged as a concern for designers, researchers and policy makers (Anderson 1998). Although the challenges of designing with children with autism make them vulnerable to exclusion from projects, there is a risk that their participation may be seen as manipulation or tokenism (Benton & Johnson, 2012). Participation, particularly within the context of design is difficult to define in a meaningful way that can suggest to us that a participant's actions clearly demonstrate 'genuine' participation (Segalowitz & Chamorro-Koc, 2017). For children with autism, the range of challenges that they face suggests a need to provide participation opportunities while acknowledging they may not be able to successfully complete particular tasks. The challenge for those wishing to offer children with autism the opportunity to participate in technology design is therefore to create the conditions that allows them to participate to the fullest of their potential (Franklin & Sloper 2007). This poses an additional challenge in terms of measuring such participation, in what way can we demonstrate the degree to which a child with autism participates in a design project or how participatory the process is?

Previously in Chapter 2 we outlined Shier's Pathways to Participation Model which illustrates a mechanism by which we can examine the levels participation afforded to children based on a continuum of listening to the child through to the sharing of power with adults through collaborative shared decision making. In this model, participation is articulated on five levels, each presenting a greater level of decision-making power for children. The highest level of participation suggest that children and adults share power and decision making equally.

This model also identifies three mechanisms to bring about the most effective participation as illustrated in the graphic below (Shier 2001).

The first of these mechanisms; 'openings', refers to the commitment or intent of the adult to support a certain level of participation. This commitment however is only operationalised by the second mechanism; 'opportunity', when the opportunity is made tangible and the appropriate supports or resources are put in place that will enable the child to participate at that level. Finally, Shier's model uses a final mechanism; 'obligations' to institutionalise a desired level of participation by making it an obligation on the adults involved to act in this way (ibid.)
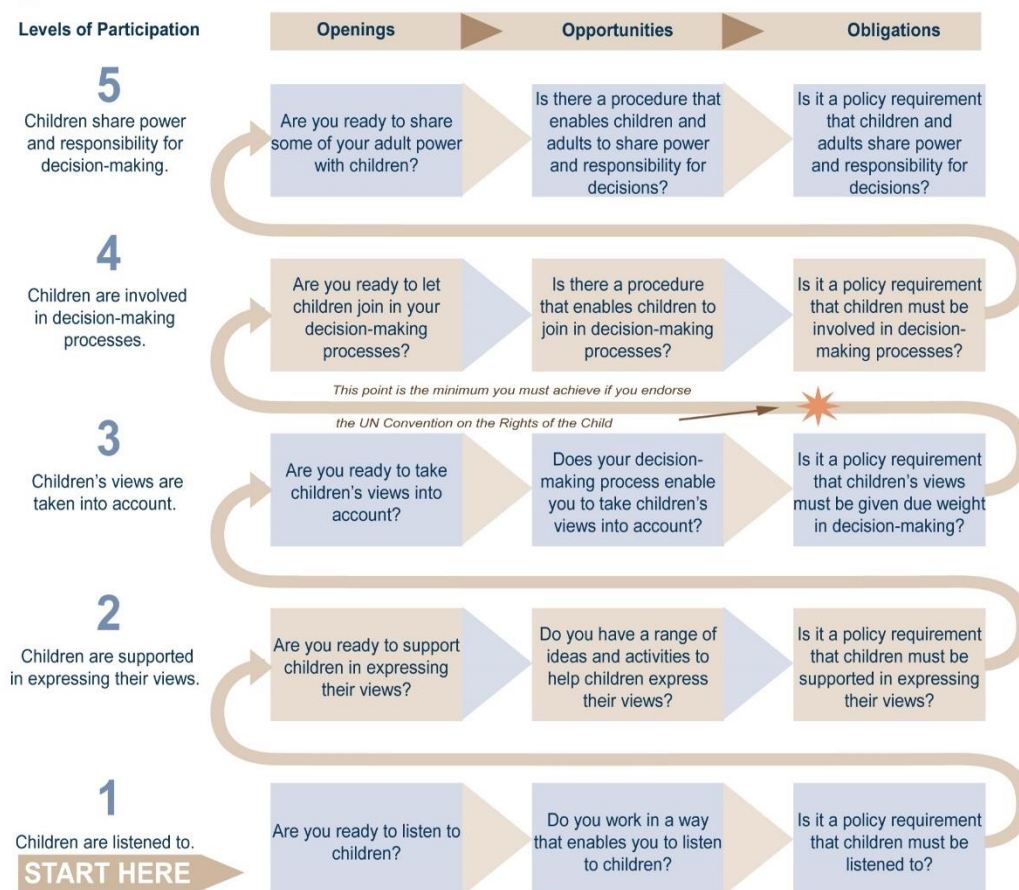
Figure 10: Shier's Model of Participation (2001)

The reliance however, on identifying decision-making as defining a child's level of participation limits the model in terms of examining participation in design projects. As we have examined throughout the previous sections of this chapter, engagement in decision making is only one mechanism by which a child's participation in a design process is evidenced. As such, without elaboration Shier's model can only present a limited view of the level of participation a child with autism may experience in a design project. Adaptation of this model requires consideration of participation as a construct in the context of design projects.

3.3.1 Understanding Levels of Participation in Design Projects

In a study of participation as a construct in PD work, drawn from experience examining participatory practices of workers, Segalowitz articulates three constituents of 'participation' in a design project; 1) impact, 2) influence and 3) agency. Impact is understood as the person's contribution of knowledge and creative content to the design solution. To gain an appreciation of a child's 'impact' in a design project therefore, we must examine the quantity of their contributions and the quality in terms of how those contributions were used. Influence refers to a measure of the amount of decision-making power that a participant brings to bear on the project that they participate in. Influence as a measure of a child's participation is determined by the number of opportunities for decision making they are given and how much these are acted upon. Agency refers to a person's drive and motivation to participate and differs from both impact and influence by its focus on the social capacity the participant brings enabling them to affect change within the project (Segalowitz, 2012). In the context of design projects, Segalowitz suggests that there may be two behavioural indicators that reflect the person's agency in a design process, motivation and engagement (2012). Motivation in this context can be seen as representing willingness or the drive to be an active part of the project and engagement as denoting solidarity, sharing purpose with those in the project. For children with autism their ability to demonstrate willingness may be misunderstood. In most aspects of their functioning they require support across all life domains and as such have limited experience of the autonomy required to understand the concept of willingness. There is an argument however that their motivation offers a glimpse of their investment in an activity or endeavour. Children with complex social dysfunction will not be expected to demonstrate the act of solidarity with others, in many instances children on the autism spectrum have a limited understanding of the concept of "other"(Holt & Yuill, 2014). For children who have a limited repertoire of interests and difficulty attending to simple tasks, it is reasonable to examine their "engagement" as a measure or reflection of their personal interest in the process.

Discussions as to how children with autism can serve to describe their participation in design however would appear to be speculative. A thorough appraisal of participation require a much more detailed examination of what impact, influence and agency can be defined for children with autism and how these dimensions of participation transfer power in the process to those children participating. To that end, this researcher asserts an evaluation framework combining Shier's model with Segalowitz's elaboration on the construct of participation in design provides us with a lens by which we can begin to analyse the that can experience of participation for children and the processes that support it.

Figure 11: A framework for the analysis of levels of participation in design projects for children with autism

	Impact	Influence	Agency
Openings	The lived experience of children with autism will guide the development of design solutions	Creative contributions of children with autism will be incorporated into design solutions	The child with autism has the drive to participate with others in the design project.
Opportunities	What methods and techniques are in place to capture and transfer understanding of the lived experience?	What techniques can support children with autism to engage in decision making?	What techniques can be used to ensure that the child is motivated and feels safe to contribute?
Obligations	Is the understanding of the child's lived experience implemented through the rest of the project	Does the decision making of children change the design solution or project outcome	Is the child with autism motivated to participate throughout the design project?

The framework presented in the table above poses a series of questions that aim to address the level of participation achieved by children with autism in term of 1) how they impacted the design project, 2) how much influence they had on the process and outcome of the project and 3) did they demonstrate agency during the project? Recognising the importance of the role adults have in creating and supporting the participation of children with autism, these questions allow us to identify how a project can create the conditions required for children with autism to participate to their potential. This evaluation framework will be examined in this research as a way in which participation in design can be better understood and to demonstrate what level of participation can be experienced by a child with autism throughout the entirety of the design process.

3.4 Summary

This chapter opens with a description of studies involving children with autism in the design of technology. This description involves an examination of the roles played by children with autism in design projects and some of the methods and approaches that have evolved to support their participation. In many instances, the opportunities children with autism have in influencing the design of the technology they use is often predicated by their intellectual, language and interpersonal skills. The merits of engaging children with better language and expressive communication skills have been well demonstrated (Parsons, Millen, Garib-Penna, & Cobb, 2011). As the severity of a child's social and communication autism increases however, evidence of their active inclusion in technology design projects appears to diminish. For those with more significant autism of language or intellectual functioning their role can easily be relegated to a more passive one (Börjesson, Barendregt, Eriksson, & Torgersson, 2015a).

Reflecting on the complexity of the needs of the children with autism addressed in this study a series of methods and techniques are identified that aim to specifically support their participation through the entirety of a technology design project. These methods and techniques provide designers with mechanisms by which to listen to the voice of the child, support their abilities to generate design content and make decisions that impact the direction and outcome of a project. The process of evaluation of how these methods and techniques support the participation of children with autism is outlined in Chapter 5 of this thesis.

Finally, recognising that the experience of participation cannot be defined simply as 'being involved', this chapter concludes with a proposed framework for examining the participation of children with autism in design projects. This framework is based on levels of participation outlined in Shier's Pathways to Participation model and with Segalowitz's dimensions of design participation. This framework provides a lens whereby the successful participation for a child with autism can be considered in terms of how the opportunities they had to impact the design, the ways in which they influenced the design and in how much agency was conferred during the process. This framework will be used in Chapter 7 to consider the findings of the evaluation of the support framework outlined earlier in this chapter.

Chapter 4: Research Methodology

This chapter aims to outline the research design and methodology of this current research and the rationale for its selection in this research. This rationale is then outlined in three parts: the first examines approaches to research and the nature of research design. The second describes research methodology and methods, including concerns related to reflexivity and bias. The third part then addresses data generation, alongside some specific data analysis concerns.

The final part of this chapter draws upon the previous sections and presents the approach methodology and research design employed in a two-stage research process and outlines the overall research objectives and the questions to be addressed. A brief description of both stages is presented and serves as an introduction to more detailed descriptions in later chapters of this thesis.

4.1 Research Approach

The purpose of this research was to firstly to develop and demonstrate a framework of techniques that facilitates the participation of children with autism in technology design and secondly to evaluate the level and nature of that participation. Denzin and Lincoln propose a hierarchical model of thinking to guide the planning of a research design: this includes drawing on the researchers' ontological world-view to a set of questions or epistemology followed by selecting a methodology to answer the research questions (Denzin & Lincoln, 2003). Each researchers background and experience brings its own understanding of how the world can be explained from its specific philosophical underpinnings (Mason, 2002). Emphasis on sensitising concepts and the disciplinary background of the researcher is advised (Charmaz, 2006). To begin a research process, the researcher must identify what is guiding the process in relation to assumptions and positions on how the world can be understood. Being explicit about such beliefs enables the researcher to conduct research in a coherent and congruent way and supports the researcher in decision making. The researcher's motivations in this research has been influenced by the methodological philosophies of pragmatism, inclusion and exploration.

Exploratory Research	Inclusive Research	Participatory Design
- Design Ethnography - - Explanatory Case Studies - Co-construction of knowledge	- Participation - Empowerment & - Equalising Power Dynamic	- Capturing participant's lived experience - Co-Design techniques - Iterative evaluation
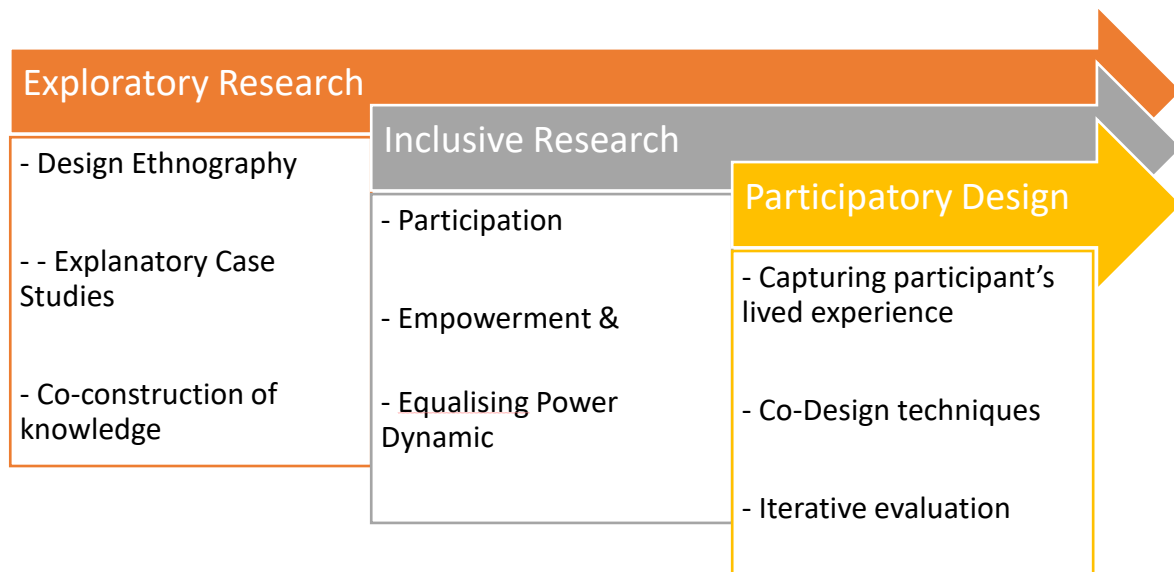
Fig 4.1: Research approaches adopted in examination of PD processes.

The pragmatic paradigm is often used to guide research in information systems and focuses on the synthesis of practice and theory through applied research. It dictates that practical action is required for the validation of knowledge or theory. New knowledge is then judged by whether it works to solve the problem at hand. Pragmatism is especially important in research concerning product development processes because, although theory is valuable, an understanding and explanation of how one can implement a process in practical, real world scenarios is essential. If pragmatism is not considered, the bridge between theory and action may be too vague, and so it will be difficult to apply the process again in the future. This bridge is particularly important in design research, because design is essentially the application of knowledge to create a useful system, service or artefact.

Inclusion is a term that has emerged from the field of education for children with disabilities and is now used to describe an ideology that focuses on ensuring that people of all abilities are supported to achieve to the maximum of their potential (Odom, Buysse & Soukakou, 2012). The idea of including stakeholders, such as children with autism in research that examines their lives, experiences, preferences and dreams is not new with researchers adopting a variety of processes and approaches when studying issues pertinent to different

minority groups (Fine, 2013; Johnson & Walmsley, 2003; Nind & Vinha, 2014). Emerging methodologies for research with children with a disability have been expanded in recent years to also embrace partnership and user-led research, child-led research, peer research, community research, activist scholarship, decolonising research, community-based participatory research, participatory action research and democratic dialogue (Nind, 2014b). Proponents of inclusive research emphasise its differences with traditional research emphasising greater participation, empowerment, an equalising of the power dynamic between researcher and researched. Inclusive research strives for collaboration and an understanding of the different ways of knowing and offers opportunities for social transformation. Inclusive research is characterised as research with, by or sometimes, for people with a disability, contrasting significantly with approaches emphasising research on people with a disability (Nind, 2014a). Inclusive research has now become an umbrella term that captures established research practice and methodologies such as; action research, participatory research and emancipatory research. Inclusive research is considered within an ethnographic research tradition with the perspective that phenomena to be studied are both context-bound and context rich (Jackson & Taylor, 2007) and that research subjects are often the locus of expertise in representing and articulating their experience (Coons & Watson, 2013).

Exploratory research is conducted when a problem or phenomenon has heretofore attracted little attention or study and describes "a broad ranging, purposive, systematic undertaking to maximize the discovery of generalizations leading to a description and understanding of an area of social or psychological life" (Stebbins, 2001, p 3). Researchers explore in order to discover new knowledge about a group, process or situation. Effective exploration requires the research adopt two specific orientations; flexibility in looking for the data and open-mindedness in terms of where it can be found (ibid.). Such generalizations should then be assimilated into a grounded theory explaining the object of the study. Exploratory research does not seek to deliver final and conclusive solution to problems, rather it is used to generate a better understanding of the problem or phenomenon To investigate methods for the participation of children with autism in design, and to subsequently develop a design framework to facilitate that participation requires an exploratory research approach. The purpose of exploratory research enquiry is to find out what is occurring in an area with little understanding, to seek new insights, to assess phenomena in a new light and to generate ideas and hypotheses for new research.

4.2 Research Methods

Qualitative research acknowledges human perceptions as an impacting factor in social science, allows exploration of these perceptions, and emphasises the importance of the investigation's context. Qualitative research is conducted when researchers want "to empower individuals to share their stories and to hear their voices" (Creswell, 2007, p. 40). Qualitative methods have attracted attention in contemporary research with and for children as they enable adult researchers to get closer to the child's lived experiences through data that is rich and descriptive (Kellett, 2011). Qualitative research typically addresses questions like: What is occurring? How is this occurring? Why is this occurring? and what impacts the occurrence of the phenomenon? A qualitative-exploratory approach to research also offers the opportunity to identify new phenomena that may not be uncovered via a quantitative study, where the research questions are developed solely from existing theory. From a constructivist perspective, the aim of research is to rely on the participant's views of a situation in which the processes of interaction among individuals is addressed (Creswell, 2009). Researchers however, recognise their own influence on the process is a co- construction of knowledge between the researcher and the participant (Finlay, 2006). The researcher is a key instrument as they play an integral part of data collection and analysis. Researchers interpret what they have seen, heard and understand and have their own background, history and prior conceptions (Creswell, 2007). Galdas (2017) states that separation of a researcher from their bias is neither possible nor desirable and rather it is a concern for researchers to be transparent and reflexive throughout the research process.

4.3 Case-Study Research

In qualitative research case studies are in-depth examinations of complex events or series of events and are based on; a comprehensive understanding of the event(s), extensive description of the event(s) and an analysis of the event(s) taken as a whole and in context. Case studies have often been viewed as a useful tool for the preliminary, exploratory stage of a research project, as a basis for the development of the 'more structured' tools that are necessary in surveys and experiments. For example, Eisenhardt (1989) says that case studies are:

"Particularly well suited to new research areas or research areas for which existing theory seems inadequate. This type of work is highly complementary to incremental theory building from normal science research. The former is useful in early stages of research on a

topic or when a fresh perspective is needed, whilst the latter is useful in later stages of knowledge (pp.548-549)."

Case-study research also lends itself to the analysis of contemporary events when the relevant behaviour cannot be manipulated or it outside of the control of the researcher. One technique unique to case studies is the participant observation. Participant observations differ from direct observations in that the researcher participates in the process under scrutiny. Case studies can add depth and realism to an audit/evaluation analysis by making it more "real life." They can also demonstrate the impact of processes, policies, or programs in human terms. There are several advantages in using case studies. First, the examination of the data is most often conducted within the context of its use (Yin, 1984), that is, within the situation in which the activity takes place.

In exploratory case-studies that typically do not start with propositions, an alternative approach needs to be adopted. Here an alternative analytic strategy is to develop a descriptive framework for organising the case-study. Thus, a framework of sections reflecting the themes in the case-study are developed and evidence is gathered within relevant themes, and analysed and compared in these categories, to achieve a description of the case-study that can be corroborated from multiple sources of evidence.

Explanatory case studies examine the data closely both at a surface and deep level to explain the phenomena in the data. Furthermore, explanatory cases are also deployed for causal studies where pattern matching can be used to investigate certain phenomena in very complex situations.

Finally, case-studies can be case studies applied in single units or multiple case studies where multiple studies are conducted in the same research. On the basis that replication implies validity, then a research design using multiple cases can be regarded as equivalent to multiple experiments. The more cases that can be marshalled to establish or refute a theory, the more robust the research outcomes. Embedded designs identify several sub units (such as meetings, roles or locations) each of which is explored individually; results from these units are drawn together to yield an overall picture.

4.4 Data Collection and Analysis

A case-study uses a range of methods for data collection such as observation, interview, documents, survey, and artefacts to probe beneath the surface of phenomena to find the in-depth data it requires this goes beyond the range of sources of evidence that might be available

in historical study (Cohen et al, 2011). A case-study may incorporate a variety of audit techniques, including interviews, surveys, questionnaires, data analysis, document reviews, and observations over time. Case-study data collection is based on two central tenets. The first is that data gathered must be rich in detail, data gathering such as recording events, interviews, and observations should be conducted with this in mind. For example, if gathering observation data then this should ideally take place over an extended period during this time, with the researcher continuously record observed events of relevance. The second central tenet of case-study data collection is the use of multiple data sources to permit triangulation during data analysis. Therefore, it is usually important to use multiple techniques when gathering information. Although observations are often the most important component of case-study analysis, they must be augmented by other evidence.

Observation has been used extensively as a mechanism for collecting user information and increasing understanding in both research and design projects (Watson & Till, 2010). Drawn from a rich history of application within psychology, user research draws on both structured observation and naturalistic observation techniques. Structured observation tends to take place in a laboratory environment where the range of existent variables can be firmly controlled. It is focused on revealing quantitative data though it may also yield qualitative observations. In contrast, naturalistic observation involves studying the user "in the wild" and tends to be significantly less structured. Conducting naturalistic observation in the context of a design project requires spending time with a user or group of users and observing their behaviour within context and engaged in activities as part of their day-to-day life. The observer records their observations as they see fit, often using field-notes, video and audio recordings. Naturalistic observation techniques support the collection qualitative data. Participant observation is a variant of the above (natural observations) but here the researcher joins in and becomes part of the group they are studying to get a deeper insight into their lives. Participant observation has been highlighted as a useful technique for gathering information that not only relates to the user but is also rich in contextual data (Jääskö & Mattelmäki, 2003).

Neuman states that data analysis means a search for patterns in data and that once a pattern is identified it should be interpreted in terms of the theory and content in which it occurred. The responsibility of the researcher in this process is to transform the description of a historical event into a general interpretation of the meaning of the pattern (1997). Patton and Applebaum build on this definition stating that the goal of data analysis in case-study research is to "uncover patterns, determine meanings, construct conclusions and build theory (2003, p.67). Yin (2009) suggests three strategies which will help the researcher to treat the evidence

fairly, produce convincing analytical conclusions and rule out alternative interpretations. These strategies comprise a) relying on theoretical propositions; b) examine rival explanations and c) develop a case description. These strategies, he contends can be used to structure data analysis using pattern matching, explanation building and cross-case synthesis (Yin 2003). Findings emerging from analysis are greatly enhanced by checking these with participants and referencing it to existing, relevant literature (Hartley 2004).

Data analysis for case studies is somewhat unusual in that much of the data collected are qualitative. In addition, analysis is often concurrent with the data collection phase rather than after it. Once data collection has commenced Yin (1994) recommends that the process of analysing that data should commence. Early analysis is a critical step in the overall interpretation of the case-studies being scrutinized. One approach suggested in early analysis is to conduct a preliminary coding or labelling of the data collected. This strategy allows for the aggregation of data into segments. Codes are tags or labels that assign units of meaning to the data and aid the quick identification of the segments relating to the research questions and any potential themes (Miles and Huberman, 1994:56). According to Miles and Huberman (1994) coding techniques as an early step in analysis utilises the case- oriented approach strategy referred to as 'partial ordered displays' to analyse the case-study data. The next stage of data analysis requires that the data is reduced further into meaningful segments and assigning names to these segments, then combining the codes into broader categories and displaying relationships in data graphs, tables and charts. Initial data analysis efforts such as this position the collected data for more extensive qualitative content analysis.

Content analysis in qualitative research is a theory guided procedure where the researcher transforms collected raw data into meaningful units while simultaneously making continual, iterative judgments about the data at hand. These units referred to by Kohlbacher as 'categories' are extracted from the data through formulation of a case definition (from the theoretical background), applying this to the data, consider 'latent' or hidden meaning, record insights (Kolbacher, 2006). These categories may begin to reveal meaning from the data however further analysis is required to conduct systematic explanation building and generate findings that are credible, valid and generalizable. Two further qualitative data analysis methods are pattern matching and cross-case synthesis. Pattern analysis is a process that involves the comparison of a predicted theoretical pattern with an observed empirical pattern from the data. This process then allows the researcher to determine how accurately the data reflects their theoretical assumptions (Sinkovics, 2018). Cross-case synthesis is a method for comparing data across multiple case studies. In research involving multiple case-studies this analysis method

identifies was in which cases differ or are similar. This type of analysis is usually conducted derived from 'thick descriptions' of the data allowing comparison of rich qualitative data (Weed 2008). A full description of the data analysis methods used in this research are presented in Chapter 5 alongside a detailed outline of the data sources and collection techniques employed.

4.5 Challenges of Conducting Research with Children with Autism

This heterogeneity of presentation of autism complicates the study of its diagnosis, prognosis and treatment interventions (Georgiades et al., 2013) and, it challenges researchers to devise methodologies that can match a diverse range of needs and preferences. As mentioned previously in this work, as many as 50-70% children with ASD also have intellectual disabilities, compromising their social, communication, cognitive, and adaptive skills (Matson & Shoemaker, 2009), impacting upon their abilities to participate in research activities (Coons & Watson, 2013) . Furthermore, one of the core features of ASD: impairment of communication; has a significant effect on a child's ability to partake in activities requiring face-to-face collaboration with others. Although deficits in language skills are by no means universal in autism, they are found in the majority of children with the disorder (Kjelgaard & Tager-Flusberg, 2001). Nonetheless, there are benefits to placing the child with ASD at the centre of the research process. For instance, the children's perspective of the world can differ significantly from that of adults (Frauenberger et al., 2011) and hence, their perceptions of the outcome of the research process may be at odds. Against this background, the question remains how we can best facilitate the inclusion of children with ASD in research. Working with children with complex needs and disabilities poses a range of methodological, practical and logistical challenges for designers or researchers. Firstly, there are issues regarding the ethics of the inclusion of children with such disabilities in projects of this nature. For children with diminished capacity for understanding and limited communication skills the process of consent or assent to participate requires consideration not only of the child's competence to participate but also the extent to which participation is in the person's best interest and the balance of researcher and participant's different agendas (Nind, 2008).

From a practical perspective, design research is typically heavily reliant on traditional, discourse based, collaborative data gathering processes such as observation, interviews, focus groups, questionnaires and simulation. For many children with complex disabilities the high level social and communication skills requires a full engagement with such data collection practices often resulting in researchers modifying and adapting their processes to meet the

needs of participants. In his recommendations on data gathering with people with intellectual and communication disabilities, Brewster (Brewster, 2004) advocates for the use of peer informants to assist researchers in better understanding the contributions children with such difficulties make in research environments. The more significant the potential participant's ID the more reliant they are upon such communication partners and the more skills that are required from a researcher in making judgements regarding the authenticity, credibility and reliability of data gathered (Lewis & Porter, 2004). Previous studies have highlighted the fact that in general, researchers have responded positively to increased user participation in their design processes (Dong & Vivat, 2008; Goodman et al., 2007). These reported benefits however tend to be very general in nature and often tend to highlight how the values of participatory research are reflected. It can be difficult however, within the context of a design project to identify the participant contributions that clarified a design problem or led to an insight that effected a change in the either the process or outcome of design.

4.6 Ethical Issues

The focus of this research involves children with autism as the primary stakeholder. This group presents the researcher with a range of additional ethical and practical challenges. Issues that may arise in research with such populations or groups include concerns regarding their capacity to consent to participate, worries about unequal power relationships between researcher and participant and problems with engagement, communication and collaboration. It has even been suggested that some of these challenges result in researchers avoiding the active inclusion of research subjects with disabilities to avoid possible risks associated with their exploitation and potential harm. This however reduces the opportunities people with a disability have to engage in research activities that may directly affect them and denies them the right to have their opinions and experiences heard (Goldsmith & Skirton, 2015). Inclusive research approaches provide a flexible research framework that can be easily combined with a variety of qualitative and quantitative methods. Inclusive research is characterised by the active involvement of groups of people that share common qualities and/or experiences, as opposed to collectives of individuals and concentrates of cooperation and collaboration. Inclusive research can be described as research that is based on the following principles:

1. Relevance: Address issues which matter most to people with disabilities and which ultimately lead to practical improvements in their daily lives

2. Represent: Actively and accurately represents their views and experiences

3. Respect: Reflects a level of reciprocal respect between the research community and the people with the disability (Johnson & Walmsley, 2003, p.16).

Furthermore, an examination of the ethics of research with children with disabilities requires consideration of the role of the researcher themselves and how they may or may not impact or influence the process, outcome or impact upon children participating. Kirk (2007) stated that ethical issues appear to be of greater concern in literature regarding research with children, due to traditional ideas of their incompetence and vulnerability. However, it has been argued that considerations regarding ethics should focus on children's unequal power relations with adults rather than beliefs around the innate difference (Punch, 2002). In Kirk's (2007) review, it was suggested that the differences between children and adults in research have been overstated and the similarities have been overlooked. Therefore, confidentiality, power relations and informed consent and assent, are ethical issues that are not unique to research with children (Kirk, 2007) but rather must be considered in terms of how they reflect and impact the power imbalance between researcher and subject. There is certainly a need for researchers to firstly reflect on the accepted roles and practices of the researcher and seek a more flexible approach that focuses efforts on creating a platform from which the voices of children with a disability can be heard (Steadman, 2019)

Researchers seeking to conduct inquiry in a more inclusive manner will often address the power imbalances by changing the locus of roles within the research relationship. Some researchers will seek to devolve responsibility for articulating the research questions, recruitment, data gathering and analysis to the research subjects. However, in research with children and adults with learning disabilities this is often not possible and may be considered as placing un-realistic expectations upon research participants and thus reinforcing a negative power dynamic. Steadman (2019) calls for a re-examination of issues of power and representation in inclusive research, suggesting that the practice of simply shifting responsibilities for traditional roles from researcher to subject ignore the often complex and dynamic nature of power balance over the course of any research endeavour. Others have suggested that it is the responsibility of the researcher to establish and put in place mechanisms that ensure that the research relationship is open, transparent and honest (Walmsley, 2004). Putting in place such mechanisms may be seen

as the researcher establishing his/her role as a role of 'supporter' (ibid.) and does not imply that the locus of power is retained with the researcher. Rather than burdening participants in research with unwelcome roles it is recommended that a mechanism for transparent understanding of roles is developed. Failure on the part of non-disabled researchers to share their expert knowledge as well as their skills can be seen to indicate disempowerment. Mechanisms that can be seen to establish a research relationship where the balance of power is more apparent and understood might involve 'role clarification at the beginning of the process, identifying areas of expertise, and establishing guidelines for the team process will mediate power and control issues' (Ward and Trigler 2001 p. 58).

This suggests that one of the most important practices that a researcher can engage in is that of reflexivity. Reflexivity is critical in qualitative enquiry. It enables adult researchers to become aware of their own assumptions about children and childhood and how these assumptions influence the process of research and their understanding of those that they study (Davis, 1998). It involves critically reflecting on the research itself as well as considering the role of the researcher in the process of analysing the data. It is acknowledged that the researcher's social status (relative to participants interviewed), gender and institutional environment has an inevitable impact on the generated data (Davis, 1998).

4.7 Addressing Credibility in Qualitative Research

Quantitative approaches to research such as case-studies have been criticised for their perceived lack of consensus for assessing their quality and robustness. Unlike quantitative research which deals primarily with numerical data and their statistical interpretations under a reductionist, logical and strictly objective paradigm, qualitative research handles non-numerical information and their phenomenological interpretation, which inextricably tie in with human senses and subjectivity. However, the issue of research subjectivity and the impact contextual factors have has fuelled controversy regarding the quality and trustworthiness of qualitative research (Leung, 2015)

The credibility of research endeavours and the confidence that the reader can have in its findings can be assessed in terms of the criteria of validity, reliability and generalizability. These will be expanded upon below; it is clear however from the literature that these standards apply in principle to quantitative and qualitative research alike. These principles however

change in terms of the nature and types of processes both ontologically and epistemologically (Leung, 2015).

Validity is a measure of confidence the reader can have that the results of research are indeed what they claim to be. In traditional research the relationship between researcher and participant is clearly defined, for the most part, as neutral or invisible. It is by this mechanism that the internal validity of the research outcomes is confirmed. Any other relationship is considered a factor that can distort or threaten the internal validity of the study itself. However, when the relationship between researcher and participants in equalised somewhat the perspectives of all participants are valued such that objectivity must be replaced by reflective subjectivity. The importance of the subjectivity of participant's life experiences has been highlighted previously;

"…. one's personal experience is of significance for researcher whether one is the subject of the research, the researcher or the research reader. It shapes how we respond within and to the research process. If we have control it also shapes the research process itself" (Evans & Jones, 2004, p. 15).

Researchers using qualitative methods must ensure that the design is valid for the methodology, the sampling and data analysis is appropriate and that the results and conclusions are validated for the sample and context (Leung, 2015). The methodology selected for this research is outlined in 4.8 below, and the sampling and data analysis are presented in Chapter 5 alongside a description of the context of the study.

Reliability in research refers to the consistency of the process and the extent to which the tools and processes used can produce results can be replicated (S. Lewis, 2015). In qualitative research the key indicator for reliability is consistency. Silverman proposes five approaches for enhancing research reliability; 1) refutational analysis, 2) constant data comparisons, 3) comprehensive data use, 4) inclusion and consideration of deviant data, and, 5) use of tables (Silverman, 2010). He suggests that a process of verification is required to accompany the process of data extraction from source with researchers providing the reader verification of form and context through triangulation, either alone or with peers.

Most qualitative research studies, if not all, are meant to study a specific issue or phenomenon that is relevant or of concern to a distinct population or group of individuals.

Generalisation of findings from case-study research so that it contributes to theory is an important objective in any research study. Generalisation can only be performed if the case-

study design has been appropriately informed by theory and can therefore be seen to add to the established theory. The method of generalisation for case studies is not statistical generalisation, but analytical generalisation in which a previously developed theory is used as a template with which to compare the empirical results of the case-study. If two or more cases are shown to support the same theory, replication can be claimed. In analytic generalisation, each case is viewed as an experiment, and not a case within an experiment. The greater the number of case studies that show replication the greater the rigour with which a theory has been established.

4.8 The Approach for the Current Research

As stated in the introduction to this chapter, the objectives of this research were to develop and implement a framework to support the participation of children with autism in technology design and to evaluate the nature and level of that participation.

The scope of these objectives suggest that the research comprise two sequential stages, an implementation stage and an evaluation stage. The first will implement a proposed framework of techniques to support the participation of children with autism in key activities during the early, intermediate and final phases of a technology design process. The second will analyse the nature and level of participation experienced of children with autism using a proposed evaluation tool. This evaluation tool developed by this researcher will be used as a lens with which to conduct a detailed analysis of the data emerging from the preceding implementation study.

The first phase of this research addresses the following research question and sub-questions:

- RQ1: How can children with autism participate in the design and production of new technology?

  o RQ1.1: What factors affect the participation of children with autism in a design project?

  o RQ1.2 In what ways can adapted PD techniques support children with autism to identify design requirements, contribute creative content and engage in the evaluation of design solutions?

  o RQ1.3: How can adults contribute to and support the participation of children with autism through the phases of a technology design process?

The evaluation study will address the following research questions and sub-questions:

- RQ2: How can the nature and level of participation of children with autism in technology design be evaluated?

  - RQ2.1: What is the nature of participation for children with autism in a technology design process?

  - RQ2.2: What level of participation can be expected of children with complex intellectual and social-communication challenges?

  - RQ2.3: In what ways does the nature of the project impact the level of participation for children with autism?

The nature of the research objectives requires a qualitative approach because such methods aim to understand and describe phenomena from a human perspective in a given environmental context. As established in the review of literature previously presented in Chapter 3, children with autism particularly those with the additional intellectual and communicative complexities associated with this condition are often overlooked in research. The limited number of research studies examining participation in design for this population suggests that new research will seek to identify new knowledge in keeping with a qualitative-exploratory approach. The relative absence of similar frameworks to support participation for children with autism also suggests that this research should be exploratory with a view to inductively deriving generalizations about the participation of children with autism in technology design. a multiple, embedded, exploratory case design was adopted in the implementation study. The implementation stage of this research comprised fourteen exploratory case studies investigation participation for children with disabilities. Four case-studies were concerned with the early phase of design while the intermediate and final design phases were analysed across five case studies each.

The evaluation study will conduct an in-depth examination of the experience of participation for children with autism in a design project using an explanatory case design. This study will draw upon the analysis of three explanatory studies described in Chapter 6. Detailed outlines of the implementation stage of this research is presented in Chapter 5 and the evaluation study is outlined in Chapter 7.

4.9 Summary

This chapter presented and discussed a theoretical rationale for the research methodology adopted in this study. It outlined principles regarding naturalistic, and ethnographic research, and argued for the suitability qualitative-exploratory methods in this current study. It presented the case-study approach and some of its typologies, data collection tools, and analysis strategies. The chapter provided an overview of the two stages of the research methodology, and describes the multiple, embedded, exploratory and explanatory cases which integrate and illuminate the investigation.

This research is rooted in an ethnographic tradition and uses a qualitative approach to support the collection and analysis of data. In addressing the main research questions an exploratory case-study approach was adopted, these were further guided by inclusive research methods that were applied to support the participation of children with autism not only in design processes but to bring a degree of influence to bear on the research process as well. This chapter concludes with an articulation of the two main research questions addressed here and three sub-questions arising from each of these.

A full description of the procedures used in this research across all of the reported case-studies will be discussed further in the next chapter.

Chapter 5: Context, Case Studies and Procedures

Chapter 4 detailed the methodology employed in this research and this chapter will further elaborate on the context in which the study took place and the procedures put in place to facilitate the study. The chapter opens with a short introduction to The State of Qatar, the country in which this study took place. The disability landscape is described in terms of the growing awareness of the issue across Arabic society and governmental actions undertaken to ensure the empowerment and participation of children with autism at different levels in society.

The chapter will provide an overview of a series of fourteen explanatory case-studies conducted over the course of a fourteen-month period with a school for children with disabilities in the State of Qatar. A description of the background to this study will be presented before a more in-depth detailing of the participants, data gathering, and analysis procedures are outlined

5.1 Context of the Study

This series of case studies took place at the Al Noor Institute on the outskirts of Doha in the State of Qatar. The context of the study provided a unique range of challenges and opportunities working across emergent services for children with autism in a country seeking to rapidly evolve such services to international standards. The following section provides a short introduction to the country, its people and culture. It also presents a brief overview of disability services in the country and the landscape of services and supports available to those with autism.

Officially called the State of Qatar, the small Arabic emirate is located on the north-eastern coast of the Arabian Peninsula, it shares a land border with Saudi Arabia to the south and the Persian Gulf. Qatar is a hereditary monarch and has been ruled by the Al Thani family since it transitioned from British Protectorate to a full sovereign and independent state in 1971.

Figure 12: Map of the Middle East highlighting Qatar

Qatar has the highest per-capita income in the world, its wealth backed by the world's third largest natural gas and oil reserves within its territorial region. Although Qatar has a total population of 2.7 million people, only a fraction (300,000) of these are Qatari citizens with the remainder comprising migrant workers. The official language in the country is Arabic and Islam is recognised as the state religion. Sharing a common Arabic heritage and culture with its Gulf neighbours on the Arabic peninsula Qatari society is considered conservative by international standards. Recognition of the rights of people with a disability has evolved rapidly across the Arab world in recent years highlighting efforts to overcome their historical disenfranchisement in Arabic society. Local and pre-Islamic customs and attitudes persisted until recent years, effectively informing the segregation of people with disabilities in the Gulf by keeping them at home, educating them in special schools and institutions thus removing them from the public eye, reducing societal acceptance and limiting their opportunities for participation (Weber, 2012). A lack of awareness and understanding has been highlighted as a significant barrier to the inclusion in civil society for people with a disability across the Arab world. Traditionally, those with disabilities including children with autism were considered a source of shame, a financial burden, even seen as a curse on their families. Such attitudes are fading, but they do still exist and constitute the basis of an awareness raising agenda across the Arab region (Al Thani, 2006). The rise to power of Sheikh Hamad bin Khalifa saw the traditionally conservative emirate of Qatar begin moves towards economic, social and progressive reform. In the early 1990s the Qatar Association for Rehabilitation of People with Special Needs was established with a view to providing cultural, social and vocational services to individuals with a disability through lobbying and collaboration with governmental and non-governmental institutions in the state (Marshall, Kendall, Banks, & Gover, 2009). In 2008, Qatar became one of the early signatories of the United Nations Convention on the Rights of People with a Disability

(UNCRPD) indicating its willingness to strive toward the empowerment of all people with disabilities within the country (United Nations, 2006). From 2008, the government in Qatar has brought in a range of legislative and civil society initiatives across a broad range of sectors including health, education, social care and telecommunications. The 2007 Social Security Act provided monthly benefits to persons with disabilities and a monthly cash allowance for domestic help. In 2014, the Department of the Elderly and Persons with Disabilities was created within the Ministry of Labour to develop and implement relevant programmes and policies. Furthermore, Qatar has implemented a national health strategy which provides free health insurance for persons with disabilities, and a Committee of Disability has been established in order to examine the health, social and family concerns of persons with disabilities (Committee on the Rights of Persons with Disabilities, 2014). Building on its commitment to transform the state into a recognised venue for international sporting events, including the World Cup 2022, Qatar hosted the International Paralympics Committee Athletics World Championships in 2015. Hosting this, the largest disability sports event since the London Paralympics in 2012, was a significant step in raising awareness of disability within Qatari society. Although, broadly welcoming of these positive initiatives, some external commentators have expressed concern that the approach to persons with disabilities was one of segregation and provision of special systems and specialized solutions for persons with disabilities, rather than their inclusion in existing structures such as schools, workplaces and local communities (United Nations Information Service, 2015).

5.1.1 Autism in Qatar

As with many other types of disability there has been limited data available regarding the prevalence of autism in Qatar. The Qatar Biomedical Research Institute, the organisation responsible for the most up to date prevalence studies has suggested that the rates are comparable with international norms. However, limited access to diagnostic services and the presence of social, cultural and religious factors may contribute to under reporting (Alshaban et al., 2017). Although awareness of autism has increased in recent years, misconceptions nevertheless abound with parents reporting poor and inconsistent diagnostic and assessment services and a lack of post-diagnostic support. Parents also expressed dissatisfaction with existing services that they utilise within the country, the availability of expertise and the length of waiting time to access services (N. M. Kheir et al., 2012). Recent research highlighted the impact to quality of life of children with autism in Qatar and their experience of childhood. It showed that children with autism participating in this study spent more time indoors, watching

television or sleeping than their typically developing peers (N. Kheir et al., 2012). Despite the growing body of research pertaining to autism, a recent review found that less than 10 percent of studies focussed on treatment and intervention with the remainder focussed on aetiology, diagnosis and identification of risk-factors (Alnemary, Alnemary, & Alamri, 2017). April 2017 saw the launch of the Qatar National Autism Plan (20017 – 2021) which seeks to address the needs and rights of people with autism and their families. The report has highlighted six areas or pillars where effort will be directed; early recognition and screening; diagnosis and assessment; interventions; education and transition into adolescence, adulthood and old-age (Guldberg, Ashbee, Kossyvaki, Bradley, & Basulayyim, 2017). Although the plan was launched in early 2017, it remains unpublished suggesting a further challenge of translating commitment to action. Notwithstanding, the country has seen a rapid expansion of services for people with autism, including diagnostic services and specialist education. Recent developments include the establishment of the Rou'a Assessment, Advice, and Support Center, the opening of Al-Hidaya, a new kindergarten for Qatari children with autism, and the Renad Academy, a Qatar Foundation specialist school for children with autism.

Figure 13: Instructor engaging with pupils at the Shafallah Center, Qatar.

This highlights a significant expansion, building upon the services provided at older specialist centres such as the Shafallah Centre and the Al-Noor Institute.

During this study, this researcher was working at the Qatar Assistive Technology Center (Mada). The Mada Center is a non-profit organization committed to connecting persons with disabilities to the world of Information and Communication Technology. Founded in 2010 in response the UNCRPD, its efforts are focused on work to improve digital inclusion for persons

with disabilities in the State of Qatar. In developing its services to people with a disability, the centre focussed on the development of key, strategic stakeholder partnerships as a way of building capacity in the country. Such partnerships range from formal institutional partnerships with other service providers such as the Al Noor Institute.

5.1.2 The Al-Noor Institute

The Al-Noor Institute was originally established as the primary non-governmental service provider to the blind community in the country. Over the years its service remit has expanded, and the institute now comprises a non-residential school and rehabilitation centre providing services to children aged 3 – 18 diagnosed with multiple physical, sensory and intellectual disabilities.

This researcher was engaged by the Al Noor Institute to support the work of the Institute's team of Speech and Language Therapists (SLT) by assisting in the design of a range of software resources to support the development and practice of prescribed, pre-verbal social interaction skills. Such a clinical focus would be typical of the therapeutic work SLTs would provide to children with a range of complex disabilities. Prior to commencing this project, a scope of work was agreed between the staff and management of the Al-Noor Institute. This scope of work included the collaborative development of a range of software resources for children with autism attending the on-site school. Over the course of the engagement it was agreed that we would work together in the development of; 1) a series of mini-games to be used with the Kinect™ motion sensor system, 2) a series of language neutral 'cause and effect'[34] games, 3) a series of touchscreen apps to support early language learning and 4) a software application providing children with control of images projected in the centre's multi-sensory room. The overarching ambition for this programme was to install and make available the developed resources as an integrated virtual-learning environment providing technology enhanced, education and therapy opportunities for children availing of the centre's services.

This work was part of a broader research objective set by the Mada Qatar Assistive Technology Centre[35] to develop a range of Arabic and language neutral software resources that

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[34] Cause and Effect games are a term used to describe software that promotes understanding of early interaction skills for children with special needs. These tend to be simple games aimed at building children's visual attention and orientation skills.

[35] The Mada Qatar Assistive Technology Centre is a dedicated service centre providing a range of disability and technology related services in the State of Qatar. The scope of the research and development collaborations included this includes research and development of software for children with autism and intellectual disabilities and resources to support children with visual impairments served by the Al Noor Institute,

could be used by children with disabilities across the Gulf Region of the Middle East. During the initial planning for this design project it was agreed that some of the children from the school would participate in the design of the technology that they would eventually use in the school.

5.2 Overview of Case-Studies

A total of fourteen case-studies were completed at various intervals across the course two years as part of this study. A summary of the case-studies is outlined in Table 3 below, briefly describing each of these in terms of the design objective for that case study, the number and gender of participating children, the location, the phase of the design process under scrutiny, the methods techniques evaluated and the output from the case-study.

The case studies took place between June 2017 and June 2018. The case-studies are numbered in terms of the sequence in which they occurred. Each of the case-studies comprised a series of workshops[36] relevant for the each of the phases of the design process.

Case-studies I, IV, VI and XI addressed participation of children with autism in the early design phase. Each of these case studies comprised four workshops; 1) observation, 2) storytelling, 3) photography and 4) wall of us. Case Studies II, V, VI, VII, XII and XIII addressed the participation of children with autism in the intermediate phase of the design process and comprised two co-creation workshops; 1) design with technology and 2) design with adults. Case Studies, III, IX, X and XIV dealt with the final stage of the design process comprised two evaluation workshops; 1) shared decision making and 2) decision making with adults. The next section describes the case-studies associated with each design phase in detail. This is then followed by a description of the workshops that comprised each case-study.

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https://www.marhaba.qa/mada-and-al-noor-institute-sign-agreement-to-support-technological-needs-of-the-blind-in-qatar/.

[36] Each of the workshops (except Workshop 1) took place in the same training room at the Al Noor Centre that had been made available for this research. Each workshop set-up was guided by principles of good practice for conducting such with children with autism. Appendix I outlines the Workshop Checklists used and an example of some of the Visual Schedulse used to guide the execution of the workshops.

Case Study No.	Design Objectives	Numbers of children with autism	Design Phase (DP) Examined	Methods & Techniques	Project Output
Case Study I	Identify User Requirements	4 Male 1 Female	Early	• Observation in context • Proxy Storytelling • Context Mapping: Photovoice • Collaborative Reflection	Kinect™ Games
Case Study II	Co-Create visual content	4 Male 1 Female	Intermediate	• Technology supported design • Adult supported design	Kinect™ Games
Case Study III	Prototype Evaluation	4 Male 1 Female	Final	• Supported decision-making • Decision-making support materials • Adult supported decision making	Kinect™ Games
Case Study IV	Identify User Requirements	3 Male 2 Female	Early	• Observation in context • Proxy Storytelling • Context Mapping: Photovoice • Collaborative Reflection	Sensory Room App
Case Study V	Co-Create visual content	6 Male 0Female	Intermediate	• Technology supported design • Adult supported design	Sensory Room App
Case Study VI	Identify User Requirements	5 Male 1 Female	Early	• Observation in context • Proxy Storytelling • Collaborative Reflection	Touchscreen Apps
Case Study VII	Co-Create visual content	5 Male 1 Female	Intermediate	• Technology supported design • Adult supported design	Touchscreen Apps
Case Study VIII	Co-Create visual content	7 Male 2 Female	Intermediate	• Technology supported design • Adult supported design	Touchscreen Apps
Case Study IX	Evaluate visual design elements	6 Male 2 Female	Final	• Supported decision-making • Decision-making support materials • Adult supported decision making	Touchscreen Apps
Case Study X	Prototype Evaluation	4 Male 1 Female	Final	• Supported decision-making • Decision-making support materials • Adult supported decision making	Touchscreen Apps

Case Study XI	Identify User Requirements	5 Male 1 Female	Early	• Observation in context • Proxy Storytelling • Collaborative Reflection	Cause & Effect Apps
Case Study XII	Co-Create visual content	5 Male 1 Female	Intermediate	• Technology supported design • Adult supported design	Cause & Effect Apps
Case Study XIII	Co-Create visual content	8 Male 2 Female	Intermediate	• Technology supported design • Adult supported design	Cause & Effect Apps
Case Study XIV	Prototype Evaluation	4 Male 1 Female	Final	• Supported decision-making • Decision-making support materials • Adult supported decision making	Cause & Effect Apps

Table 3: Description of Case-Studies

5.3 Description of Case-Studies

5.3.1 Early Design Phase Case-Studies

In Chapter 2 it was established that the early phases of the design processes are concerned with capturing the lived experience of the child with autism and translating these into a specification of requirements that can guide the remainder of the design process. The objective of these case-studies was to analyse the participation of children with autism in the early phase of design. Participation in the early phase of a design process is concerned with the capture, understanding and translation of the lived experience of children with autism. The objective of early design phase case-studies I, IV, VI and XI was to implement the relevant techniques and to investigate in detail how they contributed to the participation of children with autism in the early phase of technology design. To this end, each of these case-studies comprised four workshops outlined in Table 4 below accompanied by a description of the workshop and the relevant design technique examined:

Early Design Phase: Case-studies I, IV, VI & XI			
	Workshop Name	**Design Technique Investigated**	**Workshop Description/Objective**
Workshop 1	**Observation**	Observation in context	This workshop consisted of each designer spending three half days observing participating children with autism in class and during their therapy sessions.
Workshop 2	**Stories Workshop**	Proxy Storytelling	Provided opportunities for those with experience working with the participating children to tell stories, share experiences and anecdotes that would contribute to building a picture of each child's needs, requirements and the contexts within which they might use the anticipated software resources.
Workshop 3	**Photo Workshop**	Context Mapping: Photovoice	This workshop provided children with autism and adults working in pairs the chance to capture photography that represented their needs and preferences. The workshop also provided an opportunity for each child/adult pairing to present these with the designers with a view to furthering their understanding of the lived experience of participating children
Workshop 4	**Wall of Us**	Collaborative Reflection	The purpose of this workshop was to allow the three designers to present a series of mind-maps of the data that they had gathered and to consider this data collaboratively with participating children with autism and participating staff.

Table 4: Description of workshops in early design phase case-studies

5.3.2 Intermediate Design Phase Case Studies

It is during the intermediate design phase that participants generate content for the design solution and incorporate these into proposed design solutions. Reflecting the collaborative nature of the process, this phase is often referred to as co-design. In this phase tangible content contributions are generated upon which the team can begin to develop elements of the design solution or prototypes of various fidelities. The objective of these case-studies was to analyse the participation of children with autism in the intermediate phase of design by investigating the way they can be supported to generate visual content for incorporation into potential design solutions. Case-studies II, V, VIII, XII and XIII provided an opportunity to investigate how generating visual design content contributed to the participation of children with autism in the intermediate phase of design. The objective of intermediate design phase case-studies was to provide children with autism with supports by way of assistive technology and adult assistance and to investigate in detail how these contributed to the participation of children in the intermediate phase of technology design. To this end, each of these case-studies comprised two workshops outlined in Table 5 below accompanied by a description of the workshop and the relevant design technique examined:

Intermediate Design Phase: Case-studies II, V, VIII, XI & XIII			
Workshop No.	**Workshop Name**	**Design Technique Investigated**	**Workshop Description/Objective**
Workshop 5	**Designing with technology**	Technology supported design	This workshop saw children with autism supported by adult participants use a range of individually selected technology to generate visual content to contribute to the proposed design solution. The objective of this workshop was to explore how the technology supported children in generating visual contributions.
Workshop 6	**Designing with adults**	Adult supported design	This workshop also saw participating children use a range of individually selected technology to generate visual content to contribute to the proposed design solution. However, the objective of this workshop was to explore the nature of support provided to them by adults and how these facilitated children generating visual contributions.

Table 5: Description of workshops comprising each of the intermediate design phase case-studies

Preparation required that the participating children be provided with the appropriate equipment they required to express themselves creatively by way of generating visual content. As such, all children who participated in any of the intermediate design phase case studies were

engaged in an Assistive Technology (AT) Assessment by specialist professionals from the Mada Qatar Assistive Technology Centre[37]. Following completion of the assessments, the team from Mada finalised provision of the equipment and training for children and staff in its set up and use. The composition of the equipment provided to each child matched hardware and software to their individual profile of physical, sensory and cognitive skills. A table illustrating examples of the technology solutions provided as a result of these assessments is outlined in Chapter 6 alongside one explanatory, intermediate design phase case-study.

Once each child had been equipped with the technology he or she required each participating child was paired with an adult, from the three team designers, the four TAs and the three SLTs in this study. One to two adults were assigned to support each of the children depending on the anticipated level of support that they would require. The workshops were held in a training room that was made available specifically for use during this research study.
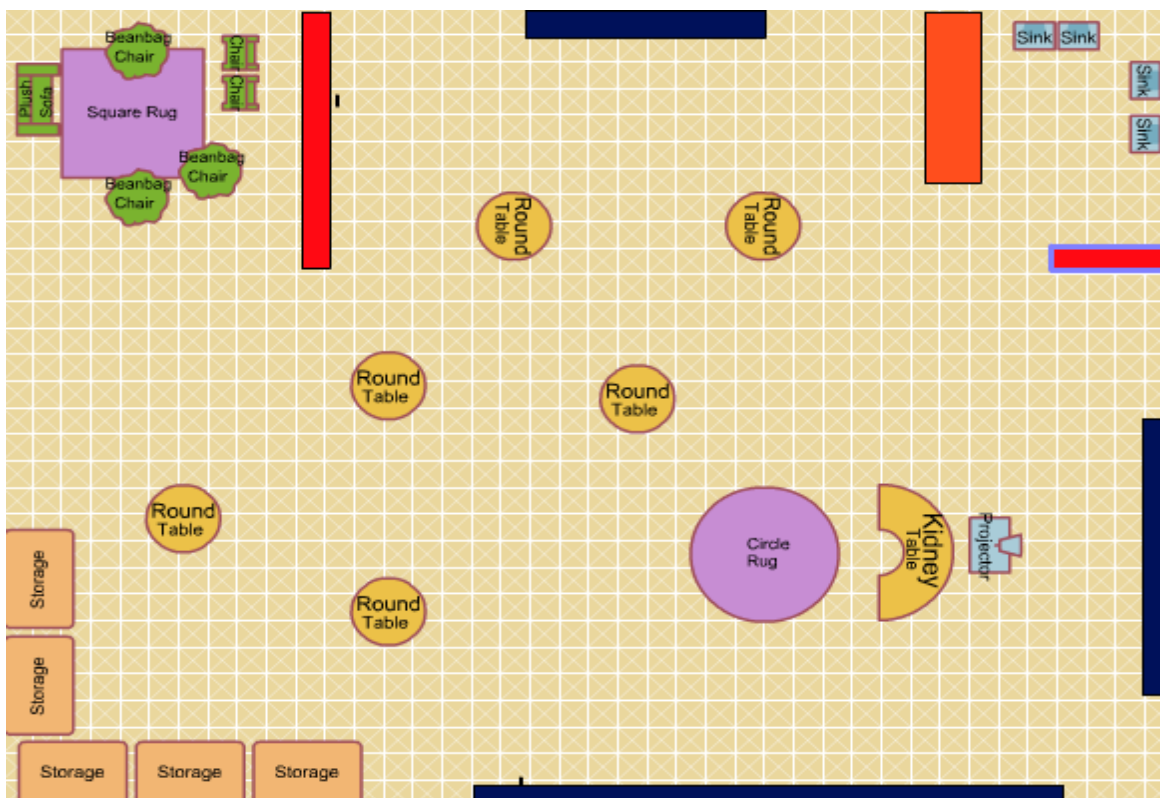
Figure 14: Set-up and lay-out of the workshop space for intermediate design phase case study workshops (5 & 6)

Figure 14 presents the set-up of equipment and the lay-out of furniture for the two workshops. Considering the needs of the children in question a separate relaxation/break out area was organised to one side of the room; this area contained a temporary partition with a

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view to minimising any unwanted visual stimulation for children who may have become agitated. A series of six round tables were located in the room with enough space to host the child and one to two additional adults. All the technology provided to the children for use during the workshops was housed in secure storage within the room to ensure that it was always available when needed. The room also contained a digital projector, screen and table to facilitate showing the visual contributions generated by the children. Following these preparations, two, short workshops were scheduled on two consecutive mornings each lasting approximately thirty minutes. Each workshop was attended by this researcher who recorded field notes throughout and videotaped both.

5.3.3 Final Design Phase: Case Studies

The final phase of design projects involves evaluating refining the emerging vision of the project outcome. It is at this stage that the ideas gathered are translated into a representation of what will become the final outcome. These representations can be elements of the design, interaction models or prototypes and provide participants in the process with their first opportunity to engage with and evaluate a tangible artefact. Proceeding to a final design outcome requires participants to iteratively evaluate the various design elements, prototypes and proposed solutions that emerge from the intermediate phase. Evaluation requires that participants actively express choices and make decisions with regard to the various options available. Participation in the final phase of design can therefore be considered in terms of how a child with autism engage in decision making. Children who are functionally non-verbal will require a degree of support to engage in decision making and thus participate in the evaluation activities that comprise this phase of design. The objective of final design phase case-studies III, IX, X, XII and XIV was to provide children with autism with the supports required to make choices and decisions during design evaluation activities. To this end, each of these case-studies comprised two workshops outlined in Table 6 below accompanied by a description of the workshop and the relevant design technique examined:

Final Design Phase: Case-studies III, VII, IX, X & XIV			
Workshop No.	Workshop Name	Design Technique Investigated	Workshop Description/Objective
Workshop 7	Shared Decision Making	1. Supported decision making 2. Support Materials for decision making (communication cards)	This workshop saw children with autism provided with a decision making script outlining all of the decisions to be made during the workshop in simplified form to match their cognitive and communication skills. Children were also provided with a range of material supports by way of communication cards with appropriate symbols as alternatives to verbal communication.
Workshop 8	Design making with adults	Adult supported decision making	This workshop also saw participating children provide with similar decision making script as in workshop 7, representing the design choices and decisions to be made over the course of the workshop. Children had access to the same material supports, however in this workshop adults were told to play a more active role in translating and representing children's choices and decisions for the designers present.

Table 6: Description of workshops comprising each of the intermediate design phase case-studies

In the planning for each of the final design phase case studies, each participating child was paired with an adult, from the three team designers, the four TAs and the three SLTs in this study. One or more adults were assigned to support each of the children depending on the anticipated level of assistance that they would need.

In preparation for the workshops the following support materials were prepared for use during evaluation tasks that featured in both workshops.

Firstly, a script was prepared outlining a visual-sequence of the decisions that were to be made during the workshop. Based on the principles of Shared Decision Making discussed in section 3.3 of Chapter 3 in this thesis, the purpose of this script was to simplify and sequence decision making to minimise the demands upon their comprehension and expressive communication skills. Referred to as a Decision Making Protocol, this tool was intended to support adults in guiding children with a process of making decisions between visual representations of the various design items fabricated by the designers following the workshops in the intermediate design phase case-studies. This Decision Making Protocol or script took the form of an A4 sized booklet and provided space to allow adults to write the decisions and choices made by children and record how they did so. An example is presented in Appendix D.

Secondly a series of alternative and augmentative Communication Cards were developed to support the communication of children with autism. These cards were developed to provide individual symbolic communication choices to children. These served as an alternative to using verbal communication with the view that children who are non-verbal could point or gesture to the cards to indicate their communicative intent. The symbols used were recommended by a specialist SLT working at the Mada Centre on a project to develop an Arabic corpus of communication symbols[38].
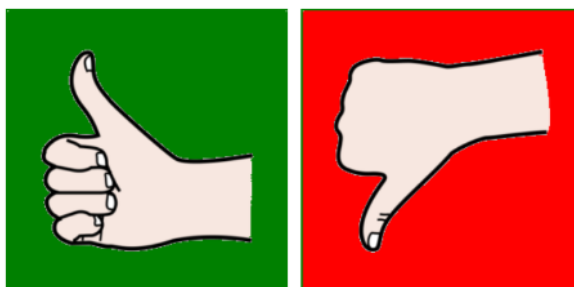
Figure 15: 'I Like' and 'I Don't Like' Communication symbols

A series of cards seven cards in total were produced for use during the workshops in the final design phase case-studies. A separate symbol representing an individual communication intent such as "yes", "no", and "I like" were printed on 35mm x 35mm coloured cards and laminated by staff at the Al Noor Centre. Six sets of these cards were produced and made available to each group of adults and children.
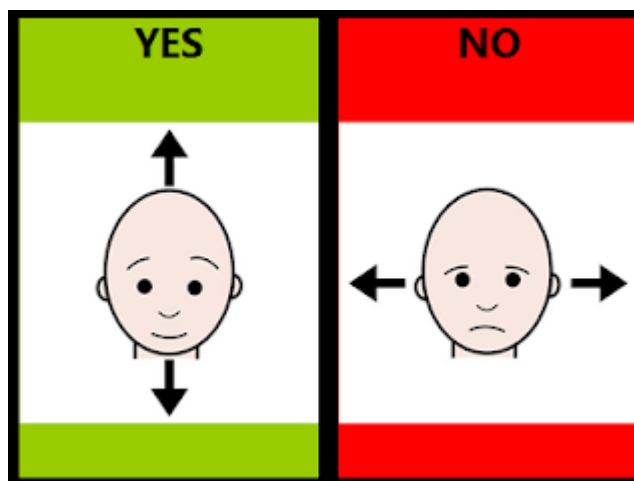
Figure 16: Yes/No symbols made available to support children's decision making

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[38] The Tawasol project was a project involving the Mada Centre and the University if Southampton's Department of Computer Science aimed at developing a bilingual Arabic/English symbol dictionary for use with and by children with communication impairments http://madaportal.org/tawasol/en/home/.

Finally, a Communication Protocol for Adults was developed to guide the behaviours and actions of adults as they supported the decision making of children with autism as they participated in the workshops. This protocol provided a behavioural guide for adults ensuring that they provided the appropriate support to each child in a logical and reasoned sequence. The aim of this was to minimise adults acting as proxies and making decisions on behalf of the children. Adults participating in the workshops were provided with a ten-minute orientation to the protocol immediately in advance of each workshop.
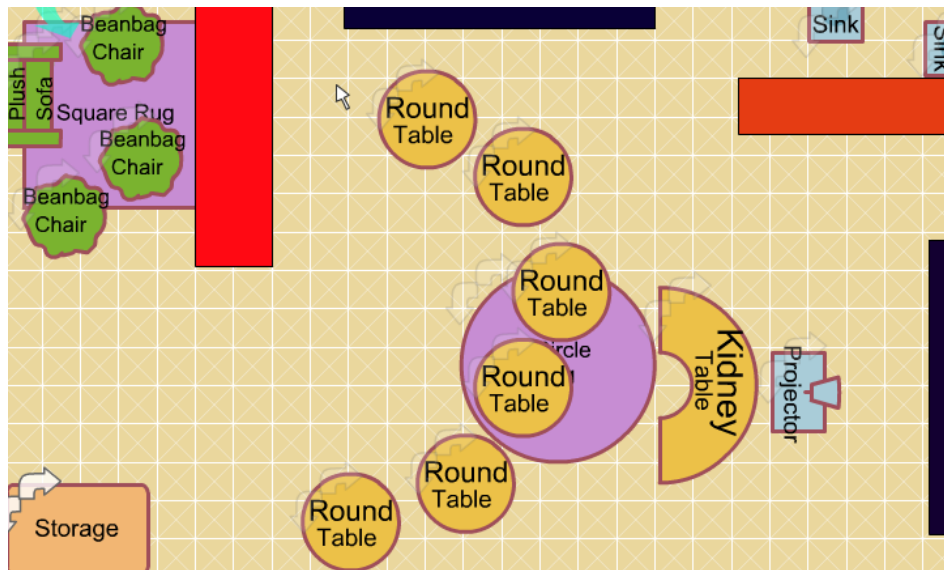
Figure 17: Set-up and lay-out of the workshop space for final design phase case study workshops (7 & 8)

Figure 17 above outlines the lay-out of the workshop space which brought the individual tables closer together providing those participating with the opportunity to engage with the paper based materials provided (Decision Making Protocol and Communication Cards) or alternatively, they could use the projection screen to view images of choice that they were making. Using a standard MS PowerPoint presentation, one of the designers introduced each of the graphic elements developed, including scene backgrounds, avatars, characters and other visual elements and when available, briefly described a narrative storyline that would underpin the anticipated software activities in the final version.
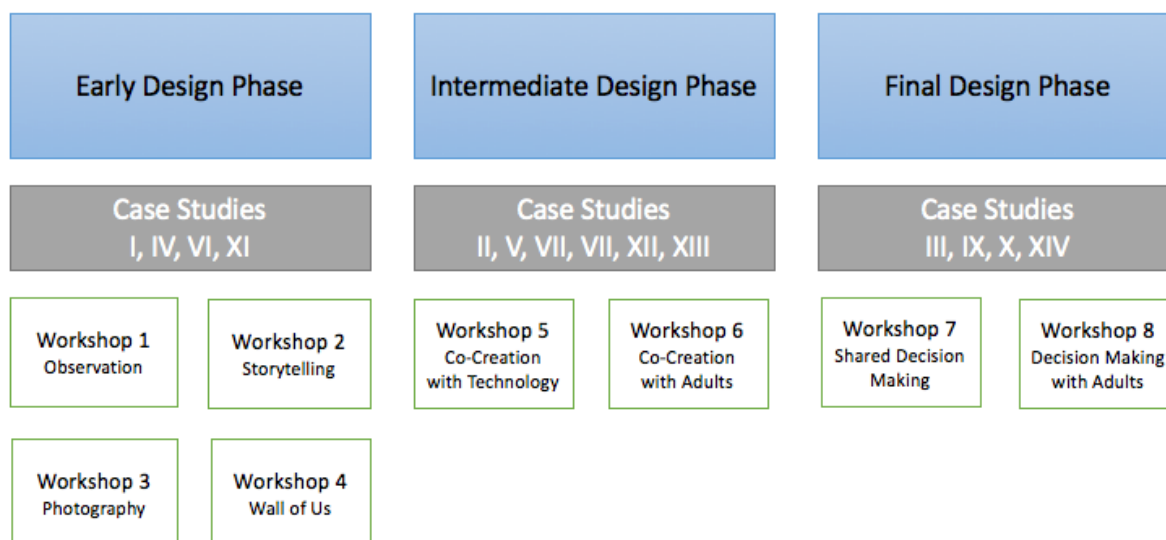
Figure 18: Graphic representing the design phase, case-studies and workshops

5.3.4 Description of Workshops

The graphic in Figure 18 above identifies the four workshops that comprises each case study associated with the respective design phase they address. These are now briefly described below. Workshops 1–4 were used in each of the case-studies addressing the objective of capturing and reflecting the lived experience of the child with autism.

Workshop 1: In the first workshop (Observation) the three designers were scheduled to spend three half-days from one week as an observer in each of the two classes attended by the participating children or in their therapy sessions[39.] Each designer rotated location daily conducting their observation sessions in the morning before coming together as a team in the afternoon to discuss their observations and to begin to develop their collective understanding of the children and context for the software that was to be developed. During these meetings which lasted approximately fifty minutes, each of the designers supplemented and annotated their collected field notes.

Workshop 2: The second workshop (Storytelling Workshop) was facilitated by this researcher who use a variety of probes to provide a platform for the three participating SLTs who had worked with the children to tell stories and share anecdotes of their experiences with the children. This workshop took place in one of the school classrooms and was scheduled as a replacement for children's circle time activity

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[39] Most therapeutic sessions (speech and language therapy, occupational therapy, behaviour management or physiotherapy) took place outside of each child's class environment. The child was typically withdrawn from the class, brought to the relevant treatment rooms and engaged by the relevant therapist.

Workshop 3: (Photography Workshop) involved the participant children directly for the first time with each child being paired with an adult participant and provided with a switch adapted-camera[40]. Each pair were then instructed to spend thirty minutes taking photos of the following: 1) "the things I love in school", 2) "the things I hate in school" and 3) "what fun looks like".

At the end of the thirty allotted minutes, all participants met again in an assigned training room with a laptop and projector and each of the adults was asked to show their photos and explain why they took these. All the captured photos were collected on separate folders on the researcher's laptop and field-notes were recorded by the facilitator during each of the participating adult's photo presentation.

Workshop 4: A final, fourth workshop (Wall of Us) was scheduled approximately one week after the completion of the three workshops described above. In preparation for this workshop, one or two design meetings comprising the team designers and this researcher were used to aggregate data collected discuss these and devise a series of initial mind-maps that represented the data on a child by child basis with the ambition of creating one, composite visual map that represented the data assimilated representing the lived experience of each child. These mind-maps were then used to engage in collective reflection with children with autism in the workshop. The workshop took place in the same activities room adjacent to the children's classrooms and with which they were familiar. The session lasted approximately thirty-five minutes and was videotaped by this researcher. Using an overhead digital image project, the collated mind-map (The Wall of Us) was projected on a wall in the training room at a size that would be visible by all. All adult participants were provided with a block of post-it notes and it was explained that once [MM] explained the contents of the Wall of Us, then adult participants would be given approximately 10 minutes to engage with the representation and could add comments, corrections or additions by writing these on the post-it notes and placing these on the projected image.

Workshops 5 & 6 took place in each of the case-studies addressing the intermediate design stage.

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[40] A switch adapted camera is a highly simplified point-and-shoot camera designed for users with a range of physical or cognitive disabilities. All of the camera's functions are controlled by either pressing the case-mounted button located at the top on the camera, or through an external button - called an accessibility switch - plugged into the side on the camera. For the purposes of this study 6 cameras were made available to this researcher by the Mada Qatar Assistive Technology Centre. Full camera details are in Appendix H.

Workshop 5: The first co-design workshop (Design with technology) was structured to facilitate children with autism to use the technology provided in preparation for the workshop an opportunity to begin generating visual content to be provided to the designers with which they could begin to develop elements of the design solution. Each child used the AT provided to them ahead of the workshop, this was set up by the participating adults

Workshop 6: the second co-design workshop (Design with adults) had a similar objective to the previous one although this time, adults were instructed to provide much more support to each of the children participating and were allocated a series of responsibilities by this researcher to facilitate children to generate visual content of their own volition during the workshop.

Workshops 7 & 8 were used in each of the case-studies addressing the final design stage.

Workshop 7: Shared Decision Making: In the first of the two workshops (workshop 7), between eight and sixteen composite images (based on the contributions previously gathered), representing elements of the visual interface for the proposed software was presented to each of the participating children were given the opportunity to choose the one they preferred.

Workshop 8: The second workshop, presented a similar number of images which translated into between six and ten 'decision-making opportunities for children typically in each of the workshops. This time however, the images were iterative elaborations of the selections made by children with autism previously in workshop 6. Each workshop lasted for a duration of between twenty-five and forty-five minutes.

5.4 Participants

A total of sixteen children with a diagnosis of autism[41] (as confirmed by their teacher and school administration) participated across the fourteen case-studies in groups ranging from four to eight children. This group was made up of twelve boys and two girls aged between 8 years and 13 years. Selection of children to participate in the project was based on several factors including information regarding their diagnosis and the presentation of their disability and other concerns such as their previous history of participation in group activities, their perceived interest in using technology and classroom timetabling.

All sixteen children participating also presented with a significant intellectual or developmental disability[42] affecting their comprehension and expression skills, their attention and concentration and their ability to engage with complex tasks. All children were reported by their relevant SLT as functionally non-verbal[43,] they could however engage in non-verbal communication with others to varying degrees. All children were reported as coming from homes where Arabic was the language spoken by their families. Similarly, all education at their school was delivered through the Arabic language. None of the children had been previously involved in any design workshops or studies of a similar nature.

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[41] Diagnostic services for children with autism in Qatar at the time of the study were limited. In many circumstances families sought diagnosis from medical services outside of the country. Record keeping practices were imprecise and independent, verifiable results of standard diagnostic tests were not available to me during this study. As such, the selection of children with autism was

[42] The school's admission policy was such that the school population comprised children that had been determined as having a severe to profound ID corresponding to a recorded IQ score of less than 55.

[43] Assessment of communicative function was based on the clinical judgement of SLTs. In many instances each therapist was making their diagnosis based on observation and clinical experience rather than using standardised tests as would typically be the case in Ireland, the UK and the US. At the time of this research study there were limited standardised assessment tools available as such SLTs were using translated versions of tests such as the Peabody Picture Vocabulary Test-4 and the Vineland II Communication subtests. As the translations had not been standardised these were mainly used as exploratory rather than diagnostic tools.

Description of Participating Children				
Anonymised names	Gender	Age	Additional Medical History/ Co-Morbid Conditions	Case Study:
Child 1	Male	8	Cerebral Palsy, ID	1,2,4,6,7,10,12, 14
Child 2	Female	10	Epilepsy, visual impairment, ID	4,7,8,9, 10,12, 14
Child 3	Female	11	ID, unspecified metabolic disorder	1,2,3,8,9,
Child 4	Male	9	Hydrocephalus, ID	1,2,4,7, 10, 12, 14
Child 5	Male	9	ID, unspecified metabolic disorder	3,5,8,9, 13
Child 6	Male	7	Visual impairment, ID	3,5,8,9, 11
Child 7	Male	7	Cerebral Palsy (non-spastic), ID	1,2,4,7,9, 10
Child 8	Male	12	Joubert Syndrome, visual impairment, ID	3,5,8, 11, 12, 14
Child 9	Male	11	Unspecified metabolic disorder, ID	1,2,3,9, 13
Child 10	Male	13	ID	4,5,8,9, 11
Child 11	Male	11	Hearing Impairment, hydrocephalus, ID	4,5.6,7, 10,13
Child 12	Male	8	Robinow syndrome, ID	4,5,6,8,
Child 13	Male	8	ID	1,7,8,9,10,13
Child 14	Male	13	Visual impairment, ID	6,8, 11, 12, 14
Child 15	Female	9	ID	9, 11
Child 16	Female	11	Cortical visual impairment and ID	9, 11

Table 7: Description of participating children

For the purposes of developing the specified range of software resources a project plan and 'design team' were established by this researcher. In establishing a 'design-team' to attend the workshops and participate in a range of prescribed procedures that aided the development of the software resources, this researcher determined that the 'team' for each case-study should comprise, 1) children with autism, 2) speech and language therapists, teachers and/or care staff familiar with the participating children, 3) software designers and 4) a facilitator. The composition of participants for each of the case studies was determined in consultation with school staff based on their availability and their perceived willingness to be involved[44]. Appointment to the 'design team' (sampling) was done on an opportunistic basis with adult volunteers sought on a one-to-one basis by this researcher and the selection of children to be approached for participation made by the three participating SLTs alongside this researcher. Assembling the 'design ream' for each case-study can be viewed as a mixture of opportunistic and snowball sampling as is often the case in qualitative research such as this (Noy, 2008., Gentles, Charles, Ploeg & McKibbon 2015). In this study three of the five departmental SLTs consented to participate with the remaining two choosing not to participate because of planned holidays and concerns regarding their ability to participate in a project where the working language would be English. The three participating SLTs all had experience working with children with autism and intellectual disabilities ranging from two to twelve years of experience each. All three were native Arabic speakers but were fluent in both Arabic and English. Two teachers (both male) from the school staff and four of the Teaching Assistants also agreed to be available for participation.

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[44] In some instances, teachers would decide as to the child's mood and the impact that this may have on his/her ability to participate in activities outside of the classroom. This assessment practice was not limited to participation in activities associated with this study but was observed to extend to other activities such as school trips, exercise classes, errands, therapy sessions and swimming.

Description of the participating school & therapy staff			
Anonymised name	**Role**	**Gender/Age**	**Description & Relevant Experience**
SLT 1	Speech and Language Therapist (SLT)	Female (44 years)	SLT with over twelve years' experience working with children with autism. Reported limited experience using technology as part of therapeutic practice.
SLT 2	SLT	Female (26 years)	SLT with less than two years' post-graduation experience working with children with autism.
SLT 3	SLT	Female (35 years)	SLT with three years' experience working with children with autism and a further seven years working with teenagers with intellectual disabilities
Teacher 1	Class Teacher	Male (48 years)	Teacher with eighteen years of experience in an education capacity with children with autism and intellectual disabilities.
Teacher 2	Class Teacher	Male (29 years)	Teacher with four years' experience working with children with autism. Previously delivered Information Technology programmes to adults with intellectual disabilities.
TA 1	Teaching Assistant/Carer	Female (20 years)	Carer with less than a year's experience working at the Al Noor Institute
TA 2	Teaching Assistant/Carer	Female (26 years)	Carer with three years' experience working at the Al Noor Institute
TA 3	Teaching Assistant/Carer	Female (26 years)	Carer with seven years' experience working at the Al Noor Institute. She has a visual impairment and was previously a service user of the Institute
TA 4	Teaching Assistant/Carer	Female (51 years)	Has worked at the Al Noor Institute of over ten years but had mainly worked with children with visual impairments only supporting their transition to mainstream schools. Newly transferred to the special education classes.

Table 8: Descriptions of participating school and therapy staff

Three software engineers (henceforth referred to as 'designers') were involved in the project with responsibility for the technical development of the various design outputs from the project. These three comprised one graduate computer scientist who was employed as a

software developer with the Mada Qatar Assistive Technology Center supported by two additional final year undergraduate, Computer Engineering students who worked on the project as voluntary interns.   Case studies I–VIII, X and XII - XIV had three software designers participating assuming the roles of professional designer. Case Studies IX and XI had only two designers present due to the unavailability of the third designer.

This researcher took the role of facilitator for which his responsibility extended to the planning and management of each of the three workshops and the final presentation. The facilitator was responsible for the logistical and management functions required to ensure that each of the workshops were organised, set up and executed as planned and to ensure that the project reached its stated objectives.

Description of the designers		
Anonymised name	Age/Gender	Description
SM	20 years old /Female	Computer Engineering student with previous experience in collaborative projects with children with a disability, specifically designing an app for the Deaf community in Qatar.
SD	22 years old /Female	Computer Engineering student with no previous experience working with children with autism.
MM	34 years old /Male	Software design professional (male) with 7 years' experience of Educational Technology development projects, including software for children with disabilities.

Table 9: Description of the Designers

Two additional, support roles were added to the design team to ensure that it functioned effectively and allowed this researcher to conduct the research project.

Although the working language for all the case-studies was English, to support translation, case-studies I to X and XII to XIV had a bilingual Arabic-English translator present throughout all activities including workshops, focus groups and interviews[45]. A bilingual, English/Arabic speaking member of the Mada team made herself available to take on this role. The translator was present for each of the case-studies in a non-participant role; rather her role was to provide translation support for this researcher if immediate translation of Arabic

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[45] This translator was unavailable for any of the activities comprising case-study XI due to prior leave commitments.

dialogue from participants was required. Similarly, the translator was available to translate instructions or communications to Arabic for participants who might have trouble understanding.

Finally, another member of the Al Noor staff volunteered for another non-participating role in the design team, taking the role of Children's Liaison, which focussed on ensuring the well-being of the children participating and providing reports back to each of the class teachers as to the children's experience during the various workshops. The two non-participating team members were clear that their responsibilities were primarily to ensure the welfare of the children participating and to support the researcher and they did not participate directly in the design activities described across the case studies.

5.5 Ethical Procedures

Prior to this study taking place an application for ethical approval to the School of Computer Science and Statistics at Trinity College Dublin was successfully completed as was local ethical approval from the Mada Qatar Assistive Technology Center. All participants (described above) were fully informed both verbally and in writing as to the purpose of the project, the implications of their participation and any potential issues or risks they may face. While the children participating were provided with an assent form, none of the children across both studies could give their active, informed assent. As such, the submission of the Parent/Guardian Consent form was required as a pre-requisite to participation. For adult participants, they signed either an English or Arabic language consent form. All ethics consent forms used in this study are reproduced in Appendix A of this thesis.

5.6 Data Sources & Management

A broad range of rich data sources was drawn upon during this study. This included: this researcher's field work notes, the designers' field notes, audio recordings and video recordings, mind maps, the digital images contributed by children and the interpreted images developed by designers and the software artefacts that emerged from each of the software design projects. A summary of these data sources is outlined in Table 10 below.

	Early Design Phase					Intermediate Design Phase						Final Design Phase			
Case Study number	I	XI	VI	IV	I	XIII	XII	VIII	VII	V	II	XIV	X	IX	III
Researcher field Notes.	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Designers Field Notes	✓	✓	✓	✓	✓	x	x	x	x	x	x	x	x	x	x
Video Recording	x	x	x	x	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Stories (audio-recordings)	6	9	9	5	6	x	x	x	x	x	x	x	x	x	x
Mind Maps	1	4	4	2	1	x	x	x	x	x	x	x	x	x	x
Digital Images	x	x	x	x	x	29	35	31	43	19	25	x	x	x	x
Decision Making Protocol	x	x	x	x	x	1	2	1	1	1	2	4	5	5	3
Design solution	x	x	x	x	x	x	x	x	x	x	x	✓	✓	✓	✓

Table 10: Summary of data sources

This researcher used a field work observation schedule developed to assist in recording all observed phenomena. This template was completed in longhand and later transcribed by this researcher to assist in engaging with and reflecting on the observations recorded. A copy of the schedule template and an example of a transcribed observation recording is presented in Appendix B of this thesis. Designers used the same template during their observation workshops, these were collated and aggregated by this researcher according to the date the observations were made. This allowed interrogation of the common observations across all three designers. Video recordings of each workshop were kept on a digital camera and passed immediately to a member of the Al Noor staff who transcribed the recording within approximately forty-eight hours of the completion of each session. This researcher then had a further twenty-four hours to review the transcription and the original making any required changes before the file was destroyed in accordance with the Al Noor data ethics policy. The

remaining, unified transcripts were then transferred from the researcher's laptop to a secure, encrypted storage location on a Trinity College Dublin's server.

Similarly, with the audio recordings of the adult's stories, these were recorded on a digital Dictaphone and were passed to the Al Noor staff member who again transcribed it in full within approximately forty-eight hours. All digital images generated by children and by the three designers were initially stored on an encrypted hard drive belonging to this researcher but were transferred to a secure, encrypted storage location on a Trinity College Dublin's server network. Finally, the Decision Making Protocol booklets provided to each child/adult group were initially collected with a view to examining the notes taken by adults, however this idea was abandoned and the booklets discarded and destroyed due to the lack of notes or comments recorded on these.

5.7 Data Analysis

In the first phase of the research, data was analysed both within and across the fourteen case-studies. Acknowledging the benefits to undertaking the process of analysis of case-studies quickly, this researcher transcribed all observation field notes recorded and those of the designers. Video and audio transcriptions were reviewed and compared with raw, source data. These processes ensured data validation and allowed the data to be checked for completeness early in the process. Transcribed data was coded on a case by case basis as it was collected using Strauss and Corbin's coding protocol which suggests first order labelling to establish initial concepts, microanalysis using open coding, selective coding and finally sorting (Strauss & Corbin, 1998). The first order labelling ordered the data into discrete fragments and assigned labels describing these fragments based on the theoretical knowledge assembled during this study. Reflecting the desire to bring a perspective informed by experience to the early analysis this researcher conducted this labelling at the same time as data completeness checks were taking place. First order labels were then collated separately as a unit for further analysis later in the process. Micro-analysis was conducted using an open coding process, which start with scanning transcriptions and field notes and is followed by coding paragraphs then sentences and finally line-by-line coding. Following selective coding and filtering each individual case-study was sorted into categories. These categories were finally aggregated alongside those case-studies in each of the design phases. An example of the coding process used in this study is presented in Appendix F. Following an initial analysis of data within case studies, all the case studies data were aggregated based on whether they address the early, intermediate and final

phases of design in three separate data repositories. This created an opportunity to conduct an analysis of data from across matching case-studies of similar purpose. Aggregating data in this way facilitated the comparison of commonalities and difference emerging through cross-case analysis. The purpose of conducting cross-case synthesis for each of the design phases was to identify further insights as to the application of the proposed techniques in supporting participation at the relevant phase of the design process.

The second phase of the research involved the analysis of three explanatory case-studies each representing the early, intermediate and final phases of the design process. This phase provided an opportunity to help understand the nature of the participation of children with autism in technology more efficiently and with a view to uncovering new insights. This phase of the research involved applying an evaluation framework developed specifically for evaluating the phenomenon under scrutiny, namely the participation of children with autism in a technology design project. The purpose of this framework was to offer a lens through which dimensions of participation could be evaluated and the levels of participation achieved could be uncovered. To this end, this researcher assembled the raw data emerging from the first phase of the research for these three case-studies.

A data repository was created to contain the raw data, first order labelling, and categories that emerged from the initial coding. A separate repository was created to contain additional data such as the digital images generated by children and designers. Each of the data sets then underwent two phases of pattern matching, firstly to identify major emerging themes and insights and secondly using the dimensions of participation and the levels of participation from the evaluation framework.

5.8 Summary

The aim of this chapter was to provide a detailed overview of the context of this study by explaining the rich cultural and social backdrop for this study highlighting a range of factors and circumstances that would not be encountered in other contexts. The research took place against a backdrop of a funded programme that was supported by the State of Qatar to develop a range of Arabic Language software solutions to support the language development of children with a range of developmental disabilities including Autism. The design objective in each of the case studies reported here was to develop a series of interactive software that would allow an end-user to match graphic representations with words and sounds.

The two phases of this research are briefly described before a more detailed outline of the first phase is presented. A detailed account of the fourteen case studies examining the participation of children with autism across the early, intermediate and final phases of technology design is provided. The implementation of these case-studies is outlined in detail describing the selected and adapted techniques employed across the three phases of design to support the participation of children with autism in the tasks and activities that comprise each phase. A full description of the participants and the procedures in this phase of the research provides a comprehensive understanding of the implementation of this research study. The chapter concludes by summarising the data sources and detailing the analysis procedures followed in this research study. This sets the scene for Chapter 6 which will present three explanatory case-studies selected from the fourteen described in this chapter, each representing a study of the participation of children with autism in the early, intermediate and final phases of design.

Chapter 6: Explanatory Case Studies

The preceding chapter presented an overview of the fourteen case-studies that comprised this research. These case-studies represented efforts to analyse, investigate and better understand participation of children with autism in the early, intermediate and final phases of a technology design project. The case-studies pertaining to each of these phases presented an opportunity to implement participatory techniques selected or modified to match the specific needs of the children with autism at the heart of this study.

This chapter provides a thick description of three case-studies, each representing a phase of the design process, detailing the findings of the implementation of participatory techniques in the design workshops for each phase of the design process. These three case-studies were selected on the basis that they provided the best illustration of the participation of children with autism in each of the individual phases of the design process. The first of these case-studies (Case Study IV) provides insights as to how designers can best understand and represent the lived experience of children with autism over the course of the early phase of design. The second case-study (Case Study VII) highlights how the participation of children with autism can find expression in contributions to design proposals in the intermediate phase of design. Participation through the democratisation of the decision making process in design over the final phase of design is exemplified in Case Study X.

Case Studies IV, VII and X: Design Team Composition				
Children	Speech and Language Therapist (SLT)s	Designers	Researcher	Support
Child 1	**SLT 1**	**DESIGNER 1**	Researcher	TA 1
Child 2	SLT 2	DESIGNER 3		TA 2
Child 4	SLT 3	DESIGNER 2		TA 3
Child 7				Children's Liaison
Child 11				
Child 13				

Table 11: Description of Case Study Design Team

A summary of the participants in case-studies IV, VII and X is outlined in the table above. The composition of participants remained the same for all three case-studies with one exception. [Child 13] had not been able to participate in Case Study IV due to his absence from school because of illness. He did however participate in Case Study VII and X; the school-based team were very keen on his inclusion in these workshops as they had spoken to him

about the process prior to his short illness and felt it would be unfair to exclude him at this stage.

6.1 Case Study IV: Early Design Phase

'Understanding the lived experience of the child with autism'

The early phases of the design processes are concerned with capturing the lived experience of the child with autism and translating this into a specification of requirements that can guide the remainder of the design process. The objective of these case-studies was to understand the participation of children with autism in the early phase of design. Case Study IV is presented here as representative of the four case-studies that focussed on the early design phase.

6.1.1 Case Study IV: Workshop 1 - Observation Workshop

The objective of this workshop was to evaluate how conducting naturalistic observation of children with autism in the context of their own school, classroom and therapeutic sessions could increase the understanding of their lived experience. In Chapters 2 and 3 it was established that for children with autism capturing and translating their lived experience is a mechanism for ensuring that their needs and preferences are reflected in the overall design.

This section provides a thick description of the first in the series of workshops that comprised Case Study IV. This description is based on the field-notes taken by the three team designers, the dedicated note-taker and the recorded observations of this researcher.

Further descriptions are provided from the follow-up interviews conducted with the three designers and videotaped by this researcher. Prior to commencing the Observation in Context workshop (Workshop 1), all three designers were introduced to the two classes that they would be embedded within for the three mornings that they would be conducting their observations. The introduction was made by the class teacher and this researcher, who at this point had spent a significant amount of time at the school and was familiar to many of the children and staff attending. The teacher explained to children from both classes that the three 'grown ups' were friends of ours and outlined the role they would play in class.

Teacher 1	We say Salaam A'laykum to Mr. Bryan's friends, they are our guests today, say Salaam A'laykum children.
Designer 2.	Salaam A'laykum
Designer 1	Happy to be with you today
SLT 1	Mr. M., Ms, S and Ms S will be with us in our class for three days and will help us do our work. They will be watching and helping and will be our new friends I think.
Teacher 1	Children! We will see Mr. M., Ms. S and Ms. S again and they will be our guests, right children? Good.
TA 4	Welcome everybody, welcome children

Excerpt 1: Pre-Workshop Introductions for Designers and Participating Children in their Classrooms

The introductions took place in each of the two classes attended by the children participating. The children had previously been told by their teachers and SLT that they would be taking part in a 'big project to make new games for the children' [SLT 1].

The focus on providing such a level of information to the children prior to the commencement of the workshops was to ensure that they were well oriented to what would be a significant change in their typical routine. As such, the purpose of such orientation was to minimise the risk of upset that may be experienced by children because of such changes in their school routines.

All three designers and this researcher also attended a meeting with the SLT team and the school administrator to plan start times and other logistical issues such as parking and access to school buildings. This was a final opportunity for the three designers to ask questions prior to the workshop. On the first morning scheduled for in-class and in-therapy observation, all three designers and this researcher arrived before the school transport bringing the children to school. It was agreed at the previous planning meeting that the 'new people', as the designers were being commonly referred to as, should be in-situ as the children were arriving so as not to cause disruption to the regular morning schedule. Designer 2 was allocated to classroom 1, Designer 3 to classroom 2 and Designer 1 to spend time at the SLT clinic observing the regular therapy sessions there. On day two, all three rotated to a new location and similarly on day three all three rotated again so that they spent a morning in each location.

Entries in their field notes diaries and discussions during the focus group indicated some discomfort on the part of the designers taking the role of observer:

Designer 2	'…I don't think there was anything to prepare me for seeing this class, I thought before it might be like a regular classroom, but I could not prepare myself for the noise and activity, it's very busy [Focus Group]
	'…children paired with activities and helped by staff, some eating, some having medicine, circle time same time….' [Field Note Entry]
Designer 3	'…. difficulty to record a thing, many things at the same time in class for different children' [Field Note Entry]
	'…. main problem was not knowing what to focus on and I didn't want to disrupt so I didn't ask questions…' [Focus Group],
Designer 2	'…. I didn't write very much today because it didn't feel like I should, it was tricky, maybe it will be easier tomorrow, we will go back tomorrow right?' [Focus Group],
Designer 1	'…. you don't think about the busy class when you go in, there is a lot happening, I think watching the Speech Therapy was the easiest, but it was difficult attending a private thing like that. The therapist is amazing with children, so patient and has so much knowledge, very smart, very smart….' [Focus Group]
	'. for me, tomorrow, I will try and be more in the back, and stay quiet, I think this will be easiest….' [Focus Group]

Excerpt 2: Case Study IV – initial feedback from designers commencing Observation in Context

The excerpt above provides a little insight into the busy nature of school classrooms, particularly in special education centres, where other needs such as feeding, provision of medication and toileting are also required. In contrast Designer 1 on his first morning observing individual, one-to-one therapy sessions appeared to find it easier and less overwhelming. The nature of the spaces occupied by children with autism starts to emerge

through each of the Designer's observations and in their own reactions to the process of seeing children in the familiar and naturalistic contexts of the classroom and therapy room.

Designer 1	'it was very interesting for me, focused and very efficient, when I hear about child centred it is a hard idea to understand until you see it…' [Focus Group]
Designer 1	'…the therapist brings out the essence of every child, it is delightful, interesting….' [Focus Groups]
Researcher	'Can you suggest ways to better prepare yourself for observing children with autism?' [Focus Groups]
Designer 1	'No, I think I was lucky to see a professional working and explain things to me that she was doing, this helped me understand the children, without her, I think it would be too difficult…if I don't have her to explain, I will have nothing to record' [Focus Groups]

Excerpt 3: Case Study IV – Observing in a one-to-one context versus a classroom

The relative structure of a one-to-one therapy session and the presence of a therapist that was happy to communicate what she was doing provided an environment where designers perceived that they could learn about each child. At this early stage as well, it was evident that the designers require the school staff to do a lot of explaining and depend on them to start building their initial understanding of the children they are observing.

The field-notes from each of the three designers also reflected that their focus during the first workshop session was very much on the children, their behaviour, their routines and their reactions to activities and stimuli. There was an obvious gap in their recorded observations of the context within which the children functioned. This did change as they progressed through the three days, they were however reminded by this researcher that their observations of the classroom context were also necessary.

As each of the designers rotated through their locations, they appeared to increase in confidence and the numbers of entries in their Field Diaries increased and became more focused on identifying each of the children's preferences.

Designer 3	'…alarm on emergency exit, children all upset…no adults notice' [Field Work Notes: Day 1]

Designer 3	'…AH[Child], does not like loud or sudden noises, locks hands on ears and is distressed…his upset level is very high.' [Fieldwork notes: Day 3]

Excerpt 4: Case Study IV – evolving understanding of the child as observations progressed

Participating designers also began to build on information on individual children across the different locations in which they were being observed. Differences in performance, ability and behaviours across different environments was becoming evident in the designers' field diaries. Entries and notes taken by designers show how they observed how their location impacted their behaviour, engagement and activity preferences.

Designer 1	'Child 3, nine years old, loves musical games, understands instructions, verbal, from therapist H' [Field Work Notes: Day 1]
Designer 1	'…Child 3 different child today, did not make eye contact with me when I said hello and is interested in only playing with fingers and wheelchair in the room, the mood for t room changed today….' [Fieldwork notes: Day 3]

Excerpt 5: Case Study IV – observing the impact of context and location on a child's performance, behaviour and choices

As the time each designer spent in close proximity to the children increased, they became less concerned with their own discomfort as observers and adopted a more engaged role with the children and school staff.

Designer 3	'today, I wish it was not my last day in class, this was my best day, I now feel good to say hello and talk to the children, I now understand it's okay they do not always say hello back to me, but it is nice and now I can talk to them….' [Focus Group]
Designer 3	'…I can help out the teacher now, like feeding children the food with the bread, it is so good…more time in the class would be good, we need more time to learn I think' [Focus Group]

Excerpt 6: Case Study IV – Designer's levels of comfort increased as their observations progressed and they became more familiar with the children and their classrooms

As mentioned, each afternoon following completion of their observation time at the school, the three designers and this researcher met for approximately ninety minutes to discuss their observations and allow them to augment or clarify their recorded field notes. During these meetings, all three designers used the time to discuss each individual child, their general observations for the day, but also their own feelings regarding their efforts to get to know and understand the children.

Designer 1	'I like AH[child], he is the centre of the action in class and he is aware of this too….' [Daily Discussion Group]
Designer 2	'…today, I think he was really laughing at us trying to show him the snack choices, no way was he going to cooperate and he was laughing at us….' [Daily Discussion Group]
Designer 3	'. he is the energy in that class, you see all the staff love him too, it is because he is naughty, but so nice' [Daily Discussion Group]

Excerpt 7: Case Study IV – Designer's reflections on their observations of the children

Excerpt 7 illustrates attempts by the designers to infer understanding of each child's character by understanding the context of their behaviours. It shows an increased awareness of the child as a person who has characteristics and personality that are evident in his observed behaviour.

The process of collaborative reflection during the daily discussion sessions allowed designers to refine their understanding of particular children and the impact their environment had on various aspects of their behaviour.

Designer 3	'when I saw AQ yesterday, he was switched off, just not really interested….' [Daily Discussion Group]
Designer 2	'…I think I saw him differently today, he was in the SLT room with F [care staff member] and seemed to be having a nice activity….' [Daily Discussion Group]
Designer 3	'. I think he is better when he's with just one person, the classroom disturbs him, he doesn't like it…' [Daily Discussion Group]

Designer 2	'.is it the classroom or just other children, when he is with H [SLT], he is very happy, she loves him…' [Daily Discussion Group]
Designer 3	'. you are right, F [care staff member] was doing music today and he got upset when it was over…' [Daily Discussion Group]
Designer 2	'it's not the class I don't think, it is having an adult to himself, maybe the attention is nice for him…' [Daily Discussion Group]

Excerpt 8: Case Study IV – Designer's collaborative reflections on children's performance in different environments

Excerpt 8 above highlights the importance of providing opportunities for discussion and collaborative reflection in achieving a level of understanding of their observations of children. Designers engaged in a process of clarifying each other's observations, supplementing the detail with the observations of their peers and gaining further insight and understanding.

As each of the designers spent more time in the proximity of the children and as they spent more time discussing and reflecting on their observations with each of the children, they began to reach further consensus in terms of their understanding of children's likes, needs and preferences, both at an individual level and as a group.

Designer 1	'I've changed my mind completely, on day 1 I thought that all of the children love the music….' [Daily Discussion Group]
Designer 3	'…yeah, in the therapy room, but not class….' [Daily Discussion Group]
Designer 1	'. that's what I am saying, maybe for AQ, he likes it in the two places…' [Daily Discussion Group]
Designer 3	'. but he won't like it for circle-time…or for the music, it's the noise I think' [Daily Discussion Group]

Designer 1	'. too many people, it's the same for the others, I think with more people the music is just like noise to them…' [Daily Discussion Group]
Designer 2	'…yes, that's right, it's not the music, but everything else, just one thing at a time, the same as at the break, I think they prefer when the class is on….' [Daily Discussion Group]

Excerpt 9: Case Study IV – Designer's attempts to establish consensus on their observations of the children

In setting up the workshops and preparing the designers to engage in school-based observation, very little direction was given in terms of what they should look for and how they should record their observations beyond being instructed to keep field-notes during their time in the school. It was anticipated that provision of observation scaffolds or supports such as checklists would constrain the observations of each of the designers and may result in them missing opportunities to engage with the children and appreciate how this would impact their developing understanding of each child. As the observation progressed, each of the designers commented on the evolution of their role from passive observers to more active observers, engaging with children and school staff and how this changed their observations. Being a more active participant in the class provided each of the designers with a different perspective than before and offered opportunities to gain further insights.

Designer 2	'FM appears so pleased when I tell the story, when I said hello yesterday she was blank for me, but with the story she is a different girl….' [Field Notes]
Designer 2	'…there is no way I could read her the story before this, but today she wanted to listen….' [Daily Discussion Group]
Designer 3	'. you know her favourite animal is a donkey…' [Daily Discussion Group]
Designer 2	'…. really…. why?' [Daily Discussion Group]
Designer 3	'. I don't know but was that not in your story…' [Daily Discussion Group]
Designer 2	'of course, I must record this in my notes or I will forget this fact' [Daily Discussion Group]

Excerpt 10: The impact of proximity on the designer's understanding of the child

The observation workshops were also opportunities for each of the designers to gain an appreciation of the use of software and technology in the classroom. Their observations illustrated not only some of the ways in which teachers in classrooms used technology, but also some of their own pre-conceptions as to why or how technology should be used.

Designer 1	' ….' [Field notes, Day 2]
Designer 2	'…SLT used computer in therapy, first chance to see this child [AQ] with computer, therapist is in charge….' [Field notes, Day 2]
Designer 3	'. laptops mainly used by teachers, YouTube very popular with [Child 6] but he loses interest fast' [Field notes, Day 3]
	'. software choices very childish, and teachers just try one after another….' [Field notes, Day 2]
Designer 1	'…teacher says the children like computers, but when on, just watch them like it's a TV….' [Field notes, Day 3]

Excerpt 11: Designer's attempts to understand how technology is used in the school

The designers used their daily discussion time to try to make sense of their observations and to begin to speculate as to how they might identify requirements that could guide their software development. The designers used each other, and this researcher to discuss their observations and to try and clarify their thinking.

Designer 1	'it's completely different in class and in the therapy room….' [Daily Discussion Group, Day 3]
Designer 2	'…I know, but why is it like that….' [Field notes, Day 2]
Designer 1	'. it's how the SLT uses it….' [Daily Discussion Group, Day 3]
Designer 2	'.no, she decides on the same app for every child, she does the same thing….' [Daily Discussion Group, Day 3]
Designer 1	'…the teacher ends up shouting over the computer, there is too much instruction for more than one child….' [Daily Discussion Group, Day 3]
Designer 1	'…. I don't know if it can really work in the classroom, even the teacher doesn't pay any attention' [Daily Discussion Group, Day 3]
Designer 2	'. but he said before it's not his job…. he needs some help…' [Daily Discussion Group, Day 3]
Designer 1	'that's not our job….' [Daily Discussion Group, Day 3]

Excerpt 12: Case Study IV – Designer's attempts to unpick the nature of technology use in the school

During these daily discussions, they expressed their frustration at the challenges of reaching a level of understanding about the children that might form the basis of tangible specifications that they could identify and report back on. Their discussions although always positive in terms of how they reported on their experience with children with autism in the school, nevertheless, often ended in frustration and a sense of a lack of progress. It was clear that they remained task focused and ultimately were interested in distilling a meaningful list of specifications that could be acted upon in their development work.

Designer 3	'it's very interesting in the class, but I'm not happy with what I know after that….' [Focus Group]
Designer 2	'…I am the same, it's with more questions now, I understand less….' [Focus Group]
Designer 3	'.no, it's a good experience for me, for sure, but how can we help with these notes, they cannot be used….' [Focus Group]
Designer 2	'. I know the job is to make some small learning apps, but this is not so easy, well easy if we don't care how to use it, the teacher won't mind I think….' [Focus Group]
Designer 1	'…we can just focus on each child but 100% every child will not be able to use it….' [Focus Group]
Researcher	'Why do you think that is the case' [Focus Group]
Designer 1	'.no way, software cannot be made for every child, some will hate it some love it, I am sure of this…' [Focus Group]
Designer 3	'. I think we have made a tiny progress for this….' [Focus Group]

Excerpt 13: Case Study IV– Designer's attempts to translate their observations into development specifications

Excerpt 13 above provides a little insight into the frustration that developed amongst the small group of designers in the team. This emerged after the conclusion of their observation sessions and became a focus for discussion during the focus group that was conducted four

days after they had completed their observations. During the focus group, each member spoke of their appreciation for the opportunity to observe and learn about the experiences of children with autism in a classroom environment but felt that they left the sessions with far more questions than answers. They debated the value of children with such limitations using computer or learning software at all and questioned the feasibility of setting up software for use by children with autism in classroom settings, suggesting that one-to-one situations were the only suitable location for computer use within the school. When pressed by this researcher as to whether more time would be of benefit in increasing their understanding of the children, the consensus was that it may help, but more likely would result in even more confusion.

In summary, the observation sessions engaged in by the team, their daily discussion groups and the focus group held several days afterwards provided those on the design team with a technical and design background with a range of opportunities to develop and understanding of the lived experience of children with autism in a special school environment. Designers with little experience of children with such disabilities quickly overcame their discomfort as observers with proximity to the children and opportunities to engage with them not just easing the process of observation but made it a richer, more meaningful encounter. Designers gained and expressed an appreciation as to the complex nature of the interplay between children with autism and their physical and social environments and their impact on children's engagement and behaviour. They had opportunities to gain a deeper understanding of the challenges of using technology as a learning tool with children with autism and expressed insights as to the rationale for the use of software in classrooms or in therapeutic sessions. There remained however, a frustration in easily transforming their new information into meaningful data points that could be distilled from their new understanding and guide them in the development of software that better meets children with autism's needs.

6.1.2 Case Study IV: Workshop 2: Story Workshop

The objective of Workshop 2 was to investigate how using proxy storytelling (adapted from ethnographic storytelling to match the needs of participating children) could contribute to efforts to capture the lived experience of children with autism with a view to informing the remaining design activities and the eventual outcome.

This section provides a thick description of the workshop based on the field-notes taken by this researcher and transcripts of the video of the workshop (Workshop 2) recorded.

The initial stages of the workshop saw the adults present responding to the instructions of this researcher to 'describe' each of the children in turn. The responses of those present started with very descriptive representations of each of the children. [Teacher 2] described each child in terms of a diagnosis, their cognitive status, their age and where they were from.

Teacher 2	'he [Child: Child 4] is 8-year-old with mental retardation for diagnosis, complex, very complex, many difficulties. He is in class with me for more than two year [sic] and more. His family is big from Pakistan I think, but here for many years' [Workshops Video Transcript]
Researcher	'what is your experience with [Child 2] in class every day?' [Workshop 2 Video Transcript]
Teacher 2	'He likes my class, very interested always, no problems with [Child 2]' [Workshops Video Transcript]

Excerpt 14: Case Study IV: Initial descriptions of participating children

In the early stages of the workshop, the field-notes suggest that much of the interactions were dominated by the [Teacher 2] who answered many of this researcher's questions while the rest of those present remained quiet or indicated their approval of his description of each of the children through non-verbal gestures such as head-nodding. The dominance of [Teacher 2] in the early parts of the workshop may reflect the authority ascribed to teachers within the particular institution or indeed may speak to deeper cultural norms reflecting broader Qatari or Middle Eastern societies. It became clear, on review of the video transcript that many of the descriptions provided by this person were very similar, with only small variances in the information provided.

Teacher 2	'he [Child 5] I think is almost 10 years old with severely disabled many difficulties in my class and is sick many days, he misses many, many days at home for sickness with his family [sic]. [Workshops Video Transcript]
Teacher 2	'[Child 1] is a big problem for my class, his family came to this country one year ago with this child and he had complex problems, in Egypt they made no report, no information, nothing. Very difficult to make him a part of my class [sic]. '[Workshops Video Transcript]

Excerpt 15: Case Study IV: Similar descriptions of children provided by teacher

As the workshop progressed there was little spontaneous contributions from the majority female membership present further highlighting the dominant impact the participating [Teacher 2] may have had in reinforcing local cultural norms where females will defer to male

colleagues. This researcher began to prompt the SLTs present to encourage contributions from people present other than the teacher, who was by this stage dominating the workshop to the extent that it appears in the transcripts that it is an interview between this researcher and the teacher.

Researcher	'in terms of Speech Therapy, how did you guys find [Child: 7]?' [Workshops Video Transcript]
Researcher	'[Child 1] it would appear is struggling to settle in the class, what about in Therapy, how is he? '[Workshops Video Transcript]
Researcher	'Is it the same in Speech Therapy, is that what you found?' [Workshops Video Transcript]

Excerpt 16: Case Study IV: Prompts to encourage contributions from the SLTs participating the workshop

When the female SLTs present began to contribute, they tended to provide quite formal information relevant to their discipline and to the focus of their work with each of the children. This appeared to reflect a desire to reflect their own work in a formal, professional manner. The cultural context of this research which was discussed in Chapter 5 can be seen to be reflected here in the contributions of female members of staff participating in the design process alongside male colleagues. It must be noted that in the absence of their male colleagues, contributions from female members of the team were more forthcoming and less inclined to assert their professionalism.

SLT 1	'[Child:7] is a very interesting case, he is non-verbal for speech, but is more complicated for understanding, the Test of Language Development[46] is not possible with him' [Workshops Video Transcript]
SLT 3	'[Child 1] is the same, no formal procedure possible with him, so we are not hopeful? '[Workshops Video Transcript]
SLT 3	'[Child 1] is very nice, he has good recognition of some symbols and is working on them every day with me?' [Workshops Video Transcript]

Excerpt 17: Case Study IV: SLT descriptions of each child

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[46] The Test of Language Development is a standardized test used with children with developmental language disabilities. This test is not available in Arabic, but has been translated for use by the SLT staff at many of the clinics and institutions in Qatar. These non-standardized translations are often passed amongst professionals in an informal manner.

Most of the initial descriptions of each child were formal and formulaic providing little detail as to each child's preferences, abilities and personality instead they reflected the extent of the challenges faced by each child and how they were performing (for the teacher or therapist) in class or in therapy. The participating teacher and the SLTs were very focused on expressing their own professional domains, describing the children in terms of the focus on concern for them in therapy or in class rather than speaking to their achievements and abilities. This was reflected in the discussions with the 'team designers' following the workshop.

Designer 1	'…it seems very negative, there is no good news in the comments' [Discussion Group: Field Notes]
Designer 3	'Maybe because of their jobs they just want to talk about children's problems only, but its negative to speak like this about the children '[Discussion Group: Field Notes]
Designer 1	'but this is not what they talk like in the class, when we were there it was different, much happier' [Discussion Group: Field Notes]

Excerpt 18: Case Study IV – Designers commentary on professional reports on participating children

Until approximately fifteen minutes into the workshop there had not been any verbal contribution by any of the three, TA's present, even though this group spent the most time with the children across a very broad range of activities in class, in therapy, during recreation and on transport to and from the centre.

As with the SLT group present, this researcher used direct verbal prompts to encourage their contribution of their reflections of each of the children. At the seventeen-minute mark in the workshop, the teacher's phone rang, and he asked to be excused from the workshop temporarily, once this researcher agreed, he left and did not return thereafter. His exit from the workshop appeared to provide a space that allowed the remainder of the participants to speak and contribute more. The tone of the contributions also became less formal, with both the SLTs and Carers providing more subjective reflections.

SLT 1	'… [Child 2] is everybody's favourite, we all love him, he is so funny….' [Workshops Video Transcript]
SLT 3	'…he is very nice, we all love his smile, you know his eyes smile every day….do you see this, yes, you think?' [Workshops Video Transcript]
SLT 1	'we can't have favourites, but sometimes you can't help it, his personality is just so funny…. everyone thinks this, I am sure' [Workshops Video Transcript]
TA 3	'he is always a happy boy, no problems, no problems with him, just laughing all the time, same same with everyone' [Workshops Video Transcript]
TA 2	

	'for the music in the class he is laughing' [Workshops Video Transcript]

Excerpt 19: Case Study IV1: More informal descriptions of each of the children

Although the descriptions of each child became more informal and less concerned with their difficulties, the SLTs and Carers participating did not offer much by way of information as to the like and dislikes of the children. To rectify this, this researcher began using direct verbal prompts asking those contributing to share their understanding of each child's palette of 'likes'. These prompts stimulated a higher volume of contributions and discussion with both SLTs and Carers sharing their own experiences and opinions. Contributions were discussed and those participating appeared to try and establish a consensus as to their own opinions as to the preferences of each of the children. These discussions, which centred on the 'likes' of each child also provided a platform for identifying and discussing the 'dislikes' of the children, thus providing the opportunity to explore the general preferences of each of the children individually and collectively.

SLT 3	'everything, thank God, everybody loves music, every kind of music….' [Workshops Video Transcript]
TA 2	'…the only thing for all the children is the music, we help them play so everyone is happy with music, even us, can you believe this….' [Workshops Video Transcript]
SLT 1	'[Child 2] will be happy when he gets attention, from the children, from me, from M[teacher] and even when P [Centre Director] comes in he laughs when we are scared….' [Workshops Video Transcript]
TA 2	
TA 3	'but they like the computers too, I know that [Child 1] this is his favourite, what do you think?' [Workshops Video Transcript]
TA 2	
	'…. when he is with me, he will like me rubbing his face, it is relaxing I think' [Workshops Video Transcript]
	'…oh no, for sure with you but for me [Child 2] does not like this, I tried but he does not like this' [Workshops Video Transcript]

Excerpt 20: Case Study IV: Discussions emerging from prompts to contribute opinions on the 'likes' of participating children

The discussions that began to emerge during the final quarter of the workshop provided the most valuable information when reviewed by the 'team designers' and were of most interest to this team. In their discussion group meeting shortly after the conclusion of the Caregiver's Stories Workshop, their reactions were recorded in the field-notes and suggested that these

discussions provided them with a better understanding of the lived experience of each of the children.

Designer 2	'…this part is nice, I can feel that the team really like the children' [Discussion Group: Field Notes]
Designer 3	'I think it is because it is the Carer Ladies and they know children better '[Discussion Group: Field Notes]
Designer 1	'they are more comfortable talking now…. maybe they were more afraid to speak until this time' [Discussion Group: Field Notes]
Designer 3	'. yeah, I was thinking this'

Excerpt 21: Case Study VII: Further reviews of workshop information by team designers

This team did however express their frustrations as to what they perceived as the lack of information that they gathered from the workshop. They appeared critical of the workshop itself but seemed to communicate an understanding as to reasons why participants might not be as happy to contribute.

Designer 1	'…for me it is a waste of time, complete….' [Discussion Group: Field Notes]
Designer 2	'no, it is just the people in the meeting, they are not happy to talk, we can see this, its maybe the wrong people for the meeting '[Discussion Group: Field Notes]
Designer 1	'no, when they are with the teacher they will not talk about the children, we know this' [Discussion Group: Field Notes]
Designer 2	'. the workshops is okay, but maybe with a family instead of the teacher, I think the teacher is too busy for these meetings' [Discussion Group: Field Notes]
Designer 1 Designer 3	'…yes, of course, the children's family, I want to hear their mother at the meetings and their fathers also….' [Discussion Group: Field Notes]
Designer 1	'nobody knows these children like their parent….' [Discussion Group: Field Notes]
	'this is a big mistake, I think the parent of the child is better for this…. They are the only people who can talk in this way….' [Discussion Group: Field Notes]

Excerpt 22: Case Study IV: Frustrations from the 'team designer's following their review of the workshop video

The above excerpt suggests that the 'designers' did not find the care-giver stories as contributed by the teacher, SLTs and Carers present particularly useful in terms of furthering their own understanding of the lived experience of the children with autism participating in this study. It is interesting to note, that they expressed an interest in hearing the stories from different perspectives other than the staff available to attend this workshop. The reflections and commentary of the 'team designers' certainly suggests that the membership of workshops and the probes used should focus on a different group of 'caregivers. Seeking contributions from parents, families and others who spend a lot of time with children should be considered in future iterations of this process.

6.1.3 Case Study IV – Workshop 3: Photography Workshop

The objective of Workshop 3 was to examine the context mapping technique as a method for gaining a better understanding of the lived experience of children with autism. The specific technique used involved providing children with autism and an adult supporter with a camera that they could use to take photographs that represented their needs and preferences with a view to sharing these as a means on transferring their tacit knowledge.

This section presents a thick description of this workshop based on the field-notes collected by this researcher of observations made of the children with autism and the adult participants supporting them in their efforts to collect photos representing their experiences. The workshop lasted approximately fifty-five minutes.

Although there had been no restriction made on where participants went to take photographs, it is interesting to note that the majority stayed within the room in which the introductions were made. [Child 1] left the room with two accompanying adults and travelled to the main concourse and reception areas of the Centre to take some photographs, another [Child 2], went directly to an outdoor courtyard area to take some photographs there. The remaining three participating children stayed within the room with the remaining adults. Both children who left the room to take photographs also had physical disabilities and were limited in their mobility such that they used wheelchairs and depended on adults to push their chairs to move location. It would appear that the choices in terms of location for taking their photographs were made by the accompanying adults. When asked during the follow-up discussion meeting about why they had gone outside to the main concourse and to the outdoor

courtyard, the adults accompanying the children inferred that their decision had been based on their prior knowledge and experience of the children.

TA 2	'…we go outside in this time, because the heat is not so high, we like to go out and listen to the sound from the roads' [Discussion Group: Field Notes]
TA 3	
	'. for me, [Child 1] likes to go to see [Receptionist], he is the main person to greet visitors when he is there, we like this job and go there many times '[Discussion Group: Field Notes]
TA 2	
TA 3	'remember not all the children like this, sometimes they cannot go outside, it is not allowed for them' [Discussion Group: Field Notes]
	'.it is easy with the wheelchair, we have choice, for some children moving so much in the outside is too difficult and we need more people to help, I cannot do this for example with [Child 6]

Excerpt 23: Case Study IV: Rationale for choosing locations for taking photographs from the perspective of staff helping

From observations of the workshop as it unfolded, it was clear that the adult staff members were assisting children in choosing what to photograph to lesser or great extents. For two of the children, who had no physical disability, they took the camera and took photographs independently, but did not appear to be actively selecting objects, scenes or people rather they appeared to click the camera indiscriminately. This was reflected in the total number of photographs that they took, and the number of similar photos taken. One further child [Child 5] who had no physical disability was offered and accepted help from one of the SLTs [SLT 1] participating in the workshop. She was prompted to take select a subject for their photograph, the [SLT 1] used a range of simplified verbal prompts to ensure that she was happy with her selection and was given physical support (hand over hand support) to click the exposure button on the camera. The two participating children with physical disabilities were provided with a similar level of support, but the adults supporting them were observed to be asking about the selection of a subject to photograph and were taking the photographs on behalf of the two children even though the cameras that they were using were fitted with a switch that the children could use themselves with no additional support. When the issue of selecting a subject to photograph was discussed in the follow up meeting, participating adults appeared to suggest that the level of support that they provided to children was based on their prior knowledge of the children and their concern that the overall experience of the activity was positive for participants.

SLT 1	'…I like to make the children feel like they are the boss in these activities, this really helps' [Discussion Group: Field Notes]
TA 3	'. I know that he is okay with me helping because we do this…. we do this every day, it is like our way to do work every day '[Discussion Group: Field Notes]
TA 2	'I like to help a little bit, because we need to finish with good time, is this what we need?' [Discussion Group: Field Notes]
SLT 1	'. sometimes there is more independence than you see, it is complicated, because we help it makes it easier, but he is still independent and we help with this, this is very important to us, we make them independent but with help and this is okay….' [Discussion Group: Field Notes]
TA 1	'. if we don't help, it will be very bad and the childrens are being [sic] very upset, this is not nice for everybody.' [Discussion Group: Field Notes]

Excerpt 24: Case Study IV: Feedback regarding the support provided by adults to participating children in selecting subjects and taking photographs

After the allocated twenty minutes, this researcher approached each of the participating adults suggesting they return with the children to the classroom where the introductions had taken place and retrieved the cameras from each of the children participating. All the photos taken were uploaded to folders on a laptop connected to a screen projector for display to the group. During the presentation, the adults participating, informally provided background information from their own perspective as to some of the meaning in the photographs taken.

TA 3	'…this has the guests coming to Al Noor all wanting their photograph with [Child 4], he likes this and keeps them for his friends, like [Centre Director], she is in many photographs, not today but different times with him, and everyone is laughing with the photographs, he is in all the phones of the important guests here, is that right [Child 2]? This is the popular man for the Centre. [Researcher field-notes]

Excerpt 25: Case Study IV: Background information on the use of photography by participating staff

For two of the children, [Child 2] and [Child 6], their collection of photographs was populated by photos of themselves with other adults, both those participating and others from around the Centre. These were described by the participating adults as 'selfies', although it was difficult to determine how much choice was exercised by the children in taking these

photographs and if they explicitly assented to their taking. In the discussion following the workshop, the participating adult staff did discuss several reservations.

TA 3	'…the problem in our culture is that you cannot take photographs of people, especially the females, even the young ladies, under 10 years of age, it is 'haram'[*sic*][47], this is important for many people, all children here are okay but even some of the ladies working will not accept to have a photograph taken, we don't like it. For me, it's okay, and I am happy in the photographs for the Centre, but many ladies and sometime the men are not happy with this practice, it is okay, of course with the children, but maybe some people will think this is 'haram' also for the children to learn about this……' [Discussion Group: Field Notes]

Excerpt 26: Case Study IV: Feedback on the cultural sensitivities of using photography as a means of representing a child's lived experience

The above excerpt was reiterated by other participants, although less comprehensively and highlighted some of the unique cultural factors that impact the process of attempting to understand the experience of children with a disability. Interestingly, there was no mention of cultural sensitivities in terms of taking photos of children with autism and intellectual disabilities. There was certainly no indication during the workshop that participating adults were concerned with the capacity of children to consent or assent to their photograph or image being taken, displayed in a somewhat public forum and discussed in the third party by adults familiar with the children. The influence of participating adults throughout this workshop was clear from the choice of location children used to take their photographs to the choice of subject and in many instances the physical act of taking the actual image. Participating adults demonstrated a high degree of verbal interaction with the children; however the interactions were one-sided and their behaviours appeared influenced by a desire to complete the activity at hand. The above findings were discussed by this researcher with the 'team designers' following completion of the workshops and the follow up discussion group. During this discussion with the 'team designers', it was collaboratively agreed that because of the concerns regarding the cultural appropriateness of the technique expressed by the adults participating in the workshop and the observations of power imbalance by this researcher, the photographs taken would not be used again during the design project and would not be considered in furthering an understanding of the lived experience of the participating children.

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[47] A commonly used word in Arabic that translates as '*forbidden*' but often describes something that a person might feel uncomfortable with, or that will be perceived by others as a practice that is considered socially unaccepted.

6.1.4 Case Study IV – Workshop 4 - Wall of Us workshop

The final workshop in this explanatory case-study was focussed on assimilating the information and data gathered and analysed over the previous three workshops described above. The assimilated data collected attempted to represent the lived experience of each child and the context within it was anticipated that they would use a software system developed for their use in the future. As such, drawing on the traditions of PD it represented the transfer of tacit knowledge from the participating groups of children to the team designers in this project. This transfer of knowledge as to the needs and preferences of children with autism were represented by a series of mind-maps and the elaborated mind-maps. The objective of Workshop 4 (wall of us) was to examine how collective reflexivity would further the designer's understanding of the lived experience of the child with autism. Furthermore, it presented an opportunity to examine how the use of mind-maps could support the engagement of children with autism in collectively reflecting on data captured about their own lived experience.

This, narrative, thick description of this workshop is drawn from the field notes recorded by this researcher and from the transcript of the video recorded of Workshop 4. This workshop lasted approximately thirty-five minutes.

During the designer's meeting, much of the discussions centred on the selection of information about each child. The three designers look for patterns, in terms of information that was repeated across different workshops or that suggested a theme for that child. For example, [Child 2] was described in terms of his sense of humour, his laugh, his general happy demeanour and his sociability. Regardless of his lack of verbal skills, the designer's pointed to the numerous examples of how his good humour was observed in different contexts, with different people across different activities. This was also evident in the stories that carers told, and the small anecdotes recorded during the Caregiver Stories Workshop and through incidental storytelling outside of these times. Another example of a theme that emerged was another child's [Child 6] discomfort participating in activities that were new or outside of his usual routine. This emerged as an observation by the designers during the Observation t workshop (Case Study IV Workshop 1) and was reinforced in statements made staff members participating in the Stories workshop (Case Study IV Workshop 2). This workshop also demonstrated an elaboration on this behaviour, such that participating staff made mention of his aversion for objects of colours (specifically green and orange), describing how these colours are avoided during colouring activities in class.

The nature of the discussions amongst the three team members lent themselves to representing their findings in mind-maps[48.] Such maps highlighted information that was discovered about each child and how such information was elaborated upon by further information or thoughts from the team. As such, each of the maps began to represent a rich, narrative representation of each child. Placing the mind-maps in one composite 'Wall of Us' provided a further opportunity for the three team designers to examine, discuss and further understand similarities and differences in each of the participating children's behaviours, needs and preferences.

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[48] During this workshop, a software application called X-Mind (version 7 - https://www.xmind.net/) was used. This mapping software was a familiar tool for the 3 team designers having used it as a method for summarizing and representing the outcomes of 'brainstorming' meetings in previous projects.
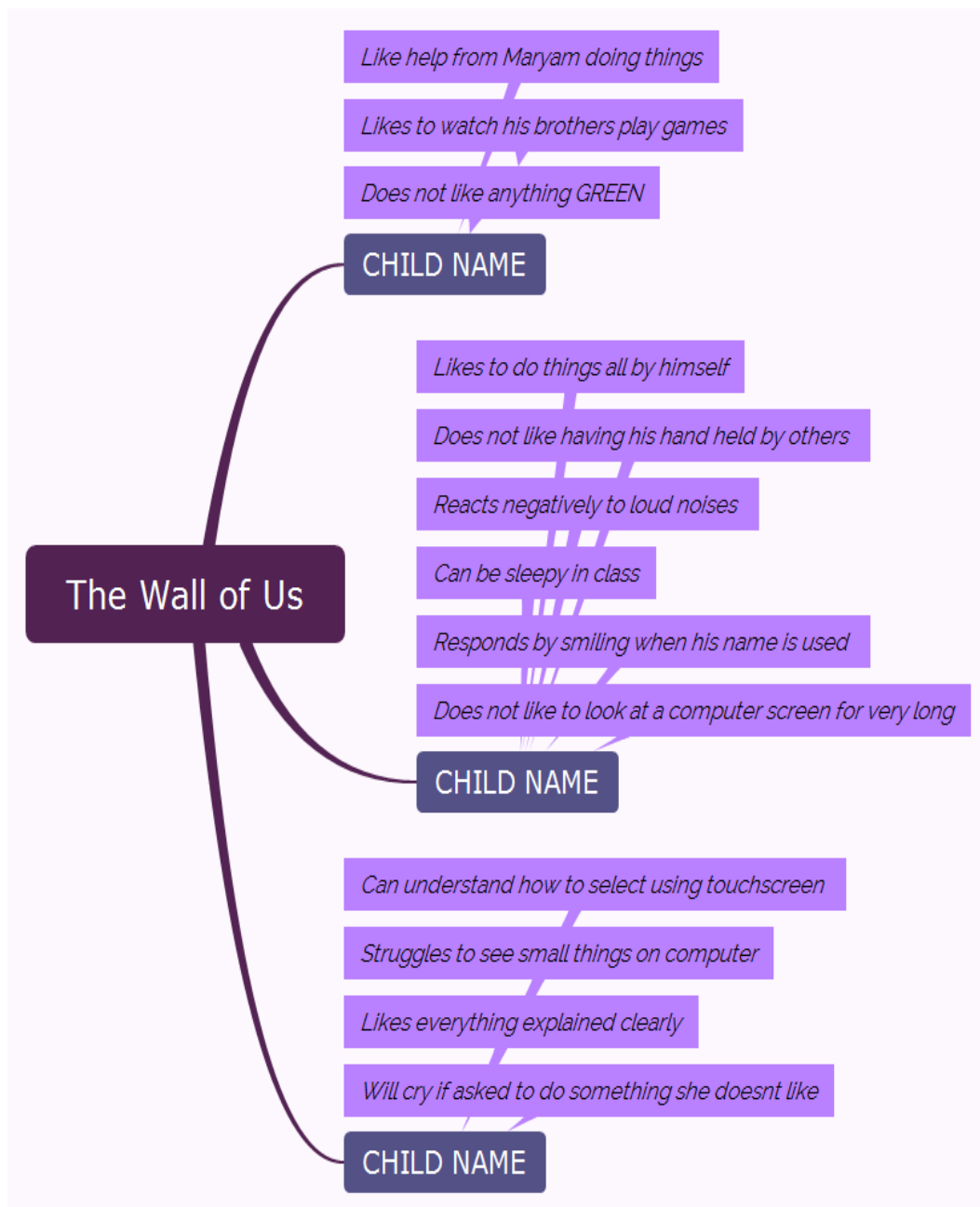
Figure 19: Mind-map (1) with first order needs and preferences highlighted for participating children

An example of one of the mind-maps described here is presented above in Figure 19 and in Figure 20 below. The images show not only the first order findings highlighted during this workshop meeting but also the elaborations and refinement of information gathered into a working picture of the lived experience of the children with autism at the heart of this process. These images are text based and demonstrated some of the early mind-maps produced by designers. Over the course of the workshop series these evolved from being text maps through to maps that comprised text, images, sketches, photos and in some instances animated GIFs.
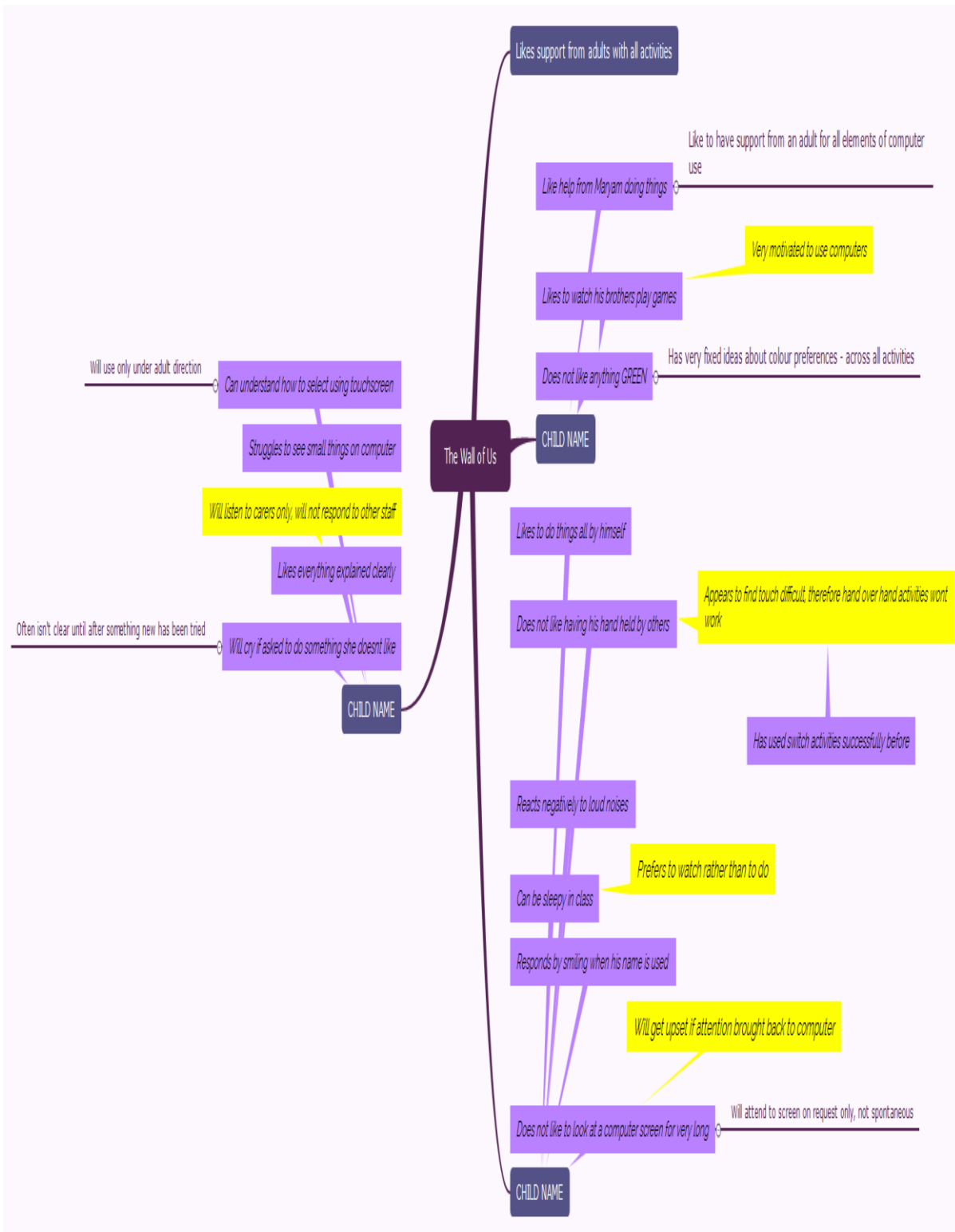
Figure 20: Mind-map (2) showing elaboration and refinement of data gathered pertaining to the lived experience of children with autism.

A workshop attended by all participants and facilitated by the Children's Liaison and one of the team designers [Designer 1]. The purpose of the workshop was to present the representations of the team's findings from Workshops 1–3 described above. These

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representations comprised the team designer's shared understanding of the lived experience of the participating children with autism.

Following a short description by [Designer 1] where he described what the experience of spending time with each of the children meant to the team designers and some of what he personally had learnt from this time.

Designer 1	' …was my pleasure to spend this time with you and with all of your children, for me it was an incredible experience and I understand why this work is rewarding……I learn so much in these days, so much that I cannot learn from the regular way, these children and you all have a beautiful time for us and we feel like this family now, thank God, we like it…..also, we see the life in this school and the life of the children, thank God, we are grateful to you children and everyone as well.…' [Workshop video transcript]

Excerpt 27: Case Study IV: A personal expression of the experience of spending time with participating children

(team designer – personal reflection)

The majority of [Designer 1]'s comments were initially addressed to the adults present, however he did then address the children directly to which the adults present began to interact with the children, by way of reinforcing to them that the comments were about them and directed to them.

Designer 1	'…we never saw children with the laughing like [Child 2] so funny for everybody…. [Child 1}is also so much fun with us and makes us feel welcome in his school ……. [Child 6] we can see here is so special, he is very special……. [Child 5] has everyone here looking after him and he loves the school yes? [workshop video transcript]

Excerpt 28: Case Study IV: Designers direct expressions of gratitude to participating children

The comments in the excerpt above give a sense of the very generalised nature of the feedback provided by way of introduction and overview by [Designer 1], contrasting with the more specific information and detail presented in the Wall of Us where children's preferred colours, food, activities and people were indicated. Furthermore, his generalized comments did not refer to any of the challenges that the team designer's experienced, particularly as they acclimatised to their role as observers in the classrooms and during therapy sessions (outlined above in this description of Workshop 1). The presentation was very positive and emphasised the gratitude felt by the small group to the rest of those participating. When participants were then invited to spend time examining the projected Wall of Us, each of the children were brought to the screen by the adults present in an informal manner appearing to begin by looking for the image and name of each of the children, then reading to each of the children what was presented as representation of their lived experience. The discussions that followed were focussed not only on the individual findings for each of the children but were often

contextualised in stories and anecdotes that illustrated the finding, either by the designer present or another member of the team. This provided a rich source of elaboration data that was recorded both during the session and afterwards. This part of the workshop did appear to be fun and pleasurable for those involved, with a large volume of interaction between adults and children and between the adults present. The adults participating were reminded on several occasions that any comments they had should be recorded on the post-it notes and placed on the Wall. Only one of the SLTs [SLT 1] took time to write a total of four comments on the post it notes, with the remaining adults directing some comments verbally toward this researcher or to the three team designers. On examination, the comments made by [SLT 1] were mostly expressions of her happiness with the process and with the behaviour of the team designers as observers.

SLT 1	'…our pleasure to welcome you here.…'
	;. happy to experience your kindness to our children….'
	'…. very good comments for the children, good work…'
	'…thanks to all from Mada and to [this Researcher] …'
	[Transcribed from post-it notes]

Excerpt 29: Case Study IV: Expressions of happiness with the process by a participant staff member

It was anticipated that the addition of participant's comments would improve the overall representation presented and add to the process of clarifying the transfer of knowledge from the children to the team designers. This, however, did not happen during the workshop and at the time it was felt that the opportunity to clarify or elaborate may have been missed. Although it had not been planned, the group spent time together informally once this researcher had concluded the workshop. During this time, all the staff participating and the designers continued conversations about the findings that remained projected on the wall. These discussions although informal, were different to those that emerged during the presentation and focussed on storytelling and collective reflection. It was during this time that the children participating were seen to be most engaged, laughing and interacting positively with the team as they collectively recalled different stories and incidents that emerged across their previous

The workshop finished up on a positive note, with the children's teacher offering a round of applause for the three team designers. After this workshop all three designers met again to remember and capture any additional information that they felt may have emerged, particularly during the informal discussions after the workshops had concluded.

6.1.5 Case Study IV: Summary

The preceding sections provided a thick description of the first of three explanatory case-studies each describing efforts to support the participation in activities comprising the early, intermediate and final phases of technology design.

This case-study represents the participation of children in the early design phase which is focussed on view to gathering and transferring children's tacit knowledge, understanding and capturing their lived experience and translating these into requirements documents that can guide the remainder of the project. The focus of this case -study was to examine the application of techniques by which the lived experience of children with autism might be understood by those responsible for the design of software for their use. This section describes the implementation techniques to support the gathering of information about children with autism, the transfer of such information and finally represent it in a manner that will guide the rest of the design. The sections above describe the success of some of these methods, the process of observing children within a naturalistic context or in activities that are and familiar to them. It also describes the opportunities and mechanisms presented to them to exert a level of autonomy on their largely non-verbal communication. The tangible benefit to participating children must be seen as not only the opportunities proffered but the descriptions provided here as to how such opportunities were taken up by participating children. Some of the methods however proved more challenging particularly in term of translating these into units of information that could be interpreted by the team designers. The Proxy Stories proved difficult to elicit with those adults present focussing on their own experiences with the children rather than providing narrative accounts of the children's experiences. Such proxy storytelling occurred much more naturally in the day to day interactions of the adults and children participating. Time spent together sharing the same space proved a more natural environment for the exchange of stories and anecdotes as opposed to a more formal workshop. It was surmised that this workshop may have achieved its desired aims by ensuring the inclusion of parents, siblings or those that had different experiences with the children.

6.1.5.1: Emergent Cultural Issues

The implementation of these workshops also highlighted the need to ensure that techniques and methods are culturally appropriate. In this instance the use of photography proved problematic highlighting cultural mores that resulted in a discomfort with the use of photography with both children and with adults. Although permissions and consent had been

given to the use of photographs during this design project and this research, the issue emerged only during the implementation of this method and as such, its use was abandoned. The applicability of such a method in other contexts was not possible during the scope of this project and the need to examine this was not anticipated or considered until after the workshop had taken place. The process of observing children in their own, familiar environments using a series of supports and probes to facilitate information gathering did appear to be the most successful method implemented in this case-study. The gathering of caregiver stories, although limited by the nature of the participants did provide a mechanism for elaborating upon and authenticating the information gathered during observations. As mentioned, the full appraisal of the value of providing participants with a mechanism for recording their lived experience using photographs was not possible in this case-study.

The contribution that opportunities for collective reflexivity provided all three designers cannot be understated. During the 'wall of us' workshops (Case Study IV Workshop 4) as the designers augmented the mind-map of their findings from observations and caregiver stories with images and personal sketches, their post workshop elaborations increased and demonstrated additional depth of understanding. In one example, where a sketch of one of the children holding their favourite toy was included in the presented workshop it initially generated excitement and discussion amongst the therapists and carers. This discussion quickly expanded to a broader conversation involving the children with the adults questioning children's likes and dislikes of their favourite toys. Because some differences of opinion emerged between adults, they directed conversation to involve the children in assenting or agreeing with particular opinions and positions. This played out in an easy, conversational and inclusive manner offering what the designers described as the 'closest thing to close collaboration' [Designer 1-personal communication]. Although Case Study IV Workshop 4 provided a structured mechanism for such collaborative reflexivity to emerge, it was however during more incidental moments, for example cleaning up after workshops or spending time together between arrival in the morning and classes starting that more natural reflexivity was observed. This took the form of stories, anecdotes and three way conversations involving the designers, other adults and the children responding in their own idiosyncratic ways.

6.2 Case Study VII: Intermediate Design Stage

'Supporting children with autism in co-creation activities'

The intermediate stages in a design project are often focussed on the process of imagining what the final outcome will look like. Designers engage in creative activities that are aimed at generating content that will comprise their vision of the final product. These creative outputs are often aggregated together as prototypes or lo-fidelity visual representations of the potential design solution. Within PD projects, such creative activities are collaborative with designers and non-designers working together in what are referred to as co-design activities. In the previous chapter, a mechanism for engaging children with autism in such co-design activities was outlined. This forthcoming section provides a thick description of the implementation of this mechanism within the context of a collaborative design project described at the outset of this chapter.

The composition of participants was as in Case Study IV with the addition of a further child [Child 13] who had not been able to participate in Case Study IV due to his absence from school because of illness. The school-based team were very keen on his inclusion in these workshops as they had spoken to him about the process prior to his short illness and felt it would be unfair to exclude him at this stage.

Preparation required that the participating children be provided with the appropriate equipment they required to express themselves creatively by way of generating visual content. As such, all six children were engaged in an Assistive Technology Assessment by specialist professionals from the Mada Qatar Assistive Technology Centre[49]. Examples of the individual technology solutions determined for and provided to each child is outlined in Table 12 below.

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[49] The Mada Qatar Assistive Technology Center provides a specialist Assessment and Technology matching service for children and adults with disabilities, this service is described in some detail in Chapter 2.

Child	Equipment provided & set-up instructions
Child 1	Microsoft Surface Pro with large Bluetooth switch and table mount with the following software installed: • Microsoft Paint 3D • Artweaver • My Paint Set-up switch for use by Child 1 using the palm of his right hand, ensure that it is securely located on his wheelchair tray.
Child 2	iPad Air set up with Bluetooth Double switch plus secure table mount with the following apps installed • Glow • Doodle Buddy Both switches to be located on either side of his wheelchair tray within range of both his hand (place them medial to his position of rest)
Child 4	iPad Air (keep in protective cover) with the following apps installed • Glow • Doodle Buddy Set Up instructions • Locate the iPad on a slanted desk surface (use provided book stand) and use non-slip material such as Dycem to ensure the stability of the device
Child 7	iPad Air (keep in protective cover) with the following apps installed • Glow • Doodle Buddy Set Up instructions • Ensure the Guided Access Accessibility Feature is switched on for chosen activity • Locate the iPad on a suitable desk surface and use non-slip material such as Dycem to ensure the stability of the device
Child 11	iPad Air (keep in protective cover) with the following apps installed • Glow • Doodle Buddy Set Up instructions • Ensure the Guided Access Accessibility Feature is switched on for chosen activity • Locate the iPad on a suitable desk surface and use non-slip material such as Dycem to ensure the stability of the device
Child 13	Microsoft Surface Pro with large grip stylus with the following software installed: • Microsoft Paint 3D • Artweaver • My Paint

Table 12: Assistive Technology recommended for each child to support creative expression activities

6.2.1 Case Study VII: Workshop 5: Design with Technology Workshop

The objective of Workshop 5 was to conduct an analysis of participation by children with autism participating in the intermediate phase of design when supported using technology selected to meet their needs and match the demands of the design task. The workshop provided an opportunity to evaluate how the provision of such technology contributed to a child's creation and generation of visual design content to contribute to the development of the design solution.

This section presents a thick description of the first of Case Study VII Workshop 5 and is drawn from the field notes recorded by this researcher and from the transcript of the video recorded of Workshop 5. This workshop lasted approximately twenty-six minutes

At the outset of the workshop, there was a reluctance by most of the children to engage with the technology that had been provided, they appeared to have no interest in the activity whatsoever. Of the participating children, [Child 2] was the first to engage in the activity requiring little encouragement from the adults participating. His technology was set up at his desk and he moved quickly moved to pressing the switch with his right hand to begin the process of drawing on the provided computer.

SLT1	'. well done. [Child 2], you know what to do now, its like the practice game with the switch …. walla [sic]...you remember already…'
TA 2	'…he does not need help with this now…. I think I can see to [Child 4] …'
DESIGNER 1	'…. Hey [Child 2], maybe you can teach us now, what do you think, this is very good, right?….' [Source: Workshop 1: video transcript]

Excerpt 30: Starting the design task using technology

In the excerpt above [SLT 1] appears to suggest that [Child 2] already has some familiarity with the technology he is using. This may have enabled him to engage in the design activity more easily than his peers.

The remaining children participating required a degree of explaining from the adults present. Adults tended to model the use of the technology provided to the children and demonstrate the task.

SLT 3	'. okay, let me show you…look, look, just move [SLT3 moves Child 4's hand over the iPad screen without touching the screen] ……you see? Can you do?.....'
DESIGNER 2	'…put your hand, no, I mean your finger on the screen…'
SLT 3	'…. No, he's not understanding you. [Child 4], look how I do it…[SLT 3 models the actions required to draw on the iPad screen]'
	[Source: Workshop 5: video transcript]

Excerpt 31: Guiding the child with autism to use the technology provided

The exchange detailed in Excerpt 31 above suggests a confusing instruction environment, where two adults are presenting the task differently and providing a variety of performance instructions. Adults with more experience working with children with autism had a different approach, allowing the child time to explore using technology themselves and providing only encouragement and positive reinforcement.

SLT 1	'. that's it, go ahead {speaking to Child 6], that's it....'
DESIGNER 3	'…will he, is he going to...?'
SLT 1	'…. Leave him, it's fine, you are doing great [Child 6], you just keep playing for some more time, this time is for you remember….'
	[Source: Workshop 5: video transcript]

Excerpt 32: Letting the child with autism have time and space to familiarise themselves with the technology

Recognising the importance of allowing the child to familiarise themselves and gain confidence and comfort using the provided technology appeared to be a knowledge or skill developed with experience as many of the other adults appeared to focus on completing the task and generating as many images as possible from the outset of the workshop.

Once participating children and adults had appeared to develop more confidence using the hardware and software available to them, the ease and speed at which children could create visual images proved very positive and offered adults opportunities to provide praise and positive reinforcement.

SLT 3	'…. oh wow, have you seen what [Child3] has made…. look here, this is so good?.....'
DESIGNER 2	'…well done you, that's very professional, you are an artist, I know…'
	[Source: Workshop 5: video transcript]

Excerpt 33: Ease and speed of generating content as opportunities for positive reinforcement

The designers in the workshop took some of the content generated and projected it on a wall monitor for all participants to see. This sharing again was a positive way of acknowledging not only children's contributions but also their efforts. This also provided an informal opportunity for some reflexivity from the group as a whole as illustrated in Excerpt 34 below.

Designer 1	'..look what we have from [Child 2], can everybody see, very nice.....'
SLT 1	'…can we guess what it is [Child 2], I think it's a picture of the school?…'
SLT 3	'…. No, no, that's boring, I think it is the Souq or the Mall, much better what do you think….
Designer 1	'…well I think it is for [Child 2], what do you think [Child 2] better like the School or the Mall, you pick….the Mall?.'
SLT 1	'..[responding to Child 2's non-verbal gesture]..of course, well done [Child 2]..'
	[Source: Workshop 5: video transcript]

Excerpt 34: Informal opportunities for reflexivity emerging from sharing generated content

The limitations of using technology to support children with autism in generating visual content arose from their apparent lack of familiarity with or awareness of the benefits of using it. This resulted in time being dedicated during Workshop 5 to adults implementing a range of strategies to accelerate children's comfort in using the technology. Once they could overcome this and focus on the design task, the benefits of using technology were evident in the ease and speed at which they could generate content, receive encouragement and have their content displayed and shared with others.

Designer 1	'what we need to do now is move our hand around until we make the shapes that you want, you can draw this to tell me what is in your heart] …'
	'…. you will need to move your finger to the bottom [of the iPad screen] to pick the colour…. I know you like green, is this your favourite, yes put it up there – yes that's colouring….'
	[Source: Workshop 5: video transcript]

Excerpt 35: Case Study VII: Setting up the child to engage in drawing

Although the adults present encouraged the children participating, by this workshop they did not tend to direct them as to what they were to draw. Instead they gave encouragement and reinforced the child's efforts to draw or engage with the technology provided such that they could create visual images on screen.

| SLT 1 | '…you use your hand now to make what you like……just like that ……yes, congratulations, that's very good'

'…that is so good, is it finished or will you do more, yes, move your hand over here to do more on this, yes [Child 6] I like it a lot, great artist….'

[Source: Workshop 2.1: video transcript] |

Excerpt 36: Case Study VII: Setting up the child to engage in drawing

The three team designers provided encouragement to the children to elaborate upon their initial drawings, and to build richer expressions. This involved providing further encouragement and checking on a continuous basis with the children as to whether or not they were finished or wanted to add to the picture. In some instances, the designers encouraged the children by demonstrating to them how to add to their drawings, through the use of both colour, the addition of further shapes and texture. This required a level of turn taking, demonstrating, waiting, encouraging and other collaborative techniques. These were exhibited in the absence of verbal feedback from the children.

| SLT 2

DESIGNER 1 | '…you could now put more colour in the picture, you know you can use any of these colours here [pointing to the colour palette] …. it's okay, I can show you, like this [demonstrates adding colour], will you try? It's okay, I can help if you like, it's like this [helps with hand over hand support] …there, you can do it now.'

'…. are you done…. wow, this is good, do you want to do more …. you can do it like with more shapes here [points to the corner of the image created]

[Source: Workshop 5: Researcher Field Diary] |

Excerpt 37: Case Study VII: Team designers encouraging and supporting children to engage in elaboration of their drawings and creative expressions

Each of the children were assisted in saving their drawing efforts to the internal memory of the device they were provided with. All the creative expressions generated by the children during this workshop were later transferred to secure laptop storage and provided to the three team designers as they prepared to develop a lo-fi prototype based on the data gathered during Case Study IV and the visual creative expressions captured here. In total, the six children with the support of those adults' present produced a total of twenty-one visual images that were saved and passed to the team designers.

6.2.2 Case Study VII Workshop 6: Adult Supported Design Workshop

The objective of Case Study VII - Workshop 6 was to examine participation by children with autism participating in the intermediate phase of design when supported by adults. The

workshop provided an opportunity to analyse the nature of the support provided by adults for children engaged in generating visual design content.

This, thick description of this workshop is drawn from the field notes recorded by this researcher and from the transcript of the video recorded of Workshop 6. This workshop lasted approximately nineteen minutes.

The second session began with a short recap on the objective of the workshops and repeat for participating adults the procedures involved in supporting each child's creative expression throughout. The three team designers also provided a quick summary of the process of saving and storage of children's drawings and images. The workshop took place at the same location as Workshop 5 which occurred the previous morning and has been described in the section preceding this. Workshop 6 which took approximately 30 minutes to complete, was videotaped by this researcher, then transcribed in the subsequent hours.

One thing that was evident in this workshop was the ease at which the children engaged in the activity and used the technology in contrast to Workshop 5. Similarly, the participating adults provided a higher degree of 'hands-on' support, assisting children in using their technology and using less verbal prompting to describe the process of using the apps and technology.

TA 1	'…you can use the space here to make it [the drawing] bigger, so the whole screen is full….s' [Workshop2 – video transcript]
TA 3	
	'. there are other colours to, you can take another one…'
SLT 1	'[Workshop2 – video transcript]
TA 2	'.it looks like a big flower, this will make a nice picture for you….' [Workshop2 – video transcript]
	'. that's okay, if you are finished I will save it for you…....' [Workshop2 – video transcript]

Excerpt 38: Case Study VII: Adult verbal support demonstrating encouragement and support

The excerpt above illustrates a change in tone in the verbal interactions between adults and children, they are less concerned with providing instruction and orienting children to task but are focussed on encouraging and elaborating their creative expressions.
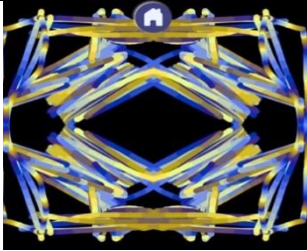
Workshop 2: Contributions emerging		
Child	**Number of creative expressions**	**Examples**
Child 1	6	
Child 2	2	
Child 4	4	
Child 7	1	
Child 11	5	
Child 13	6	

Table 13:Summary of creative expressions generated by participating children

The table above illustrates the increase in productivity for this workshop. In the absences of corroborating data, the reasons for this are open to speculation although building familiarity in the process for children with autism may indeed be a factor and may suggest that co-creation activities to be effective should be seen as a more long-term effort with children rather than a once-off event as is often the case in design projects.

Prompt Type[50]	Example [Source: Co-creation Workshop 1 - Video Transcript]
Prompts for Motivation[51]	". [Child 1] now it's your chance to pick, do you want to pick your favourite pictures?", [SLT 1] "[Child 2]do you want to do this? Let's do it….." [SLT 1] … "remember the winner will be the person who picks the best", ". how many will you do? Will we do them all?" [TA 3]
Prompts for Task Orientation[52]	"…okay, can we look here now please", [DESIGNER 1] "……let's have a look at the iPad, can we?" [SLT 1] "….the picture is here (points to the screen), can we start with this"
Prompts for Attention Engagement[53]	"…… [Child 3] ……. can we listen to…." [TA 3] "come on, we are not going to play over there until we finish our work here" [SLT 1] "…we are ready to start, are you ready to start" [TA 2] "…. will be begin now, [Researcher] wants us to look back at the screen now" [SLT 1]
Prompts for Attention Restoration[54]	"…. okay [Child 3] let's get back to what we were doing" [Abeer] "…please [Child 6] over here (points to screen)" [SLT 1]
Positive Reinforcement	"…. well done you, you picked that one", [DESIGNER 1] "that's very good, well done to you", [SLT 1] "great job, you're doing great" [TA 3] "great choice, that's my favourite too", [DESIGNER 1] "I think that's the best one", [TA 1] [Source: Workshop 6 video transcript]

Figure 21: Summary of prompts used in the workshop categorised in terms of function

The table above captures some of the prompts used by adults participating in the workshop by way of supporting activity participation by the children participating. The variety of prompts outlined above highlights the diversity of the needs children with autism have in terms of engaging them successfully in co-creation tasks go beyond the provision of positive reinforcement. At the outset of the workshop there was several prompts used by the adults

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[50] The categorisation of prompting behaviours outlined above was based on literature pertaining to the use of Motivating Operations[50], a key feature of Applied Behavioural Analysis (ABA) a common treatment approach and modality employed in the treatment of children on the autism spectrum.

[51] Refers to the internal factors that determine a child's desire, interest in or commitment to a particular task or role.

[52] Task orientation refers to the ability to focus on the tasks that need to be performed, this requires orientation awareness of individual role and anticipated outcomes of action or non-action.

[53] Attention engagement refers to the skills required to give ones focus to one particular task or activity and to disregard all desires to switch attention either temporarily or permanently

[54] Attention restoration is the process of switching a person's focus back to the job or activity in question. This process may be intrinsic (motivated internally by the person) or extrinsic (based on intervention from another person).

present to encourage most of the children to engage with the task at hand. Furthermore, in many instances the adults present reinforced the purpose of the workshop and the assigned tasks (task orientation). This was required even though the workshop had been introduced and the activities described in detail. Considering the challenges participating children had in understanding communication and verbal instructions, it is not surprising that they required further instruction, prompting and support from adults.

Children with challenges of attention and concentration skills do require prompts to help them attend to a task after the attention has been distracted. Although the location of the workshop was familiar to the children participating and external distractions were kept to a minimum, all the children still required a range of verbal and physical prompts from the adults present to re-engage them with the task. Each of the children withdrew or lost attention to the task on at least one occasion during this workshop. It is interesting to note that both the participating SLTs and the team designers all contributed to the process of prompting and providing verbal support to the children with autism. By the second of the workshops, it was apparent that the three designers had grown in confidence and benefited from their experience working alongside the more experienced TA's and SLTs. In Workshop 6 the more experienced SLT allowed children time to build familiarity with the technology provided, however it appears that in this the second of the two content generation workshops that adults were more focussed on ensuring that children proceeded through and completed the design task.

This also highlights the importance of the role adults' guidance, encouragement and positive reinforcement play in supporting co-creation activities. Their responsibility to engage the child in the task, continuously provide appropriate instructions and ongoing task orientation plays a crucial role in ensuring that they can generate multiple contributions. Supporting children with autism in activities focussed on creative expression required that adults present in the workshop set-up the process of engaging in all the steps required in the tasks in a methodical sequential manner. By the second workshop, it also appears that the adults present are more familiar with the task, the technology and how best to guide children.

6.2.3 Case Study VII: Summary

The thick description presented here outlines the implementation of the methods and techniques outlined in the previous chapter that aim to facilitate the inclusion of children with autism in co-creation workshops. The implementation described here highlights the value of

providing children with autism with technology as alternatives to more traditional tools for creative expression such as have been used in other studies with children with autism. The support of a team of AT assessment professionals and the availability of the required equipment certainly made the workshops easier to organise and execute. As was highlighted in the previous chapter, one of the factors that is indicated in ensuring successful creative expression is the availability of a diverse range of resources. For children with autism, the diversity of such resources must be coupled with the need to identify the resources that best match their abilities and compensate for the challenges that they experience. In the implementation described in this case-study, the process of matching the correct resources with each child's ability profile was conducted quickly due to the availability of external sources of support. This process of matching the correct resources that match childrens' needs must be seen as an additional benefit accrued through participation in this process. Children who hitertofore may not have had access to a range of material resources that supported their participation were provided with tools and supports that had been deliberately identified to match the profile of their particular needs. This element of the process certainly merits further examination and may benefit from a more forensic analysis of the process of identifying a range of technology solutions that support the creative expression of children with autism.

As with Case Study IV, the importance of the location in which co-creation workshops are held was further highlighted as was the importance of giving children the opportunity to acquaint themselves with the novelty of the process. The ease at which children engaged in the second workshop was indicated by the decrease in prompting behaviours by participating adults and the increase in the creative expressions generated by the children. Similarly, the use of support techniques and tools such as the visual schedule, which had been used in previous studies provided both children and adults participating with a familiarity of surroundings.

The complexity of the role played by adults supporting children engaging in co-creation activities goes further than simply encouraging and providing positive reinforcement. Supporting children with autism in co-creation activities requires that adults provide encouragement to engage in the activities, ongoing instructional support and prompting to maintain or re-engage children with the activities at hand. The process of elaborating or enriching the expressions of individual children also requires deliberate intervention by participating adults. This encouragement required not only verbal support but also some physical prompting and guidance.

The interactions between the six children participating and those adults supporting their activity engagement was such that it was difficult to see clear equalization of power relations between participants. In their efforts to ensure that the workshops were successful the three design team members and the three SLTs took responsibility to direct and guide children in participating. Prompting behaviours to encourage children's participation could be interpreted as examples of unequal power relations between children and adult participants, contrary to the collaborative practices in PD. This will be discussed further in detail in the following chapter.

The outcome of this explanatory case-study was a corpus of creative expressions that could be taken by the team designers with which the development work for initial prototype of the software could begin. This explanatory case-study suggests that a great deal more time should be dedicated to content generation or co-creation activities over the course of an entire design project.

6.3 Case Study X: Final design phase

'Supporting participation through shared decision making'

The latter stages of design projects involve refining the shared vision of the project outcome. It is at this stage that the ideas gathered begin to translate into a representation of what will become the outcome. These representations referred to as prototypes provide participants in the process with their first opportunity to engage with a tangible artefact. In PD traditions engaging with a design prototype offers design participants choices and to express their preferences. Design evaluation offers children in projects such as this with opportunities to engage in active decision making. By focussing on evaluation, the final phase of the design process defines participation in terms of children with autism's ability to express choices and make decisions.

This, third explanatory case-study offers a thick description of the implementation of a process of supported decision making and the provision of communication cards to reduce the cognitive and communicative demands on the child with autism. Furthermore, this case-study explores the way adults support children in making decisions and expressing choices during evaluation tasks. Preparation for the workshop consisted of this researcher describing (for the adult participants) how to use the Decision Making Protocol[55,] including the information that was to be recorded and the procedures for discussing the various elements with the participating children. Those present were reminded to communicate directly with children and to ensure that all processes regarding preference selection and choice making behaviours were recorded. Furthermore, the structure of the workshop and the sequence of decision-making tasks contained in the Workshop Protocol Form was discussed with suggestions in terms of the time frames involved in each section. When those adults participating expressed that they fully understood how the workshop would proceed and were happy in terms of their role in supporting children's decision making, all the children were introduced to the group

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[55] Outlined during the description of final phase design case-studies in the previous chapter, this protocol took the form of an A4 booklet that had been prepared ahead of this workshop and contained a script of all of the decision making events scheduled during the workshop with visual representations of the design elements and prototypes from which to choose or make decisions. The protocol also contained a series of 'prompts' as suggestions for the adults supporting each child.

6.3.1 Case Study X Workshop 7: Shared Decision Making: the role of support materials

The objective of Workshop 7 was to examine participation by children with autism participating in the final phase of design through their evaluation of design solutions. The workshop provided an opportunity to analyse how structuring decision making and providing material supports for children expressing choices and making decisions during evaluation design tasks.

This, narrative, thick description for this workshop is drawn from the field notes recorded by this researcher and from the transcript of the video recorded of Workshop 7. This workshop lasted approximately fifty minutes

The workshop session with all in attendance began with Designer 1 thanking everyone for their efforts to date and recapping efforts from the preceding workshops (described in case-studies IV & VII above). This was followed by an introduction to the graphics and visual images that would be discussed over the course of the workshop. Decision making opportunities for children were structured in terms of their timing within the workshop, the visual supports provided, and the initial prompts provided to adult partners. The decision-making script (Decision Making Protocol) upon which the workshop was scheduled were provided as suggestions, however the adults participating were charged with explaining, elaborating and making these clear for the children with whom they were partnered.

TA 3	**Protocol Prompt: Which of these is your favourite picture?** '…okay {Child 1}, if you can see here on the paper, also on the screen, can you see [Child 1] here, if you look to the page and the picture?........okay, okay, if you can look, do you like this one [finger pointing to paper based image] or do you like this one, which one is your favourite, is it this one [pointing at second image]? I want you to look at the one you like please, just on this page, no, not on the screen, I can't see that, Just on the page, is that okay?......is it easier to look here or on the big screen, what will be easier for you?' [Source:WORKSHOP 7 – video transcript]

Excerpt 39: Case Study X: Participating adult partner using multiple means including elaboration, clarification and explanation to simplify decision making instructions

In the excerpt above, one of the adults [TA 3] partnered with a child [Child 1] not only has to present the decision making opportunity in a variety of different verbal formats, she is also required to bring his attention to the task and specifically to the visual supports provided. In this instance, the accompanying visual slideshow of the images was distracting for

the child and drew his attention away from the task at hand. This emphasises the importance of set-up and considering the environmental distractions and the impact they may have on tasks with a degree of cognitive complexity for children with autism.

Another adult partner provided a further example of how the choices offered to children were aggregated and isolated such that the amount of information considered in making a decision was minimised.

SLT 1	'…just look with me, do you see this, yes, good, yes? What do you think? No, no, no, for now, just this – is this good, you know, if you don't like it's okay for no, no is okay too, but yes, just on this one, yes, yes, you do like it? You do like it, wow, me too, I like it a lot. If you like it, I like it. Okay, good.' [Workshop 7 – video transcript]

Excerpt 40: Case Study X: Adult partner limiting the decision making for a child with autism to consider one visual element at a time

The Decision Making Protocol was laid out to contain all the information for one decision making event on an individual page. This however appeared confusing with some of the children actively trying to turn the page, aware perhaps that there were further images contained elsewhere. In preparation for this workshop, a Communication Protocol for Adults[56] was developed to guide the behaviours and actions of adults as they supported the decision making of children with autism as they participated in the workshops. This protocol provided a behavioural guide for adults ensuring that they provided the appropriate support to each child in a logical and reasoned sequence. The aim of this was to minimise adults acting as proxies and making decisions on behalf of the children. Adults participating in the workshops were provided with a ten-minute orientation to the protocol immediately in advance of each workshop.

The availability of yes/no symbols on communication cards on each of the children's tables influenced the way in which adult partners attempted to decrease the cognitive complexity of choice making for children as evidenced in the excerpt below.

TA 1	'…for you [Child:Faisal], is the boy [character image] your favourite, yes… [long pause and points finger to relevant symbol]. or…….no………. [long pause and points finger to

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[56] Outlined in the procedures for final phase design case studies in Chapter 5, the Communication Protocol for Adults was a document provided to all participating adults to guide their communication with children and inform the support strategies they employed. The document outlined how to contribute to a positive communication environment, the sequencing of cueing to use with non-verbal children and examples of prompts to use and how to promote and understand non-verbal behaviours.

> relevant symbol] ……what do you think, you choose, yes or
> no [finger points to relevant symbol] …….' [CS
> X:Workshop7 – video transcript]

Excerpt 41: Case Study X: Using communication symbols as a tool in decreasing the cognitive complexity involved in decision making

Similarly, the availability of symbols providing 'I like' and 'I don't like' symbols did appear to influence the verbal prompting used to elicit decision making with the children. Adults focussed children on expressing judgements regarding the design elements presented to them in terms of affirmative (I Like) or negative (I don't like). This did appear to present more challenges for some of the children who may have found these concepts more challenging than indicating yes/no when asked if they like a particular design element. In some instances, the adult would present the decision making opportunity initially as a yes/no decision, and then re-present it later in terms of indicating an I like or I don't like judgement as in the excerpt below.

> TA 1   '… [Child 3], yes, that is the camel, do you like this
> picture…. okay, please tell me you like it – please, use
> the cards here [points finger at laminated card]…….'
> [Workshop 7 – video transcript]

Excerpt 42: Case Study X: Adults reframing decision making opportunities from yes/no decisions to I like/I don't like judgements

It should be noted that not all children used the communication cards that were made available to them. Of the participating children, [Child 3] and [Child 6] did not use communication cards at all with their supporting adults in the workshop indicating that their preferred means of communication was by eye-pointing and finger-pointing respectively. Such behavioural approaches to communication and decision making required a degree of interpreting and translating non-verbal behaviours into discrete decision making events. This required that adults present to support children modified their verbal prompting and instructions such that it elicited a physical response from the child.

> SLT 1   '… [Child 6] can you show me, good boy, yes, can you do
> that again, what did you do, please, good boy, yes point
> again, is this what your choice is, is this the one, show me,
> good, congratulations…….'
> [Workshop 7 – video transcript]

Excerpt 43: Case Study X: Adult partner using prompts to encourage non-verbal decision making

It is worth noting that both children who were not using the communication cards to support their engagement with adults required a higher level of prompting and direction from their adult partners and did not complete all the assigned decision making tasks assigned for the workshop.

6.3.2 Case Study X: Workshop 8: adults in supporting children's decision making

The objective of Workshop 8 was to examine participation by children with autism participating in the intermediate phase of design when supported by adults. The workshop provided an opportunity to analyse the nature of the support provided by adults for children engaged in generating visual design content. This, narrative, thick description for this workshop is drawn from the field notes recorded by this researcher and from the transcript of the video recorded of Workshop 8. This workshop lasted approximately thirty-two minutes

The adults present were given the autonomy to time the tasks at their discretion based on their experience with each child and their prior knowledge of similar tasks during their school curriculum. This allowed the adults to bring their experience with children to bear on their efforts to engage children in shared decision-making but provide a time-frame that would accommodate their particular challenges. In efforts to simplify the demands for communication with non-verbal children, adult partners limited decision making to yes/no decisions or in many instances to provide the child with opportunities to demonstrate their assent. In many instances, adults simplified decision making tasks that required a child to choose between two presented options. They did this by simply presenting one image at a time and asking for a gesture of assent from children. This approach of focussing the child in on one image and encouraging a yes/no or a like/dislike decision to be made could be seen by more than one of the adult partners and was typically resorted to when a child was uncooperative or did not appear interested in making a choice at that time. This also appeared to be the case when adult partners were struggling to assist the child in attending to the task and avoiding distraction. It resulted however, in the adult concluding the interaction with a decision upon which the child would then engage.

SLT 1	'…I think is that this…..[points to paper based character image] is the one you like from all of them, is that right [Child 6], yes?'. [Workshop 8: video transcript]

Excerpt 44: Case Study X: Adult partner providing a decision making opportunity to a child based on their own observations of the task engaged in

This would appear to suggest that the participating adults were very keen to get the tasks completed and were simplifying the process on an ongoing and iterative basis as they progressed through the workshop supporting the children involved. It also highlights a power imbalance that emerges when children who are non-verbal are engaged with adults who rely on

their own verbal skills to complete a task in a particular timeframe. It is unclear from the transcriptions from the workshop whether this process of adults capturing their tacit understanding of completing the task and then re-presenting a single choice for the child was based on their experience or their desire to successfully complete the tasks assigned.

Providing a structure to decision making tasks based on a linear progression through a series of decision making 'events' and using a visual schedule in clear view to all participants to support this provided a useful tool for the adults partnering with children to stay on task. Some of the adults participating used it as a reference for progression through the task and as a reminder to stay focussed.

TA 3	'…no, finish, that is finished now, next is this picture, this picture right here, now…… That is all gone now…… I want you to look here with me [points finger at the next section], now please? We have to follow it like this, yes, leave that it is finished, now we will look and see this, look, we should move on now.' [Workshop 8 – video transcript]

Excerpt 45: Case Study X: Adult partner using the workshop protocol as a mechanism to progress through all required tasks and retain attention

There was evidence that some of the less experienced adults participating had considered some of the advice and guidance provided in the Communication Protocol for Adults. This was evidenced at times where an adult would inadvertently move to provide a child with physical support to engage in an activity but would then check herself and go back to using a less directive method of task prompting.

TA 2	'…its okay, let me show…..[TA 2 lifts Child 1's left arm], no, its okay, you, its your turn [TA 2 removes her hand from Child 1's arm].' [Workshop 8 – Researcher Field Notes]

Excerpt 46: TA reconsidering physical support for a child

For some of the adults with more experience however there were instances where there was a degree of 'leading' the child as illustrated in Excerpt 47 below.

SLT 3	'…you do know, we know you like everything red, this one is red, don't you like the red…..'

<div style="border:1px solid black;">

[Workshop 8 – Researcher Field Notes]

</div>

Excerpt 47: Adults 'leading' the decision making of children

The above excerpt was preceded by a drawn out process of trying to engage [Child 4] who appeared to have lost all interest in being part of the workshop, such that SLT3 had brought him to another part of the room to relax. SLT 3 did appear to be keen that [Child 4] engage in the activity (he had until that time in Workshop 8 not successfully indicated any choice or decision making despite SLT3 trying various means by which to encourage him) such that she returned to the table and attempted to re-orient his attention to the workshop Communication Protocol document again. [Child 4] responded to this attempt by forcefully closing his eyes and keeping them closed until he was again withdrawn to another part of the room and away from the task. At this point however, his eye-gaze shifted to the images as they were projected on the wall monitor and his focus did remain on these for several minutes. This could possibly suggest that although he may have had some interest in being part of the workshop, he did not have any interest or motivation to engage in decision making of any description.

6.3.3 Case Study X: Summary

The thick description presented here of the third explanatory case-study illustrates participation during the final phase of the design process as illustrated by children's decision making in design evaluation tasks. Firstly, the crucial role that supporting adults play in presenting the decision-making opportunity in a manner that accommodates the child's limitations and accesses their communication strengths. Furthermore, their role in interpreting the verbal and non-verbal responses of the children participating and translating such communication as discrete decision events. These roles and functions for the adult however does indicate a lack of 'democracy' in its truest sense within the decision making processes that comprise design evaluation in this project. Ultimately, the ambition of such efforts was to make the process of decision making accessible to children with autism in this research. Such opportunities are rarely made available to children and it must be noted that the impact of how these were taken up by children will be discussed further. Although the methods, including simplifying the decisions to be made and making available a range of supports aimed to maximise the decision making opportunities provided to children with autism – the intervention

required from adults suggests that devolving decision making does not equate with equalising power relations between adults and children in a design process.

Chapter 7: Evaluation and Discussion

This chapter can be considered in two parts each examining one of the main research questions guiding this research. One of the key aims of this research was to examine the proposed framework to support the participation of children with autism through key phases of the design process.

Section 7.2 will examine the data gathered over the fourteen case-studies to address the first of the questions; **how children with autism can participate in the design and production of new technology?** (RQ1). Key findings from this research will be presented relative to the design phase in question and will also address a further two sub-questions: '**in what ways can adapted PD techniques support the participation of children with autism in a technology design process**' (RQ1.1) and **'in what way can adults contribute to the participation of children with autism through the course of a design project'** (RQ 1.2). The role of adults contributes to supporting children with autism through the design phases (RQ1.3) will be discussed throughout but will be given particular attention in Section 1.1.4.2. An analysis of the outputs of the fourteen case-studies described in Chapter 5 and the three explanatory case studies in Chapter 6 will be utilised in this analysis.

Section 7.3 of this chapter seeks to address the second major question of this thesis, namely; '**how can the nature and level of participation of children with autism in technology design be evaluated**?' (RQ2), paying attention to the application of the evaluation framework. Previously in Chapter 2 of this thesis three dimensions of participation as a construct were described. These three dimensions, 'impact', 'influence' and 'agency' offers a lens by which to examine the participation of children with autism in a PD experience by highlighting some of the behaviours that manifest some of the key principles of PD.[57] This lens will be employed as a mechanism for uncovering some of the broader findings of this research pertaining to the nature of the participation of children with autism in technology design.

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[57] In Chapter 2, these key principles are 1) the transfer of tacit knowledge, 2) the democratisation of decision making and 3) the equitable distribution of power amongst participants and 4) mutual learning.

7.1.1 A Methodology for Participation

This section provides an analysis of the implementation of the proposed framework to support the participation of children with autism across the early, intermediate and final phases of the technology design process. Attention is given to the workshops, methods and techniques that represented design activities and participation opportunities for children with autism in the early, intermediate and final design phases.

7.1.2 Techniques to Support Participation in Early Phase Design

In the early phase of the research process, the primary responsibility of the designer is to develop and understanding of the user and their context and translate this understanding into a series of design requirements that inform the trajectory of the remainder of the design process. In this research, it was important to establish how the following techniques 1) observation of the child in their familiar environment, 2) listening to caregiver's stories about the children and 3) examining artefacts created by children such as photography contributed to designer's understanding of their needs, preferences.

7.1.2.1 The Limits of Observation

In keeping with the exploratory nature of this research an 'observation without tools' approach was adopted through the case-studies reported. The three designers participating throughout were not provided with background materials related to autism, special education or indeed relevant technology applications. In an effort to minimise any bias they may introduce in their observations they were provided with no observation checklist, no specific instructions other than to spend time getting to know the children, their school and how they used the technologies in their classrooms. Beyond using notebooks to record their observations, the designers were not provided with other tools to record their observations. It was hoped that a lack of prescriptive techniques and tools would ensure that observations gathered would be personal and subjective and would allow designers to interrogate these collectively as a mechanism for examining these is depth and gaining greater understanding of their subjects and context. Such lack of preparation or protocol understandably made the designer's initial experiences in the classrooms uncomfortable and stressful. Each of the designers variously reported feeling 'unsure' what they should be doing, 'interfering' with class routines and 'in the way'. The lack of formal equipment or procedures did however allow the three designers to

get closer to the children and become an embedded part of the routine of the day in school. It also resulted in all three spending time outside of the class discussing their observations, comparing their thoughts and collaboratively making meaning of their experiences with children.

In her work examining designers' encounters with children with autism, Van Rijn found that immersion in an environment takes place most effectively when designers have no clear goal demanding that they use empathy as a mechanism for understanding the phenomena they observe (Van Rijn, thesis). This was borne out in the experiences of the three designers participating in Case-Study IV reported in the previous chapter. As the time they spent in class increased the number of observations they recorded in their field-diaries decreased, however their time in discussions and the content of their discussions changed, reflecting their need for insight rather than observation.

Much of the meaning-making that designers engaged in was prefaced by an acknowledgement of what they didn't know. Their discussions sought to find sense in what they were seeing while frustrated by what they perceived as their lack of background knowledge or experience. Furthermore, each of the designer's in their discussions spent time seeking an understanding or a rationale for the seemingly idiosyncratic and unexpected patterns of children's behaviours. Finding ways to understand the unpredictable was a feature of much of the 'meaning-making' discussions.

Designer	Making sense of observation of children in a classroom context
MM	*"I could see him getting upset every time the game is switched on"*
SD	*". it's like he won't wait for it…"*
	"no, that's not it, I'm sure of it, I think it is waiting what about you"
MM	*"it might be him…."*
SD	*"… how do we know*, we're not experts"
MM	

Excerpt 48: Understanding Classroom Observation

The concern with not being experts, not having enough knowledge and not knowing enough about their subjects dissipated as they spent longer in the school, became more

comfortable and built relationships with children and staff. Discussions began to reflect designers' empathy in their observations of children rather than spending time trying to find a discrete reason that could explain the phenomenon.

This is in keeping with other studies that highlighted the need to spend time familiarizing and building rapport with children with autism (Pares et al., 2005, Keay-Bright, 2007a) but points also to a process of change on the part of the designer. It appears that for observation not only allows designers to record phenomena, but maybe more importantly serves to build relationships and fosters empathy contributing to a more nuanced understanding of the child and their context.

7.1.2.2 Understanding Lived Experience through Carer Storytelling

Another ethnographic technique modified for use in this research project was storytelling. Without the benefit of hearing children's stories in their own voice, the utility of hearing caregiver's stories about children with autism was examined as part of this research. Of particular interest was how caregiver's stories might contribute to increasing the designer's depth of understanding of the needs and preferences of each child with a view to incorporating these into the systems requirements.

Case-study IV as outlined in the previous chapter demonstrated that carer storytelling as a mechanism for sharing information and experiences about children with autism was evident both formally, through structured workshops and informally through some of the casual interactions shared between designer's and school staff. During this research and exemplified in case-study IV, formal processes for carer story telling were of limited value to the designers in their efforts to develop their understanding of the children in this research. The tendency for formal, structured storytelling lent itself to being dominated by voices in the group and were concerned with the primacy of information and opinion rather than narrative. This may be reflective of the types of communication that are often culturally valued in medical or therapeutic environments but proved of little value in contributing to the designers' efforts in establishing a depth to their understanding of children with autism.

7.1.2.3 Formal vs Informal Storytelling

As they had done continuously throughout the time spent on classroom observations, all three designers engaged in regular discussions focussed on understanding and contextualising the information the storytelling presented to them. As they became aware of

the limited value that was to be had from the formal storytelling workshops, they became more acutely aware of the 'informal storytelling' that they were experiencing as part of their interactions with the staff working alongside the children. Their 'meaning-making' discussions focussed more on remembering, contextualising and understanding the incidental, spontaneous and natural storytelling that was happening not just about the children, but around the children. It was in such informal narrative encounters, often with the children present, that designers felt that they gained a better picture of the children

This examination of storytelling has uncovered differences in the value attributed to the various types of knowledge available when establishing understanding of a child with autism's lived experience. Early interactions in the classrooms were preoccupied with designers' concerns with their lack of knowledge and experience. Recordings in their field notes however demonstrated their increasing familiarity with the participating children showed that they had become adept at evaluating new information and had a deeper understanding of its relevance to them in their role as designers. This points to a need in early phase design to identify processes and space for informal storytelling, mechanisms for capturing the day to day narratives of children with autism as told by those around them.

7.1.2.4 Storytelling as 'Mutual Learning'

The case-study (IV) presented in Chapter 6 suggests that there is a role for children whose voice is typically not heard to be present and suggests that they can play an important role in validating the stories told about them. Such validation, albeit through non-verbal means may be one of the most valuable considerations uncovered through the examination of this case-study. If we reflect on PD as a process of 'mutual learning' (Bratteleig et al., 2013), recognising storytelling as a collaborative, narrative and inclusive process ensures that the transfer of tacit knowledge as identified by Spinzzi (2005) is part of a reciprocal process of shared understanding. Allowing children with autism the opportunity to validate through whatever communication means that they have contributes to the process of equalizing power in the design process.

This research as illustrated in this discussion and in case-study IV presented in the previous chapter paints a picture that highlights the value of carer storytelling as a technique that supports efforts to gain a deeper understanding of a child with autism's lived experience. Moreover though, it also highlights the need to carefully consider how the voice of the child

facilitated with a view to establishing a practice that is reflective of reciprocal, mutual learning in keeping with the traditions of PD.

7.1.2.5 Understanding Culture and its role in selecting PD Techniques

The use of photography in ethnographic research and as a tool in other PD projects has been relatively well established (Racadio, Rose & Kolko 2014, Hall et al 2007) its application in this research study exemplified the need to consider not only its applicability to the perceived needs of participants but to the broader physical and cultural environment. It has also demonstrated value as a context mapping technique in previous design projects (van Rijn & Stappers 2008).

The cultural context in which this research occurred has been fully outlined in Chapter 5 and it should be made clear that this researcher had spent several years working in the country across a range of roles. Regardless of this experience, the selection of photographic elicitation as a mechanism gathering further insights into the lives of a child with autism represented the application of the researcher's own western cultural bias. Although this was outside of the scope of this research project, this highlights a need to examine the selection of research and design techniques in full consideration of the broader cultural milieu in which the project will take place. The transferring and application of techniques, methodologies and philosophical approaches that are developed within western cultural environments to others suggests a range of further research questions beyond the scope of this current study.

7.1.2.6 Techniques and Processes for Collective Reflexivity

The final workshop in Case Study IV focussed on providing designers with the opportunity to affirm, clarify and reflect with the participating children what they had found over the course of their previous workshops. For the children with autism participating in this case-study the objective of to provide an opportunity for respondent validation or informant feedback as would be commonly used in qualitative research. Although there were concerns that children with the complexity of cognitive challenges that were represented across the group in this study would not be able to understand the reflexivity required to consider the information presented and to communicate their thoughts and feelings. Notwithstanding, it was felt by this researcher that the process was important in communicating to the designers who were responsible for translating their findings to date into a detailed specification of user requirements.

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Using visual representations of designers' findings worked well when designers avoided using text and instead used sketches that they had made or photographs of the objects that they had encountered with the children. In such circumstances, the mind-maps became not only visual representations the individual lives of the children in the project but of their shared experiences together across the previous workshops. It was evident from the workshop presented in case-study IV that engaging children reflexively was best achieved informally highlighting the need to build relationships with children and to establish a shared understanding that the design project was a collective experience. In this way, the designers were not just reflecting on their individual, objective findings. Instead they were sharing with the children a sense of what they understood the collective experience to be. This is an example of what has been referred to as 'participation in the plural' (Pikhala & Karastic, 2016), where reflexivity allows the collective participation in a design process to become manifest. The case-study also demonstrated the importance of time and high levels of engagement in establishing a collective sense of 'team' in a project such as this (Karasti, Baker & Millerand 2010).

7.1.3 Techniques to Support Participation in Intermediate Design Phase

In case-study VII a thick description of two co-design workshops was presented in which children with autism were engaged alongside three adult designers and a range of staff from their school in co-creation activities. This section explores the role that technology played in allowing children to creatively generate a range of visual content to contribute to the fabrication of visual prototypes for the design project. It further examines the roles adopted and played by adults within the workshops highlighting a repertoire of responsibilities that was essential in ensuring the success of the process. Finally, the section concludes with an exploration of how the nature of the support required by the children in this research shaped the co-creation process and we discuss the implication that this has in our consideration of participation as it is understood in PD.

7.1.3.1 Supporting Co-Creation with Assistive Technology

Choosing to identify and provide assistive technology to each of the children participating was an attempt to shift the power balance in the creative process from the designers to children with autism. Providing children with autism with a range assistive technology that they could use to generate visual images gave children for whom other co-creation techniques such as drawing, paper prototyping or making visual mock-ups. What emerged from its application across the series of case studies however was the high level of

support individual children needed from adults to use the technology effectively to complete the tasks associated with generating creative visual content. The level and type of support required is the discussion of the role of the adult in the next section.

All three designers debated the use of technology and questioned whether how the technology shaped the children's ability to generate a visual image or whether it did indeed contribute to improving children's creative abilities. As lack of imagination and a paucity of creative ability are both highlighted as consequences of autism (Loveland & Tunali-Kotoski, 2013), such questions and debate are reasonable but merit a further level of examination that was beyond the ambition of this research. The use of assistive technology was examined in terms of how it supported the participation of children with autism through the intermediate phase of design. In allowing them to generate visual content that could be passed to the designers for incorporation into prototypes that could be evaluated, its application could be considered successful. The broader question as to whether or not the use of assistive technology supports co-creation is examined in section 7.1.3.3 below. The question however as to the impact that the technology supports the creativity of children with autism is not the subject of this thesis.

7.1.3.2 The Role of the Adult in Supporting Co-Creation Activities

Case Study VII illustrated the need for a high level of adult support in ensuring that children engaged in the range of activities associated with co-creation.

The role of motivator played by adults in PD with children with autism has been highlighted elsewhere (Benton & Johnson, 2015). This research did however provide an opportunity to examine this role in some depth. In Case Study II both workshops showed adults taking on a variety of actions that could be loosely categorised as 'motivating'. In many instances, adults were responsible for initially engaging children in the task, orienting their attention to the technology they were using, focussing their attention on the immediate task step to be performed and providing praise and encouragement throughout. Doing this required that the adults needed a thorough understanding of the task and understood their role in guiding the child through the task, while still allowing space and time for the child to experiment and be creative. Working out the distinction in a child's behaviours is a difficult process and one that requires the type of tacit knowledge that is often only gained through experience working extensively with children with such challenges (Frauenberger et al., 2011).

Other studies have indicated the importance of adults contributing as co-designers in their own right (Benton et al., 2014, Malinverni et al., 2014), this however was largely absent in this research as is evidenced in Case Study VII. This will be discussed in greater detail in section 7.1.3.3 below. Another important responsibility assumed by adults across the two workshops and indeed throughout the process was to assess, pre-empt and cater to the care needs of each of the participating children. This reflects findings in previous research examining the role of the adult in supporting children with varying disabilities throughout the design process children (Benton & Johnson, 2014). Due to the complexity of the disabilities of each child in this research project these needs ranged from 1) physical, where a child would require support with movement, 2) behavioural, where a child would require prompting to engage with or stay on task and 3) emotional, where a child would require consolation or encouragement when they felt they were not doing well in an activity.

7.1.3.3 Co-creation with Children with Autism as a Three Phase Process

The level of support required was such that the process of co-creation could be seen as a distinct three stage process rather than a single collaborative, engaged process usually described across the literature (Sanders & Stappers, 2008, Francis, Balbo & Firth, 2009, Park, 2012). This three stage process is described here as 'contribute, interpret and confirm', reflecting the responsibilities of the children and the designers.

The nature of the support required by the children with autism in this study was such that the focus during each of the workshops was to provide the motivation, encouragement and praise children required to be able to generate creative output. There were limited opportunities for or demonstrations of elaboration, refinement or otherwise typically seen in co-creation workshops (Foss et al., 2013). In both workshops detailed in Case-Study IV, the participating designers adopted a more passive role supporting the other adults who took responsibility for ensuring that activities were seen through to completion. In this way some creative contributions could be generated by children (*contribute*) and captured by the designers for incorporation at a later stage into design prototypes for evaluation. Designers were then tasked with translating the visual images created by each of the children into elements that matched their visions of the design solution. Before doing this however, they worked on the visual images to produce an initial rendering[58] of the visual element (*interpret*).

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[58] This initial cleaning up and enhancing of images was typically conducted by the three designers off-site. The software used to do this was Blender v2.4 and Synfig Studio v1.1.4. Both are popular, open-source development platforms for creating digital visual images.

For example, an image generated by a child that was a flower was enhanced to look more like that object. Once the designers had produced their first order enhancements of the visual images, they went back to show the image to the child that had created the original to confirm that they were happy with their rendering (*confirm*). This three-stage process that emerged challenges if collaborative creative sessions are indeed realistic or feasible with groups of children that require such a degree of support. It also calls into question whether splitting the process in this way amounts to tokenism in terms of the participation of children and hands the power in the design process back to the designer and away from the child. For those designers involved it also challenged them to 'reimagine' the contributions of children and to translate these into meaningful elements of potential visual interface prototypes.

The three stage process that emerged over the course of this research can be summarised as 'capture', 'interpret' and 'confirm'. This indicates that supporting participation in design activities for children with autism goes beyond simply creating the opportunity and requires more thoughtful engagement of the child in full consideration of their challenges.

This will be discussed in further depth in examining impact as an element in children with autism's participation.

7.1.4 Techniques to Support Participation in the Final Phase of Design

In Chapter 6, Case-Study X addressed the question as to whether the techniques implemented in the study supported the participation of children with autism in the evaluation and decision making processes that represent the final stages in a technology design process.

7.1.4.1 Structuring Decision Making to match the Skills of Children with Autism

Several techniques were identified and implemented across Case-Studies III, IX, X and XIV to facilitate children with autisms' evaluation of prototypes, proposed design elements and proposed solutions.

As a core feature in PD, efforts to democratize decision making were considered a key mechanism in facilitating participation for children with autism. As such the techniques proposed aimed to serve two purposes, firstly to simplify the process of making decisions in evaluation activities and secondly to provide a range of tools that could support children making choices and decisions.

In simplifying decision making, principles of 'shared decision-making' were applied in preparation for evaluation workshops. This involved scripting choice and decision making

events for the workshop and ensuring that children could assent or make choices between a maximum of two items, objects or proposals. Scripting decision making in such a manner did minimise the cognitive or communicative demands that were made on children and did result in children over the course of the case-studies indicating preferences, making choices and decisions all using non-verbal means such as eye-pointing, gestures and other idiosyncratic behaviours[59]. Children did however require a high level of guidance for evaluation tasks and required a high degree of prompting to engage with tasks and to remain engaged. It was evident that although the decision making acts had been simplified participating children did not appear particularly motivated by the process. It was remarked in reflection by SLT1, that the simplification of the evaluation process and in particular tasks that required the child select from two presented visual choices was reminiscent of some of the practices common in many Speech and Language Therapy sessions. She commented that all the children would likely have experienced such activities during the therapy sessions that they would have attended as part of their school day. She reflected that in these sessions, it was often difficult to motivate children to make choices when their opportunities for choices making in every other aspect of their lives were severely limited. Considering the broader context of a child with autism regarding their opportunities for and experience of decision making must be borne in mind. Although using a series of structured principles to simplify decision making brings the task within the child's sphere of ability, it may in and of itself not be motivating for the child. A similar reflection can be made about the utility of the communication supports that were provided. These were drawn directly from Speech and Language Therapy practice and would have been resources that participating children would have been exposed to primarily during their therapy. It may be that their lack of motivation in using these did not give an accurate representation of their utility but rather reflected the child's association of these objects with their previous experiences of therapy. One of the other consequences of simplifying decision making was that it constrained other opportunities that are often crucial in design evaluation. Evaluation in design can be a mechanism for confirming or rejecting an idea, for selecting between choices but it may also involve elaboration and refinement of an idea. This is often achieved by way of dialogue between the designer and other participants (Ensici, Bayazi, Badke-Schaub & Lauche, 2008). For the children in this research, simplifying decision making in this manner resulted in a lack

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[59] In one such instance, Child 4 had previously demonstrated an affinity for hugging objects of interest to him while avoiding looking at the object directly. It was reported that staff had interpreted this as his expression of 'wanting' whatever it was he was hugging. During the course of the second evaluation workshop that he participated in he spontaneously began hugging the cards offered that demonstrated the choices of design elements, in this particular case a series of avatars and images of digital objects that had been sequenced in pairs to allow children to choose between them.

of opportunities to engage with the proposed design content in ways that could potentially offer opportunities for elaboration or further creative understanding. In Case-Study I, the value of finding informal opportunities for collective reflection contributed to a deepening of understanding of the lived experiences of participating children became evident during the research. In analysing the decision making process, it may be that concerns with making decision making accessible and ensuring the tasks matched the children's' limitations resulted in opportunities for reflection being missed and thus valuable opportunities to develop a further depth of understanding in the decision making abilities of children with autism being overlooked.

7.1.4.2 Adults' Role as Decision-Making Proxies

Considering the degree to which adults supported the participation of children at different levels throughout this process, it is no surprise that they would play a pivotal role in supporting their decision making when evaluating design elements, low-fi proto-types or potential design solutions. Supporting children's decision making included supporting the interpretation of verbal and non-verbal communicative gesture for those children who demonstrated an intentionality in their communication and were more likely to engage non-verbally with adults in particular. In the absence of such intentionality being demonstrated by children it was clear that those adults present would quite often offer an answer or opinion on their behalf and act as proxy respondents. In the examination of concepts of participation in Chapter 2, participation by proxy is clearly seen as a lesser form of participation. Efforts to evaluate the decision making across the case-studies in this study suggest the need for further examination where the adult as proxy for a child with autism is positioned within a continuum of support that they provide throughout the entirety of a process as opposed to focusing on single events.

7.1.5 Summary

The preceding sections have examined the implementation of a framework to support the participation of children with a disability in a technology design process. The value of a prescribed framework of techniques has been outlined focussing attention of the different participation demands required at different phases through the design process. Spending time observing children with autism in their own context and detailing their lived experience from a third party perspective is challenging particularly for the novice designer, however opportunities for natural, collaborative reflection amongst a team comprised of adults familiar with the

children and with the children themselves are invaluable. Despite the attention given in the case-studies described here there remains a challenge for researchers articulating the process of translating the designer's understanding of children's lived experience into artefacts such as documents that can then guide the research process. Further research outlining this process would be of untold value in advancing this area.

7.2 Evaluating Participation in Technology Design

7.2.1 Introduction

In Chapter 3 we discussed the challenges of examining the process of participation and highlighted the limited guidelines and frameworks that have been developed to support this. One exception was of course an adaptation of Arnstein's model of citizen participation by Frauenberger and colleagues, which outlined three levels by which a child with autism participation in design could be viewed; 1) 'non-participation', 2) 'participation by proxy' and 3) 'full 'participation' (Frauenberger, Good & Alcorn, 2012). Such a framework however is of limited value in examining the degree of participation for a child with autism across an entire design project. For example, across the case-studies outlined in this research there are challenges in terms of categorizing or defining techniques such as 'observation in context'. Such a technique aims to capture an understanding of the lived experience of children who cannot reliably communicate this to others. For children who are primarily non-verbal and observers that are tasked with conducting 'natural observation', such a method could be viewed as 'non-participation', similarly capturing the needs and preferences of children as told through carer's stories could certainly be defined as 'participation by proxy'. Is the provision of assistive technologies to support the generation of visual design ideas considered 'full participation' or 'participation by proxy'? Are techniques to support those with the most severe participation challenges then seen as lesser forms of participation or do we require a different lens through which to examine these? Previously in chapter 3 we outlined a proposed framework based on Shier's Pathways to Participation model (Shier 2001) and Segalowitz's dimensions of participation model (2012). It was proposed that we could use this framework to examine in detail how a design project supports a child with autism to have impact and influence in that project and acquire a degree of agency by highlighting the opportunities and level of commitment in place within the project.

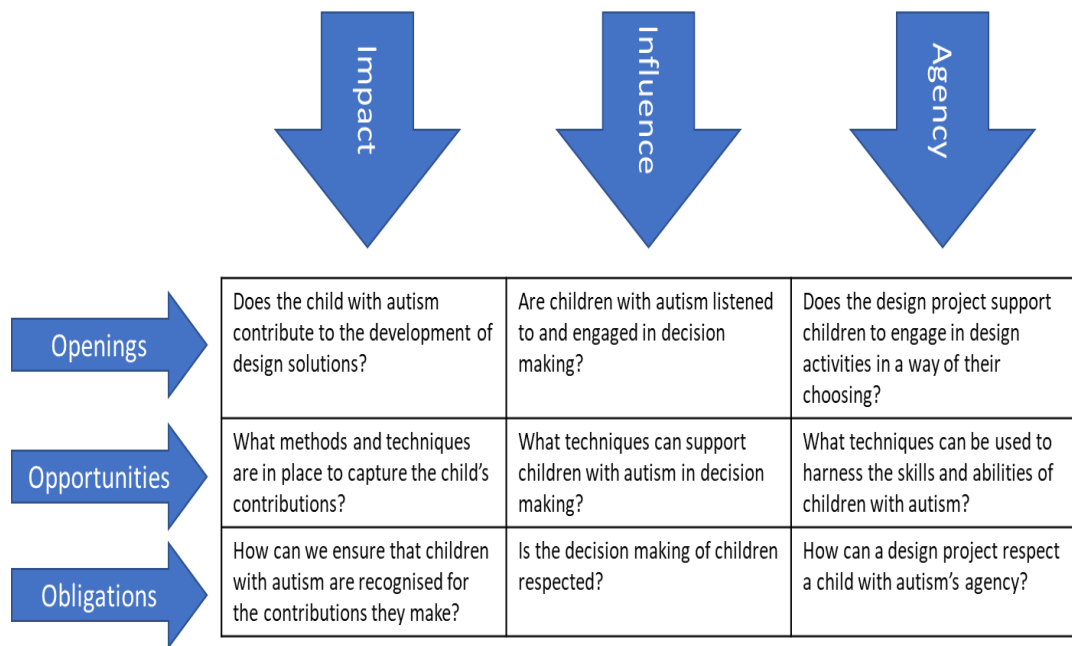|	Impact	Influence	Agency
Openings	Does the child with autism contribute to the development of design solutions?	Are children with autism listened to and engaged in decision making?	Does the design project support children to engage in design activities in a way of their choosing?
Opportunities	What methods and techniques are in place to capture the child's contributions?	What techniques can support children with autism in decision making?	What techniques can be used to harness the skills and abilities of children with autism?
Obligations	How can we ensure that children with autism are recognised for the contributions they make?	Is the decision making of children respected?	How can a design project respect a child with autism's agency?

Figure 22: An Evaluation Framework for participation in technology design

In the framework as outlined in Chapter 3, participation can be described as 1) the ways in which the person contributed to the project (impact), 2) the decision-making engaged in by the child (influence) and 3) the willingness and engagement of a child with autism. In Shier's model, the degree of participation is examined through a series of questions that interrogate the commitment (openings), opportunities available and obligations in place to support a child's participation. In the above framework, these questions have been adapted to examine the openings, opportunities and obligations in place to allow children with autism to impact a design project, influence that project and gain a measure of agency through their participation. This framework will now be used as a lens by which to examine this current research with a view to uncovering a more detailed and nuanced picture of the participation of children with autism in technology design.

7.2.2 Examining 'Impact' as a Dimension of Participation

Using the framework above, identifying if there was an 'opening' for the child with autism to impact the design process is captured in the question posed; 'does the child with autism contribute to the development of the design solution?'. In reviewing the case studies, there are two evident contributions that the child with autism makes. Firstly, in the early phases of the design projects there was a commitment to using the lived experiences of participating children in the development of systems and user specifications to guide the design project. Secondly, during the workshops reported in case studies II, V, VII, VIII, X11 and X111 the

visual content generated by children with autism was captured by the designers with a view to translating these into prototypes or other specific elements of the proposed design.

Commitment to recognize the understanding of the child's lived experience and their generated visual content as contributions to the design also required mechanisms for these to be captured and incorporated into the design outcome. Opportunities to capture children's lived experiences and creative expressions across the case studies in this research are evident in the techniques used to support the designers in the early and intermediate phases of the design as described in case studies IV and VII in Chapter 6.

Considering the limitations their disability imposed upon designers attempting to access and understand the child's lived experience, ethnographic techniques such as observation in context, listening to the stories told by caregivers and other probes were required to support the transfer of such tacit knowledge. In case-study one, presented in Chapter 6, the thick descriptions paint a picture of designers taking the time to understand each of the children in terms of their likes, dislikes, preferences and needs and engage reflexively with children and adult participants to validate these. In the second explanatory case-study outlining the application of techniques to support children with autism generating visual content a range of material, physical, cognitive and emotional supports are described. These supports allowed children with autism to use technology to generate visual content which was collated by the designers with a view to later translating these into evident components of elements of the proposed design solution.

The final consideration in the model proposed above is to examine the obligations in place to ensure that children had an impact on the design. While the techniques described in this research demonstrated opportunities for capturing knowledge and understanding and gathering the tangible contributions of children with autism, they fall short of ensuring that these demonstrate impact. To demonstrate such impact requires that we identify the obligations or practices which ensured these were incorporated into the final design solution. Case Study IV demonstrates efforts made by the designers participating in this research study to translate their understanding of the requirements of the children that they had gathered into actionable system requirements documents. They used opportunities that emerged to engage reflexively with children and participating adults to ensure that their understanding and interpretations were authentic and validated. Case-study two describes the efforts of designers to interpret children's visual contributions generated over the course of two workshops and to incorporate these into elements of the design. Also, evident in this case-study are their efforts to ensure

that their interpretations have some fidelity by confirming these with those children, in this way offering further opportunities for decision making ahead of incorporating contributions into the design solution. As such, ensuring children's impact requires not only techniques that elicit their contributions but that they are valued and creatively incorporated within the emerging design outcomes.

7.2.3 Examining 'Influence' as a Dimension of Participation

The influence that a child with autism has in a technology design project is characterized as their opportunities for decision making and whether their decisions are acted upon. It is in this context therefore that we must examine this research project with a view to identifying the opportunities children had to engage in decision making, but also how such decisions were acted upon.

Case Study IX outlined in Chapter 6 provides evidence of how the opportunities to engage children on decision making was increased by a variety of means. Firstly, providing a structure by which the process of making a decision could be simplified such that the cognitive demands of the task were reduced thus compensating for some of the challenges the children had. Secondly, providing supports by way of alternative and augmentative communication options such as a specific repertoire of symbols made the decision making process more accessible for children with very limited verbal expression. Finally, in addition to this, opportunities to ensure that children could make decisions and that these decisions were made clear to designers were maximised by utilising those adults familiar with the children in interpreting and parsing the non-verbal communication of participating children. Those adults familiar with children were encouraged to use their skills, expertise and experience to assist in translating the choice and decision making behaviours for the designers who did not have the skills to do so. This ensured that the decisions of the children participating were captured. Offering the opportunity to make decisions however does not reflect a true democratisation of decision making. This required that the designers acknowledged and respected the decisions made by children and respected these by acting accordingly. In most instances, this involved taking the preferred options of the participating children and refining design prototypes to incorporate these.

This process could certainly be seen as reductive and the reliance on the interpretation and parsing of children's non-verbal communication could easily be construed as reverting to a reliance on adult proxies. It may also fall short of Shier's definition of the highest level of child participation which states that 'children share power and responsibility for decision-making'

(Shier 2001). It does however reflect a trend towards building a framework of supports for the child that demonstrate a commitment from adults to actively involving children in the decision-making process[60].

7.2.4 'Agency' as a Dimension of Participation

Agency, as a dimension of participation, is perhaps the most challenging of the three to determine, particularly so in the case of children with autism where the severity of disability has on their ability impacts profoundly their ability to act independently (Newman & Vogely 2008). For children where the severity of their disability limits all their daily functioning, expecting demonstrations of agency, or the experience of independently choosing, initiating and controlling one's actions may appear unrealistic (Zalla & Sperduti 2015).

As outlined in Chapter 3, for children with autism with a limited repertoire of independent skills expressions of willingness and engagement may be considered indicators of agency in the context of a design project. Considering the case-studies that comprised this research however, participating children demonstrated varying degrees of willingness and engagement, occasionally at odds with that of adults. One example was in some children's reactions to the photography workshops (described in explanatory case-study outlined in Chapter 6). Very few, if any of the children fully understood or appreciated the cultural sensitivities to taking and using photographs as part of a design activity. They engaged in the activity and demonstrated the same willingness that was observed in other activities such as the design workshops reported in case-study II. From observations recorded in the designers' field notes that despite the misgivings of participating adults, it would appear that some of the children demonstrated excitement and pleasure taking photos and examining the photographs that they had taken. It would appear therefore that defining agency simply as willingness or engagement defines a very low degree of participation experienced by the child with autism analogous to Shier's first and second levels of participation[61].

In the context of design activities therefore, it may be that we must consider agency as a shared experience in the same manner as we do with influence and impact. In examining how children can impact a project through the quantity and quality of their contributions, we must

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[60] This is analogous with level 4 in Shier's 5 level model, which states that children are involved in decision-making (Shier 2001).

[61] In the context of children's decision making Shier defines the first level of participation as 'children are listened to' and the second as 'children are supported in expressing their views'. Translating this to examine agency – we must consider children's engagement and willingness as equivalent to being listened to in that opportunities for further participation are not made available.

acknowledge that the absence of adult participants or designers removes the openings, opportunities and obligations that make such impact possible. Similarly, the influence a child with autism can make in a design project remains limited without the openings, opportunities and obligations described in the section preceding this . If we consider that agency emerges from the openings, opportunities and obligations of others.

From examining the experiences of children in these case studies across the various design activities within which they were involved it may be that, 'agency' can be seen as more than willingness and engagement. A clearer expression of a child with autism's ability to act independently might be better defined as the child's ability to engage in a desired activity in their own way, free from the demands imposed by the task or the participating adults. An expression of this that is evident in Case Study II where children were provided with the support and tools they required to generate visual content. This content however was not guided by the task or by the adult participants. The lack of prescribed standard of outcome allowed children to simply draw. Behaviours that might otherwise be viewed as repetitive or idiosyncratic and characterised as a negative symptom for children with autism were harnessed in detailing visual images. Low levels of concentration and attention did not impact on the value that was attributed to the resultant visual contributions. In this way, design activities were structured to harness the abilities of children with autism and see the characteristics of their condition as strengths and not weaknesses to be overcome. This reflects other work where the focus on the outcome of the design process is considered less important that the act of participation ((van Rijn & Stappers, 2008) Agency therefore becomes more than a child with autism's willingness to engage in design and is transformed as their ability to engage in activities in a manner of their choosing, thus redefining their disability in the positive. This bears similarity with the suggestion that we reconsider the triad of impairments in autism as a 'triad of strengths' certainly in the context of design activities (Gaudion, Hall, Myerson & Pellicano, 2015).

Considering agency in such a manner however suggests that we consider the 'opening' as a commitment to engage children with autism in design activities in a manner of their choice free from the direction of participating adults. We must therefore consider how the techniques or opportunities are designed to accommodate the ways in which a child might perform certain activities. Finally, in terms of our 'obligation' to ensure that opportunities for agency are realised then our focus must be on the process of participation and not be guided by the outcome. With this reconsideration in mind and in contrast to the previous example outlined, we can reflect on a design task in this research study (Case Study III) that conferred only limited agency on

participating children. Structuring decision-making to support children's abilities to evaluate design options by simplifying the process constrains how the activity can be performed and therefore the freedom by which a child with autism can engage in evaluation tasks. Previous studies examining decision making in design for children with disabilities provided limited opportunities in discrete tasks and activities (Bartoli et al 2014) but made little attempt to examine the process by which decisions are made by children. By simplifying decision making we consequently limit the ways in which a child can engage in that task and run the risk of reducing their participation to that of willing or unwilling without any sense as to whether or not these behaviours reflect the child's intentions. Herein lies a conflict between the desire to democratise decision making as a means of ensuring a way in which a child can influence a project and providing a degree of agency that shifts the focus to their abilities rather than their disabilities.

7.2.5 Participation Evaluation Framework Reconsidered

Drawing upon the work of Segalowitz (2012) this framework was used in this study to conduct a detailed analysis of the participation as it manifested over the course of the fourteen case-studies that comprised this research. This analysis demonstrated how the series of methods and techniques proposed in this study contributed to the participation of children with autism across the design projects represented in the case-studies. The framework provides a structure by which participation in a project can be reflected and expressed. Using the framework in this manner offers designers and researchers an instrument that can represent participation in a design project in a manner akin to a scorecard. The analysis emerging from the application of the evaluation tool in this study is outlined in the figure below:

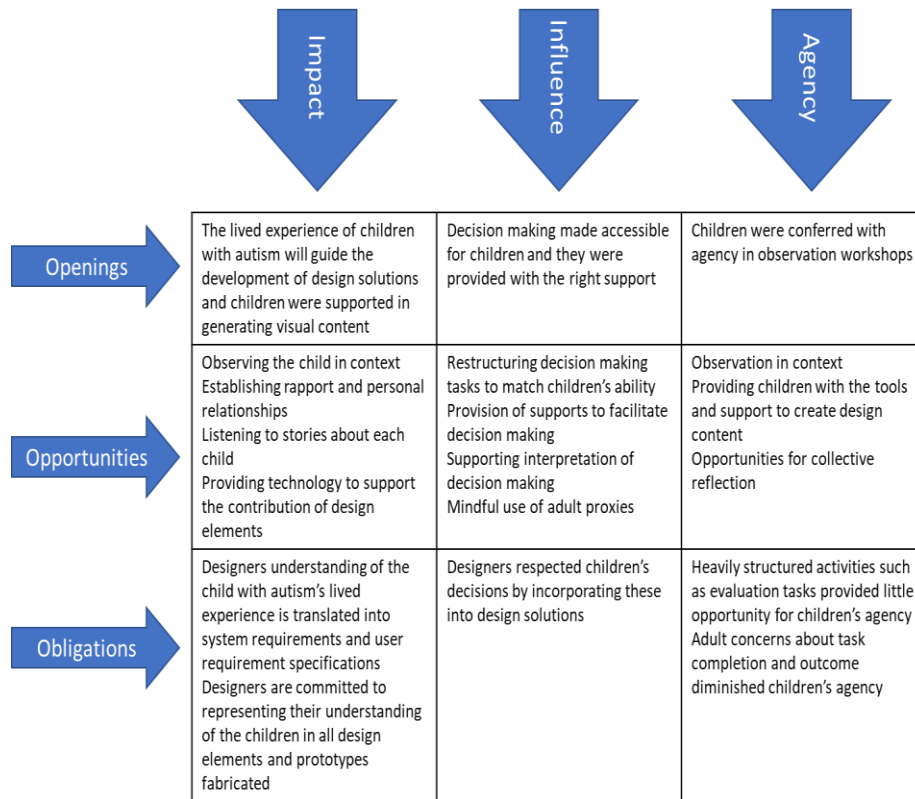|	**Impact**	**Influence**	**Agency**
Openings	The lived experience of children with autism will guide the development of design solutions and children were supported in generating visual content	Decision making made accessible for children and they were provided with the right support	Children were conferred with agency in observation workshops
Opportunities	Observing the child in context. Establishing rapport and personal relationships. Listening to stories about each child. Providing technology to support the contribution of design elements	Restructuring decision making tasks to match children's ability. Provision of supports to facilitate decision making. Supporting interpretation of decision making. Mindful use of adult proxies	Observation in context. Providing children with the tools and support to create design content. Opportunities for collective reflection
Obligations	Designers understanding of the child with autism's lived experience is translated into system requirements and user requirement specifications. Designers are committed to representing their understanding of the children in all design elements and prototypes fabricated	Designers respected children's decisions by incorporating these into design solutions	Heavily structured activities such as evaluation tasks provided little opportunity for children's agency. Adult concerns about task completion and outcome diminished children's agency

Figure 23: Using the Evaluation Framework to represent analysis of participation

Additionally, using the evaluation tool to conduct this retrospective analysis revealed how some dimensions of participation, namely, influence and agency could be redefined to better reflect the strengths and potential of children with autism. The consequence of this reconsideration resulted in a refinement of the evaluation framework to update the participation dimensions of influence and agency. The updated framework is outlined in the figure below.
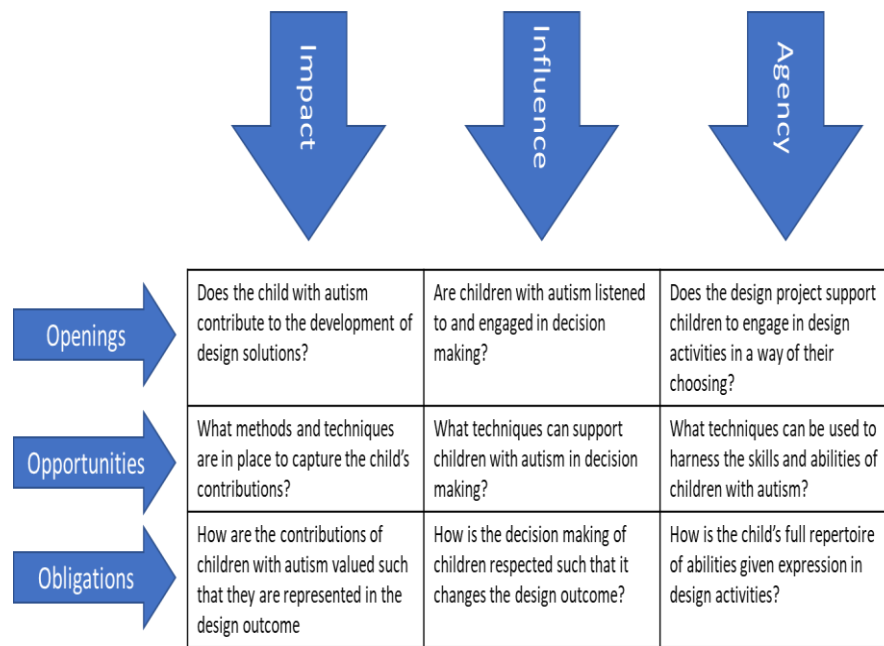
Figure 24: An Evaluation Framework for participation in technology design: reconsidered

The reconfigured framework presented in Figure 24 above offers a series of questions for designers and researchers and is intended for use in aiding the planning process for a design project or retrospectively conducting a thorough analysis of a project as was the case in this research.

7.2.6 Summary

The absence of evaluation tools that specifically examine the process of participation within design projects has been well documented elsewhere (Benton & Johnson, 2015., Bossen, Iversen & Dindler, 2016). The lack of available tools may have contributed to the paucity of studies examining the process of participation rather than the outcomes or benefits that are accrued. This evaluation framework seeks to offer a lens through which the different dimensions of the experience of participation for a child with autism can be investigated. Furthermore, it offers a way to determine how a project can identify and establish opportunities and mechanisms for participation in a technology design project.

Although developed and refined specifically to examine the participation of children with autism it provides a mechanism to present the experience in a more comprehensive fashion than simply characterizing participation as 'non-participation', 'participation by proxy' and 'full participation'. Application of the framework in other studies with children may reveal further elements of participation that were not evident amongst the children in this study. Using the

framework to highlight the adult responsibilities in creating the conditions for participation suggests that it could be applied in other studies focussing on typically developing or children with disabilities other than autism.

It is certainly hoped that further application of the framework will prove useful and can contribute to a deeper understanding of the experience of participation for children in technology design projects.

Chapter 8: Thesis Summary and Concluding Remarks

The overall objective of this study was to examine ways in which children with autism could meaningfully engage in the design of technology intended for their use. For a population of children with significant challenges in communication, intellectual ability and social functioning, their participation in any process occurs against a backdrop of perceptions that this is considered beyond the scope of their abilities. This study aimed to create and structure participation opportunities for children with autism and to support their inclusion in projects and processes concerned with the development of technology for which they would be considered potential end-users. Chapter 2 of this thesis provided a description of the impact a lifelong neurodevelopmental condition such as autism has on the participation of children across society. Exploring the heterogeneous nature of the condition and the differing manner of presentation from one child to another complicates the landscape for those wishing to work with children considered on the autism spectrum. This serves as a preface for understanding typical processes associated with technology design and an examination of how children with autism can engage in and affect a design project. Chapter 3 presented a detailed examination of literature reporting on studies which focused on the participation of children with autism in technology design. This review explored the increased popularity of exploring the design and fabrication of new technology in partnership with those for whom the technology is being developed. Although there has been a marked increase in the volume of studies examining the inclusion of children with ASD in design projects, much of the work has depended on engaging children with a degree of communication or verbal ability and a requisite level of comprehension and understanding. For children with more significant limitations of ability the reported cases of their inclusion in design practice is significantly more restricted. An examination of the literature pertaining to the design of technology for children with ASD, highlighted the lack of any guidance or exemplars that could serve to operationalise the participation of children throughout the entirety of the technology design process.

Following a discussion regarding the methodology underpinning this research study in Chapter 4 a series of fourteen technology design case-studies was presented in Chapter 5. This chapter set out a description of the case studies in terms of the objectives, the participants and the methods and techniques that guided their participation. Chapter 6 offered a 'thick description' of a selection of three explanatory case studies with Chapter 7 providing an outline of findings from these and the remaining case studies alongside further discussion and analysis reflecting how these are positione alongside the existing literature.

8.1 Contributions

The sections below outline and discuss the contributions emerging from this research and outlined in this thesis. These contributions include a framework to support the participation of children with autism through the design process.

8.1.1 A Framework to Support Participation through Design

A series of fourteen technology design case studies presented an opportunity to evaluate and iteratively refine a range of techniques that could support design participation for children with autism despite the complexity of their social-communication, cognitive and in some cases physical challenges. This portfolio of techniques was designed to; 1) ensure participation for children with autism in requirements identification at the start of a design process, 2) contribute to the tangible elements of the emergent design proposal or solution and 3) support children's decision making such that they could participate in the evaluation processes in a design project. Each of the three sets of techniques correspond with the typical roles associated with general design research and confirm that children with autism can be considered as an informant, design partner or tester, . These techniques may be considered as three contributions as they can be flexibly applied in just one phase of the design process or across the full design process.

The first of the three contributions made in this thesis is the provision of techniques that can assist in capturing the lived experience of children with autism and translate these to requirements that can guide the further development of a final design product. These emerged primarily from Case Studies I, IV, XI and XI where techniques were employed and refined on an iterative basis. Some of the insights listed below however were further refined through reflection on other case studies where there were opportunities to reflect on how the collective understanding of the child's lived experience translated into design elements.

Several mechanisms were identified to support the capturing and understanding of the child's needs and preferences and translating these into actionable requirements:

1. The importance of observation in context. Natural observation with little scaffolding or preconceptions assists the designer gain an understanding of children by:

   a. Allowing rapport to build and relationships to develop

b. Establishing a familiarity that guides inter-working through the remainder of a project

c. Assisting in understanding a picture of a child and the nature of the relationships he/she has with those in that context

2. Observation in early phase design takes time. Effective observation is a process that benefits from time and requires a level of immersion from novice designers. How long this time should be dependent on the experience of the designer, the characteristics of the children and the environment that they are in.

3. The engagement of the designer with children with autism should be 'child-led', and should focus as much as possible on observing children doing what they want to do. In this way children's preferences will become clear.

4. Iterative field notes support the development of a designer's understanding. The process of gaining a deep understanding is one which requires consideration and then further reconsideration of one's observations. Opportunities that allow designers to check their observations with experienced staff advances understanding.

5. Culturally appropriate ethnographic techniques such as story-telling are useful in building a broader picture of children's needs and preferences and offer an opportunity to validate observations.

6. In embedding storytelling and other ethnographic techniques in the normal routine of the child, designers should be reflexive and responsive to such collaboration opportunities with children with autism and with other adult participants.

7. Ethnographic techniques however should be selected with a clear understanding of the social and cultural context of the design project. Designers should be cognisant of this and ready to change or modify procedures quickly and not be tied to prescribed approaches or techniques.

8. Establish opportunities for collective reflexivity. Having time with children with autism and other stakeholders to reflect on findings should be done on an ongoing basis throughout the entirety of the early design phase.

A second contribution that is made here relates to how best to support a child with autism to contribute content that can be incorporated within developed design elements or prototypes for collective evaluation later in the process.

1. Co-design for children with the complexity of social and cognitive challenges in this research should be considered as a three phase process. This process should see designers working with children with autism to *capture* design content that they generate. This content requires the designer *interpret* the child's contribution and reimagine it as an element of the design. A final step, where the designer *confirms* their interpretation of the child's contribution ensures that they retain a degree of power in the design process. Traditional collaborative practice with children remains challenging. Providing children with opportunities to generate visual or possibly audio content that can be taken by the designer and incorporated into the emerging design minimises stress and works to children's abilities.

2. Identify and provide children with technology solutions that allow them to generate content. There is an ever-increasing array of hardware and software solutions that can be modified or adapted to give children with complex challenges opportunities to engage in creative activities usually associated with design.

3. Recognise the need for the provision of individual support. Fully engaging children with autism requires that they have one-to-one support.

4. Adults can support children with autism in the use of technology but designers or researchers must remain cognisant of the risk of them focussing on the child's output in such processes rather than their enjoyment and pleasure. Adult support should be focussed on 1) orienting children to activities, 2) explaining and guiding their performance, 3) motivating them and providing encouragement and praise and 4) assisting to re-engage the child when they have become distracted.

5. Workshops to create content should be structured with the supports typically used with children with autism, such as visual schedules, relaxation/break-out area.

6. Use projectors and circle time activities in workshops as opportunities for reflexive collaboration with children using the generated content as the focus for these.

7. Designers must be committed to using, modifying, adapting or otherwise incorporating children's generated content into elements of the design.

Regarding participatory techniques, this thesis makes a final contribution by offering a means to engage children with autism in design decision making. This is particularly relevant to supporting the participation of children with autism in the evaluation of emerging, tangible design ideas such as prototypes. The following list emerged from the experiences of evaluating

a range of supports throughout the course of Case Studies II, V, IX, X and XIV which specifically examined the techniques required to engage children with autism in decision making during evaluation workshops.

1. The principles of Shared Decision Making should be employed to construct decision making opportunities that are in keeping with the communication abilities of each of the participating children. If necessary, such opportunities should be individualised with the appropriate supports put in place for each child.

2. Appropriate supports such as symbol based communication systems such as PECS should be tailored to provide children with communication choices that match the task in hand.

3. Structuring decision-making or evaluation workshops should be structured with careful consideration of the demands a child with autism can cope with and provide the requisite supports that would typically be required by a group with this level of needs.

4. Elaboration of design ideas should be the responsibility of the adults in the project, however children should be informed of such elaborations and they should be presented in such a way as to allow children to offer their assent.

5. Adults familiar with participating children should be able to 1) support the interpretation of verbal and non-verbal communication by children, 2) present the appropriate choices for children to simplify decision-making, 3) provide motivation and prompting for children and 4) recognise when children are communicating that they do not want to participate.

8.1.2 A Framework for the Evaluation of Participation

In Chapter 3 of this thesis this author proposed an evaluation framework to comprehensively analyse children with autism's participation in design projects. By combining an articulation of the responsibilities of adults with different expressions of participation, a framework emerged that could uniquely examine the level of participation of children with autism in a technology design project. This framework extended previous models to consider three dimensions of participation in design, 1) impact, 2) influence and 3) agency and three mechanisms by which adults can support participation; 1) openings, 2) opportunities and 3) obligations.

The application of this framework as a 'lens' to examine the level of participation of children with autism in this current research, reported in Chapter 7, provided a way to demonstrate the level of impact that the child had in the project. This framework facilitated children with autism to make contributions to the project and value these contributions by creatively incorporating them in design solutions. Similarly, examining how both supporting and respecting decision making contributes to decisions being incorporated in the design solution demonstrated a measure of the influence that a child has in a design project.

Using the framework in this way however also raised questions as to the levels of participation that could be achieved if efforts to make decision making accessible for children with autism were reductive and did not represent a shared value or collective decision making. Application of the framework also allowed for a reconsideration of agency for children with autism as a dimension of their participation. Examination of the various design activities highlighted that agency could only be conferred in a design project when activities were configured to allow children to engage in a manner of their own choosing free from the direction and guidance of adults.

The framework was reconfigured to reflect the refinement of understanding of influence and agency for children with autism as dimensions of their participation in technology design.

Previously the levels of participation for children with autism were considered as 'non-participation', 'participation by proxy' and 'full participation' (Frauenberger, Good & Alcorn, 2012). This framework builds upon this and provides a mechanism for detailing a nuanced understanding of participation for children with autism in technology design projects.

8.1.3 The Role of Adults in Supporting the Participation of Children with Autism

A fifth contribution made in this thesis is an elaboration of the roles played by adults in supporting children's participation. This research by virtue of the needs of the children at its core saw a high degree of involvement by adults, particularly teachers, therapists, carers and designers. Each of these categories of adult participants varied in their experience and understanding of children with autism, thus presenting an opportunity to conduct a careful examination of how they can best support a child with autism in the various activities that comprise a technology design project. The role of the adult in supporting children in design has often focussed on a generic description of the role, however what emerged over the course

of this research was differences in the role based on each group's knowledge, expertise and skill working with children with autism.

For designers with limited experience of working with children their responsibility in the early phases of a design project was to; 1) build rapport with participating children, 2) increase their understanding of children's needs and preferences in their own context and 3) organise their emerging understanding within the typical workflow of a design project. In these earliest phases of a project, the responsibility of the those adults familiar with participating children is to; 1) ensure the comfort and safety of children is maintained in the midst of the change that is brought about when new people are brought in to their environment, 2) facilitate the building of rapport between children and these new unfamiliar adults and 3) begin a process of establishing the design project as a collective endeavour and to ensure that children are made aware that this is happening and the ways in which they will be involved. As designers progress their understanding of the children's lived experience they require opportunities to discuss and reflect on their findings. In the earliest phases before trust has been built with participating children, the remaining adults play an important role in clarifying, verifying and adding further depth to designers' emerging understanding. Similarly, this infers a responsibility on the designers to reciprocate by increasing other adult participants' understanding of the design process and how that is expected to unfold. As the design processes transition to the development of potential solutions participating adults play key roles in ensuring children with autism are supported in participating in this development. Those most familiar with children provide; material support (through the provision of suitable technology), physical support (through assisting with activities), cognitive support (by explaining the process and helping to finish activities) and emotional support (through prompting, encouragement, motivation and withdrawal if required). As mentioned above, in design projects with children with autism it may be necessary to consider co-design as a two-phase process. In such circumstances the role of the designer is to take a child's contribution and to transition this clearly and opaquely into the emerging design solution. This requires that the designer value each contribution and seeks to creatively represent all contributions as clearly as possible.

Supporting children in the evaluation of potential design solutions or options requires that adults support differing elements of the decision making process with children. Firstly, designers will be expected to present options and simplify the decisions a child needs to make. To do this, they may need to supplement or validate their understanding of the child's comprehension, reasoning or communication skills with the other adult participants. Secondly those more familiar with the children will be responsible for 1) presenting and explaining

decision making tasks in a manner that the child can understand, 2) encouraging and motivating children to engage and make decisions and 3) interpreting and communicating their interpretation of the child's communication. In such circumstances, those adults supporting each child must remain cognisant of their responsibility to assist in representing the communication of the child and not to present their own understanding of the child as a proxy. Finally, to support the participation of children with autism, designers are required to value the contributions of children and respect their decision making by creatively examining ways in which these can be represented in the final design outcome. For teachers, therapists and carers that may be familiar with children with autism a key part of their role is to harness children's strengths and abilities and provide the required support that each child needs to participate to their full potential.

8.2 Study Limitations

This research proceeded with acknowledged constraints and, as with many endeavours of this scope, it encountered additional challenges during implementation. These are summarised below.

8.2.1 Children with Autism

As outlined in Chapter 1, the target group for this research were those children most severely impacted by autism. This could be considered in both positive and negatives terms for this study. Firstly, working with and examining the participation in technology design of children who are often overlooked in terms of research participation was personally rewarding. It also encouraged those working with the children to potentially reconsider the children's abilities and aptitudes as a result of this project. Secondly, the demands of working with children with such complex needs was that the nature and scope of the research required ongoing consideration and reflection, resulting in changes being made on an ongoing basis based on not only analysis that was emerging from each of the case studies but some of the day to day challenges of working within a Special Education facility. The nature of the needs of the children in this study was such that the focus on the research became almost exclusively about their participation leaving little time to fully consider and address the participation of other stakeholders who might be considered 'participants'. One consequence of this was that the way novice designers translated their understanding of the child into meaningful design requirements and the process by which they incorporated the contributions of children into design solutions was given limited attention. Further research examining these areas would

certainly build upon the body of work focussed on the development of mutual understanding between children and adults in design.

The demands of examining how to support individual children's participation also meant that there were limited opportunities to examine the group of children as a collective. Exploring how the peer relationships, shared experiences and member solidarity evolves for children with autism through the course of a design project has not been examined to date and may cast a light on some of the more intrinsic benefits that can be gained from participation.

8.2.2 The Design Process

Examining participation at different phases throughout a technology design process had the advantage that it yielded a contribution for supporting participation through the entire process and additional contributions to support participation in just one single phase.

The demands of facilitating participation through the entirety of the process provided a broad platform for an examination of that participation. Opportunities were missed however that might have provided a better understanding of participation challenges that may be specifically associated with individual design processes. The research however was limited in terms of how the design process was defined. In this research we consider the starting point of a project as the time when designers engage with users with a view to identifying their requirements. In many design projects however, there is a previous phase focussed on design conceptualisation. Furthermore, this research centred on the concept that the end-point of technology design was the production of a fully working agreed solution. Many software solutions continually undergo further iterative design throughout its early deployment. These two ends of the technology design process may benefit from closer examination. In the review of literature presented in Chapter 3 there were a number of examples outlined where researchers sought children with autism as 'testers' to provide verification or validation for potential designs. Limiting the use of children with autism in this manner would appear to be missing an opportunity to gather a body of data upon which to conduct further development or improvement to a design outcome. Recognising that PD research such as this is not often reflected in commercial product development, it merits consideration as to whether or not the lessons learnt in projects like this can be adapted and applied to informing early life cycle software development. In such a model, users such as children with autism could be facilitated to contribute to rapid design improvement cycles through the early phases of its deployment.

8.2.3 Participation

This research focussed on one expression of participation for children with autism, namely; participation in technology design. Notwithstanding the potential benefits for children from their active involvement in technology design, this focus raises the question as to whether or not it is should be considered a priority for children who have such limited opportunities to participate across much of their daily lives. In considering children's priorities in terms of participation we are also reminded of how dependent children with complex challenges such as this are upon the opportunities and supports for participation being engineered by willing adults. This highlights the need for further examination of a structural power imbalance between children and adults in design projects initiated by adults. How authentic can participation be if the presence of children with autism as participants is at the behest of the adult who created the process?

Considering participation as it was manifest across the entire design process meant that opportunities to conduct a deeper examination of individual expressions of participation such as decision-making was limited. PD research places a strong emphasis on the devolution of design decision making as a key factor in participation, this research however has shown that making the process accessible for children with autism may not be an act of empowerment as it may be seen with others. A thorough and more nuanced understanding of how power in design projects can be devolved in ways that match the abilities of children with autism rather than compensating for their limitations must be considered a pressing and valuable contribution to this research field.

A question that was not resolved during this research is if children who are severely impacted by the nature of their disability need or want to participate in a technology design project. Shifting the focus from the outcome of a design project to the process of a design project also raises a question as to what can be gained by children from such participation. If the focus of the efforts of adults is to ensure authentic or meaningful participation in design does this come at a cost to the eventual outcome. These issues and the further exploration of the meaning of participation for children with autism in technology design provide a rich vein of research opportunities that may see a broader contribution to the understanding of participation for those children whose voice is typically not heard and their decisions remain unacknowledged.

8.3 Summary

The ambition of this study was to reach a small group of children, their therapists, teachers and their carers who live every day with a range of challenges that in many instances limit their participation in society. They constitute a group within society that many of us don't come across, don't engage with and do not concern ourselves with. Working with such a group is not only challenging but it is also rewarding, it focuses attention on small things such as the moments of individual and collective fun and laughter that accompanied this process. These are some of those intangibles that are difficult to capture and reflect in the context of a study such as this. This research was conducted within the context of a Middle Eastern culture that had only recently recognised the place citizens with a disability have in society, work of this nature challenges emerging opinions about the nature of disability and the responsibilities broader society has not only to provide support and care to its most vulnerable but also to offer opportunities for learning and growth.

This study aimed to demonstrate what was possible, to offer new opportunities both for children on the autism spectrum and those adults with whom they worked alongside and with through the course of their participation in this project. It is hoped that the challenges inherent in such work does not discourage further, future study.

REFERENCES

Alexander, C., Ishikawa, S., Silverstein, M., Jacobson, M., Fiksdahl-King, I., & Shlomo, A. (1977). A pattern language : towns, buildings, construction. 1171.

Agarwal, Ravi, Harini Alagarai Sampath, and Bipin Indurkhya (2013) "A Usability Study on Natural Interaction Devices with ASD Children." *Lecture Notes in Computer Science (Including Subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics).* 8010 LNCS. Springer, Berlin, Heidelberg. 447–453. Web. 3 Aug. 2017.

Arnstein, Sherry R. (1969): "A Ladder Of Citizen Participation." *Journal of the American Institute of Planners* 35.4 216–224.

American Psychiatric Association,. (2013). Diagnostic and Statistical Manual of Mental Disorders. *Arlington*, 991. doi:10.1176/appi.books.9780890425596.744053

Atkinson P (2017) The Design Journal and the Meaning of Design, The Design Journal, 20:1, 1-4, DOI: 10.1080/14606925.2017.1253247

Avramides, K., Bernardini, S., Foster, M. E., Frauenberger, C., Kossyvaki, L., & Mademtzi, M. (2012). State-of-the-art in TEL to support social communication skill development in children with autism: a multi-disciplinary review. *International Journal of Technology Enhanced Learning, 4*, 359-372. doi:10.1504/IJTEL.2012.051819

Bai, Z., Blackwell, A. F., & Coulouris, G. (2015). Using augmented reality to elicit pretend play for children with autism. *IEEE Transactions on Visualization and Computer Graphics, 21*, 598-610. doi:10.1109/TVCG.2014.2385092

Balcazar, F., Keys, C., Kaplan, D., & Suarez-Balcazar, Y. (1998). Participatory action research and people with disabilities: principles and challenges. *Canadian Journal of Rehabilitation, 12*, 105-112 108p. doi:10.1017/CBO9781107415324.004

Bano, M., & Zowghi, D. (2015). A systematic review on the relationship between user involvement and system success. *Information and Software Technology, 58*, 148-169. doi:10.1016/j.infsof.2014.06.011

Barrow, D. M. (2017). A Phenomenological Study of the Lived Experiences of Parents of Young Children with Autism Receiving Special Education Services. In.

Bartoli, L., Garzotto, F., Gelsomini, M., Oliveto, L., & Valoriani, M. (2014). Designing and evaluating touchless playful interaction for ASD children. *ACM International Conference Proceeding Series*, 17.

Bate, P., & Robert, G. (2007). Bringing user experience to healthcare improvement : the concepts, methods and practices of experience-based design. 207.

Baron-Cohen, Simon. "The Empathizing System: A Revision of the 1994 Model of the Mindreading System." *Mind* (2005): 1–44.

Bauminger, Nirit. "Brief Report: Individual Social-Multi-Modal Intervention for HFASD." *Journal of Autism and Developmental Disorders* 37.8 (2007): 1593–1604.

Bedir Erişti, Suzan Duygu. (2016): "Participatory Design Based Digital Storytelling and Creativity in Elementary School." *Turkish Online Journal of Qualitative Inquiry* 7.4 462.

Beier, J. Marshall, 2018, "Implementing children's right to be heard: Local attenuations of a global commitment" Journal of Human Rights pp 1, 1475-4843

Bell, Adam, and Katie Davis. (2016), "Learning through Participatory Design." *Proceedings of the 15th International Conference on Interaction Design and Children - IDC '16*. New York, New York, USA: ACM Press,

Benton, L., & Johnson, H. (2014). Structured approaches to participatory design for children: Can targeting the needs of children with autism provide benefits for a broader child population? *Instructional Science, 42*, 47-65. doi:10.1007/s11251-013-9297-y

Benton, L., Johnson, H., Ashwin, E., Brosnan, M., & Grawemeyer, B. (2012a). Developing IDEAS: Supporting Children with Autism Within a Participatory Design Team. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. Austin, TX: ACM.

Benton, L., Johnson, H., Ashwin, E., Brosnan, M., & Grawemeyer, B. (2012b). IDEAS: An Interface Design Experience for the Autistic Spectrum. *Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12*. New York, New York, USA: ACM Press.

Benton, L., Vasalou, A., Khaled, R., Johnson, H., & Gooch, D. (2014a). Diversity for design: A Framework for Involving Neurodiverse Children in the Technology Design Process. *Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14*, 3747-3756. doi:10.1145/2556288.2557244

Blum-Dimaya A , Reeve S, Reeve, K, & Hoch, H. (2010). Teaching Children with Autism to Play a Video Game Using Activity Schedules and Game-Embedded Simultaneous Video Modeling. *Education and Treatment of Children*, *33*(3), 351–370. http://doi.org/10.1353/etc.0.0103

Benton, L., Vasalou, A., Khaled, R., Johnson, H., & Gooch, D. (2014b). *Diversity for design: a framework for involving neurodiverse children in the technology design process*. Paper presented at the Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, Toronto, Ontario, Canada.

Bodker, S., & Pekkola, S. (2010). A short review to the past and present of participatory design. *Scandinavian Journal of Information Systems, 22*, 45-48.

Börjesson, P., Barendregt, W., Eriksson, E., & Torgersson, O. (2015a). Designing technology for and with developmentally diverse children. *Proceedings of the 14th International Conference on Interaction Design and Children - IDC '15*.

Börjesson, P., Barendregt, W., Eriksson, E., & Torgersson, O. (2015b). Designing Technology for and with Developmentally Diverse Children – A Systematic Literature Review. *Idc 2015*. New York, NY, USA: ACM Press.

Bossavit, B., & Pina, A. (2013). An interdisciplinary methodology for designing and implementing educational tools for children and youth with special needs. *ACM SIGACCESS Accessibility and Computing*, 4-8. doi:10.1145/2444800.2444801

Boster, J. B., & McCarthy, J. W. (2018). Designing augmentative and alternative communication applications: the results of focus groups with speech-language pathologists and parents of children with autism spectrum disorder. *13*(4), 353.

Bowen, S., McSeveny, K., Lockley, E., Wolstenholme, D., Cobb, M., & Dearden, A. (2013). How was it for you? Experiences of participatory design in the UK health service. *CoDesign, 9*, 230-246. doi:10.1080/15710882.2013.846384

Boyd, Brian A, Stephen G McDonough, and James W Bodfish. (2012): "Evidence-Based Behavioral Interventions for Repetitive Behaviors in Autism." *Journal of autism and developmental disorders* 42.6 1236–48

Boyle, B., & Arnedillo-Sanchez, I. (2016). Exploring the role of adults in participatory design for children on the autism spectrum. *Design, user experience, and usability : design thinking and methods : 5th International Conference, DUXU 2016*. Toronto.

Brady, B, Kennan, D, Forkan, C, Tierney, E, Jackson R & Holloway R, (2019) The participation of children and young people in care: insights from an analysis of national inspection reports in the Republic of Ireland, Child Care in Practice, 25:1, 22-36, DOI: 10.1080/13575279.2018.1537257

Bringolf, J. (2008). Universal Design : Is it Accessible? *Plurality and Diversity in Design, 1*, 45-52.

Capaldi, E. John. "The Organization of Behavior." *Journal of Applied Behavior Analysis* (2006).

Carpenter, C. and Suto, M. (2008). *Qualitative research for occupational and physical therapists*. Oxford: Blackwell Publishers.

Cavet, J., & Sloper, P. (2004). The participation of children and young people in decisions about UK service development. *Child: Care, Health, and Development, 30* (6), 613-621. https://doi.org/10.1111/j.1365-2214.2004.00470.x

Chamberlain, S., Sharp, H., & Maiden, N. (2006). Towards a framework for integrating agile development and user-centred design. *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics), 4044 LNCS*, 143-153. doi:10.1007/11774129

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.

Christensen, Deborah L. et al. (2016): "Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012." *Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C. : 2002)* 65. 1–23.

Christiansen, L. G., Brooks, A. L., Petersson Brooks, E., & Rosenørn, T. (2014). A Virtual Dressing Room for People with Asperger's Syndrome. *Universal Access in Human-Computer Interaction: Design for All & Accessibility Practice*, 163. Retrieved from

Cobb, S., Parsons, S., Millen, L., Eastgate, R., Glover, T. (2010). DESIGN AND DEVELOPMENT OF COLLABORATIVE TECHNOLOGY FOR CHILDREN WITH AUTISM: COSPATIAL. *INTED2010 Proceedings*. Valencia.

Constantin, A., Johnson, H., Smith, E., Lengyel, D., & Brosnan, M. (2017). Designing computer-based rewards with and for children with Autism Spectrum Disorder and/or Intellectual Disability. *Computers in Human Behavior, 75*, 404-414. doi:

Coons, KD, and SL Watson. (2013): "Conducting Research with Individuals Who Have Intellectual Disabilities: Ethical and Practical Implications for Qualitative Research." *Journal on Developmental Disabilities* 19.2

Cooper, A., & Ireland, D. (2018). Designing a Chat-Bot for Non-Verbal Children on the Autism Spectrum. *Studies in health technology and informatics, 252*, 63-68.

CRC (Committee on the Rights of the Child), (2009) General Comment no. 12: The right of the child to be heard (UN document CRC/C/GC/12).

Creswell, J. W. (2009). *Qualitative Inquiry Research Design: Choosing Among Five Approaches* 2nd ed.). London: Thousand Oaks Sage Publications

Dawson, Geraldine et al. (2004): "Early Social Attention Impairments in Autism: Social Orienting,
Joint Attention, and Attention to Distress." *Developmental psychology* 40.2 271–283

David N., Newen A., Vogeley K. (2008). The "sense of agency" and its underlying cognitive and neural mechanisms. Conscious. Cogn. 17, 523–534. 10.1016/j.concog.2008.03.004

Denzin, N. K., & Lincoln, Y. S. (2003). *The landscape of qualitative research: Theories and   issues*, Thousand Oaks, Calif: SAGE Publications.

DePape, A.-M., & Lindsay, S. (2016). Lived Experiences From the Perspective of Individuals With Autism Spectrum Disorder. *Focus on Autism and Other Developmental Disabilities, 31*, 60-71. doi:10.1177/1088357615587504

DeVaney, S. A. (2016), Yin, R.K. (2016). Qualitative Research from Start to Finish, Second Edition. New York: The Guilford Press. ISBN: 978-1-4625-1797-8.pp 386 Fam Consum Sci Res J, 44: 324-325. doi:10.1111/fcsr.12144

Donaldson, K. (2009). The Future of Design for Development: Three Questions. *Information Technologies & International Development, 5*, 97-100.

Druin, A. (2002). The role of children in the design of new technology. *Behaviour & Information Technology, 21*, 1-25. doi:10.1080/01449290110108659

Ehn, P. (2008). Proceedings of the Tenth Anniversary Conference on Participatory Design 2008.
Proceedings of the Tenth Anniversary Conference on Participatory Design 2008. Bloomington: Indiana University

Ensici, A., Bayazit, N., Badke-Schaub, P. & Lauche, K. (2008). Decision Making in DesignTeams: Analysis of Used and Rejected Decisions. *International Design Conference Design 2008*. Dubrovnik - Croatia.

Eisenhardt, K. (1989). Building Theories from Case Study Research. *The Academy of Management Review, 14*(4), 532-550.

Escobedo, L., Ibarra, C., Hernandez, J., Alvelais, M., & Tentori, M. (2014). Smart objects to support the discrimination training of children with autism. In (Vol. 18, pp. 1485-1497).

Evans, Claire, and Roy Jones. (2004) "Engagement and Empowerment, Research and Relevance: Comments on User Controlled Research." *Research Policy and Planning* 22.2: 5–13

Farley, Megan et al. (2009): "Twenty Year Outcome for Individuals with Autism and Average or near Average Cognitive Abilities." *Autism Research* 2.2 109–118.

Farr, William, Nicola Yuill, and Hayes Raffle. "Social Benefits of a Tangible User Interface for Children with Autistic Spectrum Conditions." *Autism : the international journal of research and practice* 14.3 (2010): 237–52

Fabri, M., Elzouki, S. Y. A., & Moore, D. (2007). Emotionally Expressive Avatars for Chatting, Learning and Therapeutic Intervention. *Human-Computer Interaction, III*, 275-285. doi:10.1007/978-3-540-73110-8

Fenici, Marco. "What Is the Role of Experience in Children's Success in the False Belief Test: Maturation, Facilitation, Attunement or Induction?" *Mind & Language* 32.3 (2017): 308–337.

Fine, M. (2013). Echoes of Bedford: A 20-year social psychology memoir on participatory action research hatched behind bars. *American Psychologist*, *68*(8), 687–698. http://doi.org/10.1037/a0034359

Finlay, L. (2006). Title of the chapter to find. In L. Finlay & C. Ballinger (Eds.), *Qualitative research for allied health professionals: Challenging choices* (pp. 185–199). Chichester, England: Wiley.

Fletcher-Watson, S., Pain, H., Hammond, S., Humphry, A., & McConachie, H. (2016). Designing for young children with autism spectrum disorder: A case study of an iPad app. *International Journal of Child-Computer Interaction, 7*, 1-14. doi:10.1016/J.IJCCI.2016.03.002

Fombonne, E. "Epidemiology of Pervasive Developmental Disorders." *Pediatr Res* 65.6 (2009): 591–598

Franqueira, Teresa, Gonçalo Gomes, and Sara Gonçalves. "Participatory Design for Public Services: A Food Diary for Children." *10th European Academy of Design Conference.* Gothenburg: EAD, 2013. Web. 21 June 2018.

Frauenberger, C., Good, J., & Alcorn, A. (2012). Challenges, opportunities and future perspectives in including children with disabilities in the design of interactive technology. *Proceedings of the 11th International Conference on Interaction Design and Children - IDC '12*, 367-370. doi:10.1145/2307096.2307171

Frauenberger, C., Good, J., & Keay-Bright, W. (2010). Phenomenology, a framework for participatory design. *Proceedings of the 11th Biennial Participatory Design Conference on - PDC '10.*

Frauenberger, C., Good, J., & Keay-Bright, W. (2011). Designing Technology for Children with Special Needs - Bridging Perspectives through Participatory Design. *CoDesign, 7*, 1-28.. doi:10.1080/15710882.2011.587013

Frauenberger, C., Makhaeva, J., & Spiel, K. (2017). *Blending Methods: Developing Participatory Design Sessions for Autistic Children.* Paper presented at the Proceedings of the 2017 Conference on Interaction Design and Children, Stanford, California, USA.

Freeman, Nerelie C. et al. (2016): "A Cross-Syndrome Evaluation of a New Attention Rating Scale: The Scale of Attention in Intellectual Disability." *Research in Developmental Disabilities* 57 18–28.

Fusar-Poli, Laura et al. (2017): "Long-Term Outcome of a Cohort of Adults with Autism and Intellectual Disability: A Pilot Prospective Study." *Research in Developmental Disabilities* 60 223–231.

Gal, E., Bauminger, N., Goren-Bar, D., Pianesi, F., Stock, O., Zancanaro, M., & Tamar Weiss, P. L. (2009). Enhancing social communication of children with high-functioning autism through a co-located interface. *AI and Society*, *24*, 75–84. http://doi.org/10.1007/s00146-

Galdas, P. (2017). Revisiting bias in qualitative research: reflections on its relationship with funding and impact. *International Journal of Qualitative Methods, 16,* 1-2. https://doi.org/10.1177/1609406917748992

Garzotto, F., Valoriani, M., & Bartoli, L. (2014). Touchless motion-based interaction for therapy of autistic children. *Intelligent Systems Reference Library, 68*, 471-494. doi:10.1007/978-3-642-54816-1_23

Gastgeb, Holly Zajac, and Mark S Strauss. (2012): "Categorization in ASD: The Role of Typicality and Development." *Perspectives on Language Learning and Education* 19.2 66.

Gaudion, K., Hall, A., Myerson, J., & Pellicano, E. (2015) "A Designer's Approach: How Can Autistic Adults with Learning Disabilities Be Involved in the Design Process?" *CoDesign* 11.1, 49–69, 10.1080/15710882.2014.997829

Gentles, S. J., Charles, C., Ploeg, J., & McKibbon, K. "Sampling in Qualitative Research: Insights from an Overview of the Methods Literature." *The Qualitative Report* (2015): doi: 10.1016/j.exger.2006.09.013

Goh, W. B., Chen, M., Trinh, C. H., Tan, J., & Shou, W. (2014). The MOY framework for collaborative play design in integrated shared and private interactive spaces. *Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems - CHI '14*, 391–400. http://doi.org/10.1145/2556288.2557104

Goodman-Deane, Joy, Patrick Langdon, and John Clarkson. (2010): "Key Influences on the User-Centred Design Process." *Journal of Engineering Design* 21.2–3 345–373.

Guha, M. L., Druin, A., Chipman, G., Fails, J. A., Simms, S., & Farber, A. (2004). Mixing ideas: A New Technique for Working with Young Children as Design Partners. *Proceeding of the 2004 Conference on Interaction Design and Children Building a Community - IDC '04*, 35–42. http://doi.org/10.1145/1017833.1017838

Guha, M. L., Druin, A., & Fails, J. A. (2008). Designing with and for Children with Special Needs: An Inclusionary Model. In *Proceedings of the 7th International Conference on Interaction Design and Children* (pp. 61–64). New York, NY, USA: ACM. http://doi.org/10.1145/1463689.1463719

Guha, M. L., Druin, A., & Fails, J. A. (2008). Designing with and for Children with Special Needs: An Inclusionary Model. *Proceedings of the 7th International Conference on Interaction Design and Children*. New York, NY, USA: ACM.

Guldberg, K., Parsons, S., Porayska-Pomsta, K., & Keay-Bright, W. (2017). Challenging the knowledge-transfer orthodoxy: Knowledge co-construction in technology-enhanced learning for children with autism. *43*(2), 394-413.

Halskov, K., & Hansen, N. B. (2015). The diversity of participatory design research practice at PDC 2002–2012. *International Journal of Human-Computer Studies, 74*, 81-92. doi:10.1016/j.ijhcs.2014.09.003

Hansen, C. T., & Andreasen, M. M. (2004). A mapping of design decision-making. *Proceedings of DESIGN 2004 : 8th International Design Conference*. Dubrovnik: Faculty of Mechanical Engineering and Naval Architecture & The Design Society.

Happé, Francesca, Angelica Ronald, and Robert Plomin. "Time to Give up on a Single Explanation for Autism." *Nature Neuroscience* 9.10 (2006): 1218–1220.

Happé, Francesca, and Uta Frith. (2006): "The Weak Coherence Account: Detail-Focused Cognitive Style in Autism Spectrum Disorders." *Journal of Autism and Developmental Disorders* 36.1 5–25.

Harris, Jennifer. "The Use, Role and Application of Advanced Technology in the Lives of Disabled People in the UK." *Disability & Society* 25.4 (2010): 427–439

Hartley, Jean (2004). Case study research. In Catherine Cassell & Gillian Symon (Eds.), Essential guide to qualitative methods in organizational research (pp.323-333). London: Sage

Herriott, Richard. "The Use of Proxies: Lessons of Social Co-Design for Inclusive Design for People With Cognitive Disabilities." *Journal of Accessibility and Design for All* 5.2 (2015): 100– 124.

Hong, A. P. C. I., van Heugten, S., Kooken, T., Vinke, N., Vromans, M., & Shahid, S. (2010). The augenda. *Proceedings of the 12th International ACM SIGACCESS Conference: Computers & Accessibility*, 283.

Horgan, Deirdre. (2015) *Children and Young People's Experiences of Participation in Decision-Making at Home, in Schools and in Their Communities.* Dublin.

Howlin, Patricia et al. (2013), "Social Outcomes in Mid- to Later Adulthood among Individuals Diagnosed with Autism and Average Nonverbal IQ as Children." *Journal of the American Academy of Child and Adolescent Psychiatry* 52.6 572–581

Imms, Christine et al. (2016): "'Participation': A Systematic Review of Language, Definitions, and Constructs Used in Intervention Research with Children with Disabilities." *Developmental Medicine & Child Neurology* 58.1 29–38.

Janzer, C. L., & Weinstein, L. S. (2014). Social Design and Neocolonialism. *Design and Culture, 6*, 327-343. doi:10.2752/175613114X14105155617429

Jääskö, Vesa, and Tuuli Mattelmäki. "Observing and Probing." *Proceedings of the 2003 International Conference on Designing Pleasurable Products and Interfaces - DPPI '03.* New York, New York, USA: ACM Press, 2003. 126–131.

Jensen, M. M., Thiel, S.-K., Hoggan, E., & Bødker, S. (2018). Physical Versus Digital Sticky Notes in Collaborative Ideation. *Computer Supported Cooperative Work (CSCW)*, 1-37. doi:10.1007/s10606-018-9325-1

Johnson, K., & Walmsley, J. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present and Futures.* Jessica Kingsley Publishers.

Kagohara, Debora M. et al. (2013): "Using IPods?? And IPads?? In Teaching Programs for Individuals with Developmental Disabilities: A Systematic Review." *Research in Developmental Disabilities* 34.1 147–156.

Kang, Mihyun, Phil Choo, and Craig E Watters (2015): "Design for Experiencing: Participatory Design Approach with Multidisciplinary Perspectives." *Procedia - Social and Behavioral Sciences* 174 830–833

Karasti, H., Baker, K.S. & Millerand, F. Comput Supported Coop Work (2010) 19: 377. https://doi.org/10.1007/s10606-010-9113-z

Keates, S., Clarkson, P. J., Harrison, L.-A., & Robinson, P. (2000). Towards a practical inclusive design approach. *Proceedings on the 2000 conference on Universal Usability - CUU '00*. New York, New York, USA: ACM Press.

Keay-Bright, W. (2007). The reactive colours project: demonstrating participatory and collaborative design methods for the creation of software for autistic children. *Design - Principles & Practices, 1*, 7-15.

Keay-Bright, W. (2012). Designing Interaction Though Sound and Movement with Children on the Autistic Spectrum. *Arts and Technology, 101*, 1-9. doi:10.1007/978-3-642-33329-3

Keay-Bright, W., & Howarth, I. (2012). Is simplicity the key to engagement for children on the autism spectrum? *Personal and Ubiquitous Computing, 16*, 129-141. doi:10.1007/s00779-011-0381-5

Kellett, Mary (2011). Accessing children's voices and experiences. In: Moyles, Janet; Georgeson, Jan and Payler, Jane eds. *Beginning Teaching Beginning Learning in Early Years and Primary Education*, Volume 4th ed. Maidenhead: Open University Press, pp. 226–238.

Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies, 44*(7), 1250-1260. https://doi.org/10.1016/j.ijnurstu.2006.08.015

Koegel, RL & Koegel, LK (2006), *Pivotal response treatments for autism: communication, social and academic development.* Paul H Brookes, Baltimore

Koen, P., Ajamian, G., Burkart, R., Clamen, A., Davidson, J., D'Amore, R., . . . Wagner, K. (2001). Providing Clarity and A Common Language to the "Fuzzy Front End". *Research-Technology Management, 44*, 46-55. doi:10.1080/08956308.2001.11671418

Kohlbacher, F. (2006). The Use of Qualitative Content Analysis in Case Study Research. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 7* http://dx.doi.org/10.17169/fqs-7.1.75

Krieger, B., Piškur, B., Schulze, C., Jakobs, U., Beurskens, A., & Moser, A. (2018). Supporting and hindering environments for participation of adolescents diagnosed with autism spectrum disorder: A scoping review. *PloS one, 13*(8), doi: 10.1371/journal.pone.0202071

Kujala, S (2003): "User Involvement: A Review of the Benefits and Challenges." *Behaviour Information Technology* 22.1 1–16.

Kujala, S. (2008). Effective user involvement in product development by improving the analysis of user needs. *Behaviour and Information Technology, 27*, 457-473. doi:10.1080/01449290601111051

Langford, Joe, and Deana. McDonagh. (2003) *Focus Groups: Supporting Effective Product Development (Google EBook)*. Vol. 2002. Taylor & Francis, 2002

Lee , Y. (2008). Design participation tactics; the challenges and new roles for designers in the co-design process. *Co-Design, 4*(1), 31 - 50. doi:10.1080/15710880701875613

Leung, Lawrence. "Validity, Reliability, and Generalizability in Qualitative Research." *Journal of Family Medicine and Primary Care* 4.3 (2015): 324.

Logan, Kristy, Teresa Iacono, and David Trembath. "A Systematic Review of Research into Aided AAC to Increase Social-Communication Functions in Children with Autism Spectrum Disorder." *Augmentative and alternative communication* 33.1 (2017): 51–64

Loveland, K. A. and Tunali-Kotoski, B. (2013). The School-Age Child with an Autistic Spectrum Disorder. In Handbook of Autism and Pervasive Developmental Disorders (eds F. R. Volkmar, R. Paul, A. Klin and D. Cohen). doi:10.1002/9780470939345.ch9

Luck, Rachael. "Dialogue in Participatory Design." *Design Studies*. Vol. 24. N.p., 2003. 523–535. Web. 21 June 2018.

Lyons, Gregory L et al. "Assessing the Social Skills and Problem Behaviors of Adolescents with Severe Disabilities Enrolled in General Education Classes." *American Journal on Intellectual and Developmental Disabilities* 121.4 (2016): 327–345.

Mackay, Wendy E., and Anne Laure Fayard. (1999) "Video Brainstorming and Prototyping." *CHI '99 Extended Abstracts on Human Factors in Computing Systems - CHI '99*. New York, New York, USA: ACM Press

Maddox, Brenna B et al. (2018): "Lagging Skills Contribute to Challenging Behaviors in Children with Autism Spectrum Disorder without Intellectual Disability." *Autism* 22.8 898–906.

Marshall, C. A., Kendall, E., Banks, M. E., & Gover, R. M. (2009). *Disabilities: Insights from across fields and around the world, Vol 2: The context: Environmental, social, and cultural considerations*. (R. M. Gover, Ed.), *Praeger perspectives*. Santa Barbara, CA US: Praeger/ABC-CLIO

Malinverni, L., Mora-Guiard, J., Padillo, V., Valero, L., Hervás, A., & Pares, N. (2017). An inclusive design approach for developing video games for children with Autism Spectrum Disorder. *Computers in Human Behavior, 71*, 535-549. doi:10.1016/J.CHB.2016.01.018

Malinverni, L., Mora-Guiard, J., & Pares, N. (2016). Towards methods for evaluating and communicating participatory design: A multimodal approach. *International Journal of Human-Computer Studies, 94*, 53-63. doi:10.1016/j.ijhcs.2016.03.004

Marchi, Anna Rita. (2015): "The Importance of Early Intensive Behavioural Intervention in Autism Spectrum Disorder." *Journal of Psychiatry* 18.5

Matson, Johnny L, and Mary Shoemaker (2009): "Intellectual Disability and Its Relationship to Autism Spectrum Disorders." *Research in developmental disabilities* 30.6 1107–14.

Mesibov, G. B., Shea, V., Schlopler, E., Adams, L., Merkler, E., Burgess, S., . . . CVan Bourgondien, M. E. (2004). *The Teacch Approach to Autism Spectrum Disorders*. Boston, MA: Springer-Verlag.

Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook (2nd ed.). Thousand Oaks, CA, US: Sage Publications, Inc.

Millen, L., Cobb, S., & Patel, H. (2011a). A method for involving children with autism in design. *Proceedings of the 10th International Conference on Interaction Design and Children - IDC '11*. Participatory design approach with children with autism, 10 289-294 (2011b).

Millen, L., Edlin-White, R., & Cobb, S. (2010). The development of educational collaborative virtual environments for children with autism. … *of the 5th Cambridge Workshop on*

Moran, J. M. et al. "Impaired Theory of Mind for Moral Judgment in High-Functioning Autism." *Proceedings of the National Academy of Sciences* 108.7 (2011): 2688–2692.

Mora Guiard, J., Malinverni, L., Pares, N., Mora Guiard, J., Malinverni, L., & Pares, N. (2014). Narrative-based elicitation: orchestrating contributions from experts and children. *Proceedings of the extended abstracts of the 32nd annual ACM conference on Human factors in computing systems - CHI EA '14*. New York, New York, USA: ACM Press.

Morrison, Cecily, and Andy Dearden. (2013): "Beyond Tokenistic Participation: Using Representational Artefacts to Enable Meaningful Public Participation in Health Service Design." *Health Policy* 112.3 179–186

Munoz, R., Morales, C., Villarroel, R., Á, Q., & Albuquerque, V. H. C. D. (2019). Developing a Software That Supports the Improvement of the Theory of Mind in Children With Autism Spectrum Disorder. *IEEE Access, 7*, 7948-7956. doi:10.1109/ACCESS.2018.2890220

Newell, A. F., & Gregor, P. (2000). "User sensitive inclusive design"--- in search of a new paradigm. *Proceedings on the 2000 conference on Universal Usability - CUU '00*. New York, New York, USA: ACM Press.

Neuman, W. Lawrence (1997). *Social research methods, qualitative and quantitative approaches* (3rd ed.). Boston: Allyn and Bacon.

Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: methodological challenges. *ESRC National Centre for Research Methods*, *12*(November), 1–24.

Nind, M. (2014a). Inclusive research and inclusive education: why connecting them makes sense for teachers' and learners' democratic development of education. *Cambridge Journal of Education*, *44*(4), 525–540. http://doi.org/10.1080/0305764X.2014.936825

Nind, M. (2014b). *What is inclusive research?* (1st ed.). London: Bloomsbury.

Nind, M., & Vinha, H. (2014). Doing research inclusively: bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, *42*(2), 102–109. http://doi.org/10.1111/bld.12013

Noy, Chaim. "Sampling Knowledge: The Hermeneutics of Snowball Sampling in Qualitative Research." *International Journal of Social Research Methodology* (2008): doi:10.1080/13645570701401305

Noyes, A., 2005. Pupil voice: purpose, power and the possibilities for democratic schooling British Educational Research Journal. VOL 31(NUMB 4), 533-540

Odom, S. L., Buysse, V., & Soukakou, E. (2011). Inclusion for Young Children With Disabilities: A Quarter Century of Research Perspectives. Journal of Early Intervention, 33(4), 344–356. https://doi.org/10.1177/1053815111430094

Parés, N., Carreras, A., Durany, J., Ferrer, J., Freixa, P., Gómez, D., . . . Sanjurjo, À. (2006). Starting Research in Interaction Design with Visuals for Low-Functioning Children in the Autistic Spectrum: A Protocol. *CyberPsychology & Behavior, 9*(2), 218-223.. doi:10.1089/cpb.2006.9.218

Parés, N., Soler, M., Sanjurjo, À., Carreras, A., Durany, J., Ferrer, J., . . . Ribas, J. I. (2005). Promotion of creative activity in children with severe autism through visuals in an interactive multisensory environment. *Proceeding of the 2005 conference on Interaction design and children - IDC '05*.

Parsons, S., & Cobb, S. (2014). Reflections on the role of the 'users': challenges in a multi-disciplinary context of learner-centred design for children on the autism spectrum. *International Journal of Research & Method in Education, 37*, 421-441. doi:10.1080/1743727X.2014.890584

Parsons, S., Guldberg, K., Porayska-Pomsta, K., & Lee, R. (2015a). Digital stories as a method for evidence-based practice and knowledge co-creation in technology-enhanced learning for children with autism. *International Journal of Research & Method in Education, 38*, 247-271. doi:10.1080/1743727X.2015.1019852

Parsons, S., Guldberg, K., Porayska-Pomsta, K., & Lee, R. (2015b). Digital stories as a method for evidence-based practice and knowledge co-creation in technology-enhanced learning for children with autism. *International Journal of Research & Method in Education, 38*(3), 247-271.. doi:10.1080/1743727X.2015.1019852

Parsons, S., Millen, L., Garib-Penna, S., & Cobb, S. (2011). Participatory design in the development of innovative technologies for children and young people on the autism spectrum: the COSPATIAL project. *Journal of Assistive Technologies, 5*, 29-34. doi:10.5042/jat.2011.0099

Pascualvaca, Daisy M. et al. (1998): "Attentional Capacities in Children with Autism: Is There a General Deficit in Shifting Focus?" *Journal of Autism and Developmental Disorders* 28.6 467–478.

Patton, Eric, & Appelbaum, Steven H. (2003). The case for case studies in management research. *Management Research News, 26*(5), 60-71.

Phillips, Rebecca L. et al, (2013). "Measuring Activity and Participation in Children and Adolescents with Disabilities: A Literature Review of Available Instruments." *Australian Occupational Therapy Journal*: 288–300

Ploog, Bertram O. et al. (2013): "Use of Computer-Assisted Technologies (CAT) to Enhance Social, Communicative, and Language Development in Children with Autism Spectrum Disorders." *Journal of Autism and Developmental Disorders* 43.2 301–322.

Picard, Rosalind W. (2009): "Future Affective Technology for Autism and Emotion Communication." *Philosophical transactions of the Royal Society of London. Series B, Biological sciences* 364.1535 3575–84

Pierce, K, and L Schreibman. (1995): "Increasing Complex Social Behaviors in Children with Autism: Effects of Peer-Implemented Pivotal Response Training." *Journal of applied behavior analysis* 28.3 285–95.

Piper, A. M., Piper, A. M., O'Brien, E., O'Brien, E., Morris, M. R., Morris, M. R., . . . Winograd, T. (2006). SIDES: a cooperative tabletop computer game for social skills development. *Proceedings of the 2006 20th anniversary conference on Computer supported cooperative work*, 1-10. doi:10.1145/1180875.1180877

Porayska-Pomsta, Frauenberger, Rajendran, Smith, Pain, Menzies, Lemon. (2010). Developing Technology for Autism needs an interdisciplinary approach. *Personal and Ubiquitous Computing, 14*, 117-127. doi:10.1007/s00779-011-0384-2

Preece, Jenny. (2015) *Interaction Design: Beyond Human-Computer Interaction,* Sage Pub.

Rajendran, Gnanathusharan, and Peter Mitchell. (2007): "Cognitive Theories of Autism." *Developmental Review* 27.2 224–260.

van Rijn, H., & Stappers, P. J. (2008). The Puzzling Life of Autistic Toddlers: Design Guidelines from the LINKX Project. *Advances in Human-Computer Interaction, 2008*, 1-8. doi:10.1155/2008/639435

Ringland, K. E., Zalapa, R., Neal, M., Escobedo, L., Tentori, M. E., & Hayes, G. R. (2014). SensoryPaint. *Conference on Human Factors in Computing Systems Proceedings*, 1681.

Rogers, Sally J. "Interventions That Facilitate Socialization in Children with Autism." *Journal of Autism and Developmental Disorders* 30.5 (2000): 399–409.

Rosenwasser, B, and S Axelrod. (2001): The Contributions of Applied Behavior Analysis to the Education of People with Autism." *Behavior Modification:* 25.5 671–677.

Salah, D., Paige, R. F., & Cairns, P. (2014). A Systematic Literature Review for Agile Development Processes and User Centred Design Integration. *Proceedings of the 18th International Conference on Evaluation and Assessment in Software Engineering (EASE '14), London, United Kingdom, 13-14 May, 2014*, 5:1--5:10. doi:10.1145/2601248.2601276

Sampath, H., Indurkhya, B., & Sivaswamy, J. (2012). A Communication System on Smart Phones and Tablets for Non-verbal Children with Autism. *Computers Helping People with Special Needs (9783642315336)*, 323..

Sanders, E. B. (2002). From user-centered to participatory design approaches. *Design and the Social Sciences Making connections*, 1-8. doi:10.1201/9780203301302.ch1

Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign, 4*, 5-18. doi:10.1080/15710880701875068

Sanders, E. B. N., Brandt, E., & Binder, T. (2010). A framework for organizing the tools and techniques of participatory design. *Proceedings of the 11th Biennial Participatory Design Conference on - PDC '10.*

Schuller, Björn et al. (2013). "ASC-Inclusion: Interactive Emotion Games for Social Inclusion of Children with Autism Spectrum Conditions." *Proceedings 1st International Workshop on Intelligent Digital Games for Empowerment and Inclusion (IDGEI 2013) held in conjunction with the 8th Foundations of Digital Games 2013 (FDG)*

Schuler, D., & Namioka, A. (1993). Participatory design : principles and practices. 319.

Schuler, D., & Namioka, A. (1993). Participatory design: Principles and practices.

Shier, Harry. (2001): "Pathways to Participation: Openings, Opportunities and Obligations." *Children and Society* 15.2 107–117. Web. 19 Sept. 2017.

Shier, Harry et al. (2014): "How Children and Young People Influence Policy-Makers: Lessons from Nicaragua." *Children and Society* 28.1 1–14

Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity*. New York: Avery, an imprint of Penguin Random House.

Simonsen, J., & Robertson, T. (2012). Routledge international Handbook of Participatory Design. *Routledge International Handbooks*, 320. doi:10.1177/0963662512444848

Sinkovics, N. (2018). Pattern matching in qualitative analysis. In C. Cassell, A. L. Cunliffe, & Grandy (Eds.), *The SAGE handbook of qualitative business and management research methods* (pp. 468-485). Thousand Oaks, US: Sage Publications Ltd

Spinuzzi, C. (2005). The Methodology of Participatory Design. *Technical Communication, 52*, 163-174. doi:10.1016/j.infsof.2008.09.005

Stebbins, R.A. (2001) *Exploratory Research in the Social Sciences*. Sage University Papers Series on Qualitative Research Methods, Vol 48, Thousand Oaks, CA: Sage.

Stephanidis, C. (1995). Towards user interfaces for all: some critical issues. *Advances in Human Factors/Ergonomics, 20*, 137-142. doi:10.1016/S0921-2647(06)80024-9

Strauss, A., & Corbin, J. (1998). Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks, CA: Sage Publications, Inc.

Sullivan, W. F., & Heng, J. (2018). Supporting adults with intellectual and developmental disabilities to participate in health care decision making. *Canadian family physician Medecin de famille canadien*, *64*(Suppl 2), S32–S36.

Tager-Flusberg, H., & Kasari, C. (2013). Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum. *Autism Research, 6*, 468-478. doi:10.1002/aur.1329

Tang, H., Jheng, C., Chien, M., Lin, N., & Chen, M. Y. (2013, 12-16 March 2013). *iCAN: A tablet-based pedagogical system for improving the user experience of children with autism in the learning process*. Paper presented at the 2013 1st International Conference on Orange Technologies (ICOT).

Tisdall, E. M. (2018). Challenging Competency and Capacity? *The International Journal of Children's Rights*, *26*(1), 159-182. doi: https://doi.org/10.1163/15718182-02601003

Uddin L. Q. (2011). The self in autism: an emerging view from neuroimaging. Neurocase 17, 201–208. 10.1080/13554794.2010.509320

UN Committee on the Rights of the Child (CRC), *General comment No. 12 (2009): The right of the child to be heard*, 20 July 2009, CRC/C/GC/12, available at: https://www.refworld.org/docid/4ae562c52.html [accessed 1 March 2019]

Unger, R. (2012). A project guide to UX design : for user experience designers in the field or in the making / Russ Unger and Carolyn Chandler. In (pp. 0-1).

The United Nations. (1989). Convention on the Rights of the Child. *Treaty Series*, *1577*, 3.

The United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Treaty Series*, *2515*, 3

United Nations Information Service. (2015). "OHCHR | Committee on the Rights of Persons with Disabilities Considers Initial Report of Qatar." *Press Release*. N.P., Available at https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=16353 last accessed - 26 Feb. 2019

de Villiers, J. "The Interface of Language and Theory of Mind." *Lingua. International review of general linguistics. Revue internationale de linguistique generale* 117.11 (2007): 1858–1878

Visser, F. S. (2009). Bringing the everyday life of people into design. In *TEZ* (Vol. Ph.D., pp. 273).

Volkmar, Fred R. et al. *Handbook of Autism and Pervasive Developmental Disorders: Assessment, Interventions, and Policy (Volume 2) (4th Ed.)*. Hoboken, NJ, USA: John Wiley & Sons, Inc., 2014.

Wagner, L., Baureis, D., & Warschat, J. (2012). How to develop product-service systems in the fuzzy front end of innovation. *International Journal of Technology Intelligence and Planning, 8*, 333-357. doi:10.1504/IJTIP.2012.051782

Weber, Alan S. (2012): "Inclusive Education in The Gulf Cooperation Council." *Journal of Educational and Instructional Study in The World:* 2.2 85–97.

Weed, M. (2008) A Potential Method for the Interpretive Synthesis of Qualitative Research: Issues in the Development of 'Meta-Interpretation', *International Journal of Social Research Methodology*, 11:1, 13-28, DOI: 10.1080/13645570701401222

Weiss, P. L., Gal, E., Zancanaro, M., Giusti, L., Cobb, S., Millen, L., . . . Eden, S. (2011). Usability of technology supported social competence training for children on the Autism Spectrum. 1-8.

Wilkinson, C. R., & De Angeli, A. (2014). Applying user centred and participatory design approaches to commercial product development. *Design Studies, 35*, 614-631. doi:10.1016/j.destud.2014.06.001

Wing, L. & Gould, J (1979), Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification, J Autism Dev Disorders, 9-

Winograd, T., & Terry. (1996). Bringing design to software. 321.

Wobbrock, J. O., Kane, S. K., Gajos, K. Z., Harada, S., & Froehlich, J. (2011). Ability-Based Design. *ACM Transactions on Accessible Computing, 3*, 1-27. doi:10.1145/1952383.1952384

Won, Hyejung, Won Mah, and Eunjoon Kim. (2013): "Autism Spectrum Disorder Causes, Mechanisms, and Treatments: Focus on Neuronal Synapses." *Frontiers in Molecular Neuroscience* 6 19.

Wood, Jeffrey J. et al. (2009). "Brief Report: Effects of Cognitive Behavioral Therapy on Parent-Reported Autism Symptoms in School-Age Children with High-Functioning Autism." *Journal of Autism and Developmental Disorders*

Zakari, H & Simmons, D. (2014). A Review of Serious Games for Children with Autism Spectrum Disorders (ASD). In *Serious Games Development and Applications. 5th International Conference, SGDA 2014, Berlin, Germany, October 9-10, 2014. Proceedings* (pp. 93–106).

Zalla, T., & Sperduti, M. (2015). The sense of agency in autism spectrum disorders: a dissociation between prospective and retrospective mechanisms? *Frontiers in psychology, 6*, 1278. doi:10.3389/fpsyg.2015.01278

APPENDIX A: CONSENT FORMS AND PARTICIPANT INFORMATION

1. Participant Information Sheet
2. Design Participant Consent Form
3. Parent (Informed) Consent Form: Child Participant

TRINITY COLLEGE DUBLIN

INFORMATION SHEET FOR PARTICIPANTS

Project Title: CoVE: *Using Participatory Design to inform the development of software harnessing computer supported collaborative learning to support the development of Social Skills for Children with Autism Spectrum Disorder.*

Introduction

Thank you for your interest in this research study, your name and contact details were provided by _____ Director of the Al Noor Institute/Mada Qatar Assistive Technology Centre. This research is being conducted by Bryan Boyle of the School of Computer Science and Statistics and forms part of his PhD studies. The purpose of this participatory research project is to build and evaluate a collaborative, virtual learning environment for children on the autism spectrum.

Background

The first part of this research will involve parents, teachers, therapists and other carers of children with autism spectrum disorders (ASD) in a series of collaborative, participatory workshops to design a range of software applications that will allow.

Your Participation

As a participant in these workshops you will have the opportunity to learn more about software for learning and education, how computer environments can be made more accessible for children with disabilities and you can bring your own opinions, experience and knowledge to bear on the design of such software. As the project progresses and the software is developed you will be asked to give your opinion and feedback on the various versions and your suggestions and recommendations will be incorporated into future designs. The final version developed will then be made available to you and will be installed for field-testing by children with disabilities who may benefit from its use and a thorough examination of its value will be conducted. As researchers we are interested in collecting, collating and analysing your opinions, your knowledge of children with disabilities, your experiences of their use of technology and your contributions to the design of new learning software. This data will be gathered by way of anonymous questionnaires, note-keeping, photographs, audio and video recordings. The data be transcribed and coded anonymously so as to *ensure the confidentiality of all participants*. Following transcription, all original materials such as audio, videos and written notes will be destroyed with certificates of destruction stored securely beyond the lifetime of this project. You are, of course free to withdraw your participation from the study at any time. If you choose to withdraw from the study prior to the anonymization of the data gathered all of your recorded contributions to the study will be destroyed and will form no part of this study. However, once the data has been anonymized and all originals destroyed this will not be possible and all anonymous data gathered will form a part of this study. Here is an outline of the commitment that would be involved as an adult participant in this study.

You will be briefed as to how the research will be conducted. After attending this workshop, you will be asked to participate in a range of (up to four) two-hour workshops during which you will work with a research team of software designers to collaboratively design software based learning application(s) for children with disabilities. The software will be intended as a

learning tool that will provide children with opportunities to learn and practice social skills with other children in a safe and stress-free environment.

Name	Description	Estimated Time Commitment
Design Workshops	You will be invited to participate in an introductory workshop during which the researcher will give you an overview of the Collaborative Virtual Environment, its functionality and its application as a learning tool for children on the autism spectrum. You will be considered a "Co-Designer" and will be fully involved in all phases of the design of virtual environment for children that you care for or work with. Your experience and expertise will be drawn upon and we will work collaboratively through a series of group design exercises to develop a software application that can be used to promote social interaction and joint attention skills. As the prototypes are developed you will be given the opportunity to provide feedback and to determine the direction of further developments of the software.	**2hours x 4 sessions**
Main Activities: Field Trials/System Testing	Following production of a suitable prototype for trial, we will set up field trials in locations that are familiar to and comfortable for children with disabilities. We will then make the virtual environments developed available to children to play with, experience and provide us with valuable feedback as to their experience playing and engaging with the developed technology.	**15 minute sessions three times per week over the course of 8 weeks**
Reports	You will be given a number of opportunities during the project to offer your comments on the effectiveness and efficiency of the technology developed, the appropriateness of the learning content provided, and to suggest modifications to the system that would enhance learner participation. Following completion of the field trials and system testing you will be provided with a summary report of initial findings and the opportunity to provide further feedback to the researcher.	

Your participation is completely voluntary and you may withdraw from this participatory design project at any time without penalty. If you do decide to withdraw from the research inquiry you must inform the researcher by email. All collected information from your participation in the inquiry will be removed immediately, it will not be included in the research documentation and will be destroyed according to the relevant standards.

There are no anticipated risks to your involvement in this research. It is envisaged that during the project you will not only experience new technologies which will be helpful to you in your work but also collaborate and share your experience with other carers.

Your consent

Each participant must provide their own consent in written form by signing a consent form provided by the researcher. For children participating in this research, full, informed consent must be provided by one or both parents or guardians (see attached child assent forms).

> No personal details will be recorded by the virtual learning environment. As this research project forms part of a PhD thesis, anonymized data collected during the course of this project (as outlined above) may be entered into the dissertation of the researcher, will be held in the libraries of Trinity College Dublin for up to and exceeding seven years.

Permission

For participating teachers, if you are employed by a school, and pupils of this school will be involved indirectly in this research, please inform the researcher so that permission can be obtained from the School Board of Management and the Principal of your school before this research can proceed in your school. If you happen to be employed as a School Principal then the researcher full permission must be obtained from the school Board of Management prior to commencement with this research.

Parents' Consent

During this research project the outcomes of the design workshops will be tested by children with diagnoses of autism spectrum disorders. All of this data will be anonymised and under no circumstances will it be possible to trace this information back to the individuals concerned. However, it will be necessary for the researcher to obtain consent from the parents of the children involved by asking them to **sign separate consent forms**.

Information Collection

During participative research project the researcher will gather evidence via questionnaires, semi-structured interviews, observations, audio and video recording, experimental design, rating scales, database logs, text-based communication and documentation. All data will be anonymised and stored in compliance accepted best practice and with the Data Protection Acts. Extracts of data may be used in presentations etc but under no circumstances will identities of carers or children be made known. The information will be analysed based on the pedagogy and learning theories underpinning this research inquiry.

In the extremely unlikely event that illicit activity is reported to the researcher during the interview the researcher will be obliged to report it to the appropriate authorities. Do not mention third parties during the study or interviews.

The documentation of the findings will be published and disclosed to a body of examiners in Trinity College Dublin as well as external examiners. There may be lectures, PhD

theses, conference presentations and peer-reviewed journal articles written as a result of this project but on no account will the carers and the children be identified.

Debriefing
The researcher will hold a debriefing session after the findings of this project have been published. During this session the collected data and a summary of the analysis will be presented. This session will provide you with the opportunity to examine how your contributions to the study have been used and interpreted, and to ensure that your contributions have not been used inaccurately or out of context.

Conflict of Interest
Although the researcher is conducting this inquiry himself, he is unaware of any conflicts of interest regarding this research. The data collected during this project will not be used against you in any way.

If you require further information or have questions during or after the research project, please do not hesitate to contact researcher at boyleb5@tcd.ie or by phone at 087 2215685.

Parent/Guardian Informed Consent Form

Introduction: Research Background

Thank you for your interest in this research study, your name and contact details were provided by _____ Board Of Management/Director of the Al Noor Institute/Mada Qatar Assistive Technology Centre . . This research is being conducted by Bryan Boyle (boyleb5@tcd.ie) from the School of Computer Science and Statistics and forms part of his Ph D.

The purpose of this research is to build *"CoVE",* a collaborative virtual environment that will provide children with Autism Spectrum Disorder a range of software applications to help develop their social interaction and joint attention skills. The software applications will use the Kinect Movement Control sensors to allow children to interact with the software using movement and gesture.

To this end, Bryan Boyle is working directly with _____ School/Organization to conduct this research project. _____CHILD's NAME_____ was provided by _____ at _____ School/Organization as a potential participant in this research project.

Your child's participation

We would appreciate if you would permit your child to take part in this investigation, as we believe it will contribute to furthering our knowledge of how virtual environments and related software can improve the learning experience for children with autistic spectrum disorders (ASDs). Children participating in similar projects have been shown to gain from such learning experiences. During the research the virtual environment will provide children with the chance to play alongside each other. Before playing the game, their skills will be evaluated using a questionnaire called the ***Early Social Communication Scales*** – this involves organizing and observing your child in a short series of semi-structured tasks that will allow us to measure your child's non-verbal skills. These tasks and questions will be repeated after concluding your child's participation in the virtual environment. I will also videotape your child playing with the software system developed. All of this data will be anonymised so it will be impossible to trace any private personal details back to the individuals involved. The collected video materials will be analysed and transcribed by the Researcher and will subsequently be permanently deleted so as to further protect the anonymity of participants. If you choose to withdraw your child from the study prior to the anonymization of the data gathered all of your recorded

contributions to the study will be destroyed and will form no part of this study. However, once the data has been anonymized and all originals destroyed this will not be possible and all anonymous data gathered will form a part of this study. Gathering video of children playing with the software applications will help us determine the ways in which the system can assist in a child's learning and practice of social skills. The software applications are to be developed as fun, computer activities and will involve the participation of parents and professionals in the design process. As such there are no anticipated risks to your child's involvement in this research. The documentation of the findings will be published and disclosed to a body of examiners in Trinity College Dublin as well as external examiners. There may be lectures, PhD theses, conference presentations and peer-reviewed journal articles written as a result of this project. Extracts of data may be used in these lectures etc., but under no circumstances will identities of children, parents or other professionals be made known and information will not be traced back to the carers and children concerned.

Declaration

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction

I understand the description of the research that is being provided to me

I agree that my child's data is used for scientific purposes and I have no objection that this data is published in scientific publications in a way that does not reveal my child's identity

The researcher will not reuse my child's data for any other purpose than those outlined above

Any observational sessions will be carried out only with my prior consent

All recordings (i.e. audio, video and photographs) will not be identifiable

If I decide to withdraw my child from this project, all collected information from his/her participation will be removed and will not be included in the research documentation

I may email/call the researcher requesting a copy of the findings and/or the dissertation after the project has been completed

I understand that if my child or anyone in my family has a history of epilepsy then he/she is proceeding at his/her own risk

I shall declare any conflict of interest with this research

If any illicit activity is reported during this project that the researcher is obliged to report it to the appropriate authorities

I understand that everyone concerned in this project will treat the data compiled with confidentiality, including examiners and reviewers who will be marking this dissertation.

I have received a copy of this agreement

PARENT'S NAME:_____

PARENT'S SIGNATURE: _____**Date:** _____

Statement of researcher's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHER'S CONTACT DETAILS:_____

RESEARCHER'S SIGNATURE:_____**Date:**_____

ASSENT FORM: Participating Child

Your Special Project Name: _____Insert Anonymous Child Identifier Code____

Today is: _____Insert Date, time & location of assent meeting _____

Who's All here? _____Identify those present for Assent Meeting_____

My name is Bryan Boyle and I'm from Trinity College Dublin
Let me tell you what's this
project is all about?

I would like you to help me make some new computer games that you can use in school.
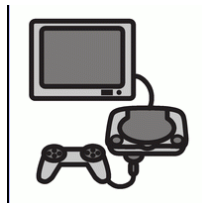
To help me make a new computer game, I will show you some games and give you and your friends a chance to play these

And I will ask you some questions about the games, thing like what bits of the game make you happy and what bits you don't like.
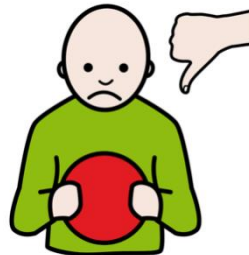
When you and your friends are playing the games I will make a video that I can show you of you playing the computer game.
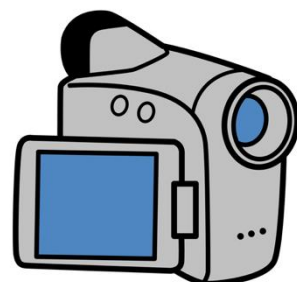
I will also be taking some notes in my book.
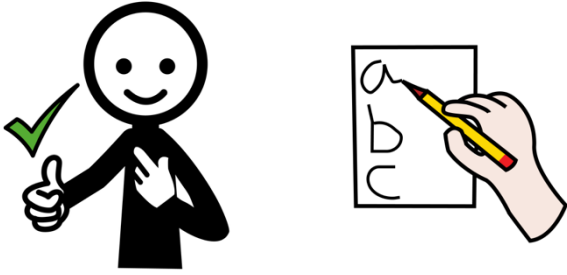
When we are finished making the computer game, I will keep my notes and videos in a safe place and I will make sure no-one else can look at them
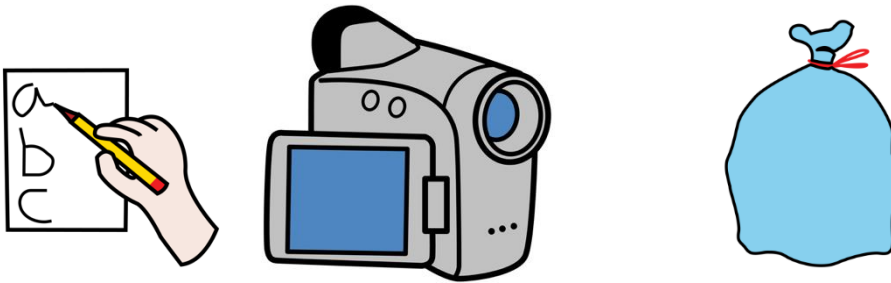
Would you like to help me make some computer games?

Yes   No

Field Work Observation Template: __

Date:　　　　　**Time:**　**Duration:**
Case Study:IV　　**Workshop:**

People:
Who was there?
What was their role?
What did you notice about them?

Place:
Whats the name of the place?
What's it used for?
Who uses it?
Describe it!

Words:
What is said?
How is it said?
What's the emotion?
What started it?

Objects:
What are the physical objects?
Who is using them?
How are they used?

Interactions:
Who talked to who?
How did it go?
Why did they talk?

Impressions:
What were your feelings?

Children:
Who were they?
What did they do?
Why did they do it?
What did they like?
What did they not like?
How did they tell you?
What were your feelings?

Field Work Observation Form: 4 (*Bryan*)

Date: Feb 8th   **Time:8.330a.m.**   **Duration: 70 mins**
Case Study:IV   **Workshop: WORKSHOP 61.1**

People:
Altogether 8 people there with 2 more in/out(driver and cleaner), two teachers as normal, three children (3, 8 & 14), others absent because they're sick. Three TA's assigned to the class. Looks like Child No3 is getting to

---

Place:

Classroom 4 used for the whole time, not trips out for anyone this morning,

---

Words:
It was colours class followed by circle time singing then Child 14 went off for some solo work with TA4, not sure why?
Teacher 1 doing all of the talking this morning, T2 writing notes, just a quick hello from him to me this morning, nothing communicated to the rest of the team or children. Teacher 1 is slow and measured in his delivery, Arabic is easy to follow, his tone is pronounced and he really focuses visually on the kids as he is talking. He is able to ignore me and get on with lessons without looking at me or explaining everything.

Objects:

The tuning fork to start off the signing appears to be Teacher 1's idea, he uses it really well to orient attention to himself – kids transfixed – although Child 13 disengages after a few seconds, but he did response initially – it would appear to the sound

Teacher 2 using the iPad for the most part – although he showed T1 something on it towards the end of the circle time session. Not used by the kids this time. Child 13 still fascinated by the small casters on Child 8's wheelchair just looking though, hasn't touched them

Interactions:

Mainly Teacher 2 to children….except for TA3 to Child 13,checked verbally if he's okay at least 4 times before circle time and appears to be focusing on one-to-one with him ? Note – asks teacher and TA3 about this?   Why?

Impressions:

Teacher 1 makes it easier, easier to be in the background? Some questions to be asked though before tomorrow's class

Children:

Ch 3 & 8 very engaged with teacher, 8 a little distressed when circle time signing was over, but the break for food helped the mood and was back laughing within a few seconds

Child 13, very solitary, changed from the previous day, not sitting, not attending, lots of stimming with fingers, hand in mouth a lot, attention doesn't appear to be welcome, not leaving the room but moving and not settling in one position, okay at first, but starting to upset 3 towards he end of the time, feeling in the room was changing continuously.
Asked TA1 who just said that it was normal, but it didn't feel so…remember to check with Teacher 1 tomorrow.
Child 3 loves bread, saw it today used as a reward during the food break, TA was putting it aside until other food was eaten, 3 tried to keep swapping it – reached for her hand with it several times, the offered her the spoon and pushed the plate towards her smiling then tapping her hand with the food. He is one of the children in the group most motivated by food, appears to understand names for items, eye-pointed to plate and to the chicken when mentioned by TA, also turns to look for named adults.
Child 8 distracted by voices, any voices, anytime 13 made any auditory noises he looks and if he cant locate the sound or voice, he will not re-engage. Worth checking him in busier place with multiple sounds at the same time
8 still looking for the fish- (soft toy), although this appears to have become something that the TA reminds him of now. When mentioned, he goes straight to the old toy storage box.
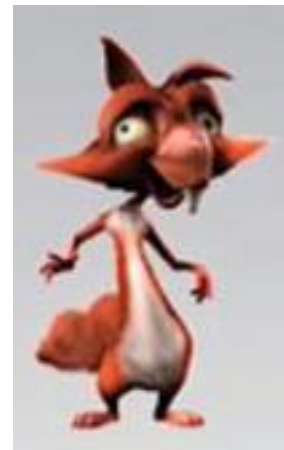
Prototype workshop

DATE:-
Workshop:-

ورشـة النموذج الأولي

شـخصيات بشرية

Who would you choose?
أي من الاثنين سوف تختار؟

مشهد خلفي

Where would you like to play?
اين الملعب

اين الملعب

Workshops 3.1 & 3.2

Decision Making with Children with Autism
A communication protocol for adults

This guide aims to support your efforts to assist with encouraging, motivating, interpreting and representing the communication of children with autism in design evaluation workshops.

Provide a positive communication environment:

Assume Competence. Believe that your learner can complete the challenges presented to them.	☐
Focus on use, not testing. Respond to all modes of communication. This includes AAC messages, gestures, signs, and vocalizations produced by your child. Encourage multimodal communication.	☐
Wait patiently for responses. Do not rush your learner to respond. AAC is typically slower than traditional speech so it's normal for it to take a minute to produce a message.	☐
Provide support when it is needed. Always support your learner and offer assistance when they are struggling.	☐
Address challenges and focus on positive results. Discuss the difficulty of challenges with your learner while still focusing on what the CAN do.	☐

> **Look for and celebrate success**. It comes in many forms such as increased attention to interaction, initiation of communication, use of more vocabulary, longer interactions

Communicating WITH a child with autism:
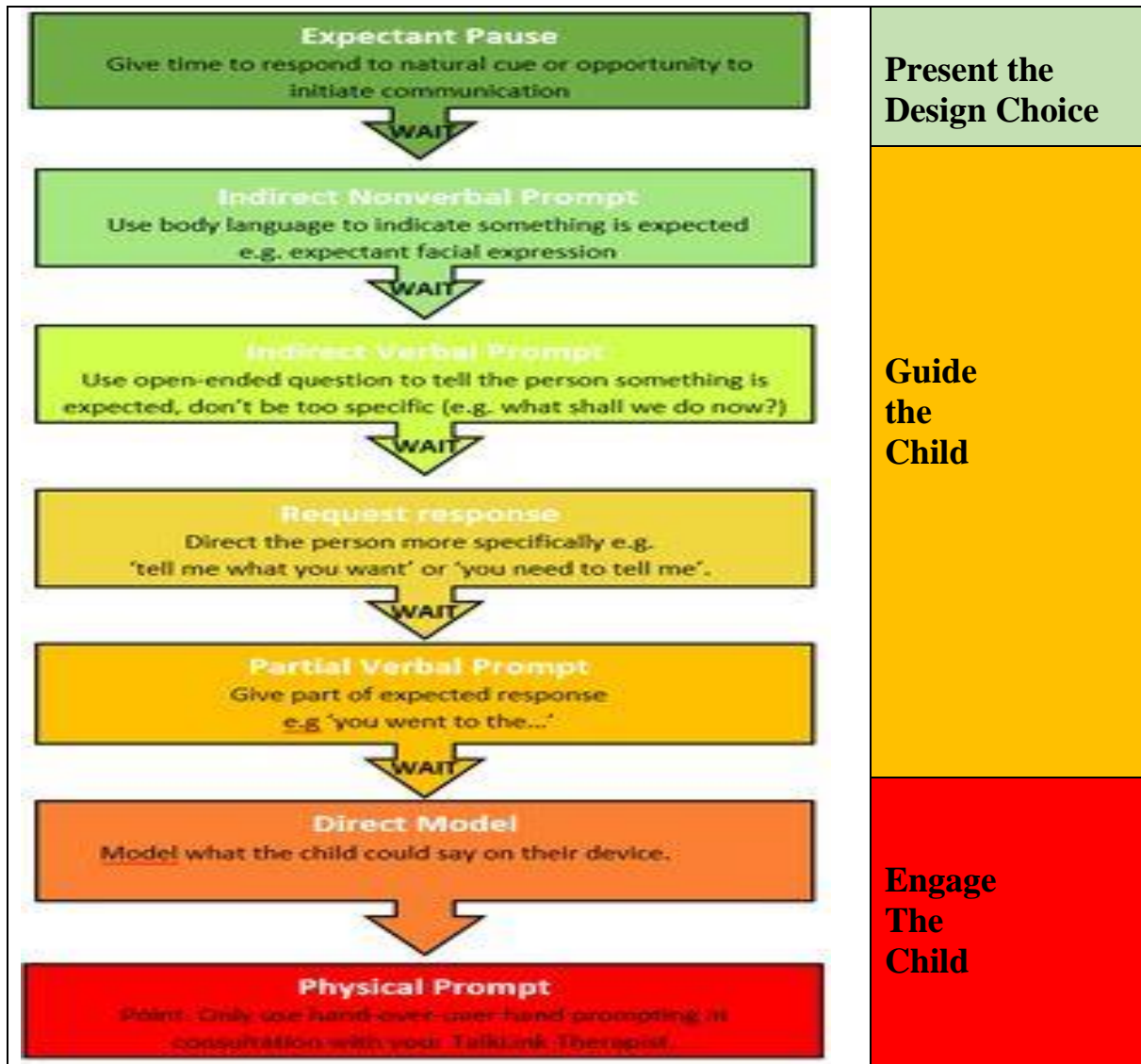
Data Analysis: Example of Coding used for Adult Prompting Behaviours
Adult Prompting Behaviour: CODING TABLES

Category	Sub-category
Adult Support	Prompting

Table 1: Identification and initial coding

No	Initial Code	Description	Examples	Source
1	PR –MOT1	Prompting that results in motivating target	'..you've done very well, can you try again?'	TS-CSIIIWORKSHOP 62.2
2	PR-MOT2	Prompting that encourages motivation	'…I think we can do great work today…'	TS-CSIIIWORKSHOP 62.1
3	PR-OR	Prompting for orienting a child	'….can you look here { } please…'	TS-CSVIIIWORKSHOP 62.2
5	PR-OR	Prompting to orient child to a person/ the	'….look here can you, look to me, yes, me….'	TS-CXIIIWORKSHOP 62.2
6	PR-OR-OB	Prompting for object orientation	'…can you see that…', '… look at this….' ' …watch the screen…'	TSCSXiVWORKSHOP 63.1
7	PR-PHY	Physical prompting	'…[SLT 1 – places hand on Child x arm]..'	RFN – CSIII WORKSHOP 63.1
8	PR-MOD	Prompting by modelling	'..look the way I do..'	TS CIX_WORKSHOP 63.2

9	PR-CON	Prompting for concentration	'…keep going you are doing very well….'	TS-CSXIVWORKSHOP 63.2

Table 2: initial Categorization & Frequency of Occurrence

Case Studies		I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII	XIV
No	Initial Code														
1	PR –MOT1														
2	PR-MOT2														
3	PR-OR														
5	PR-OR														
6	PR-OR-OB														
7	PR-PHY														
8	PR-MOD														
9	PR-CON														

Green = >40 Yellow = 10 – 39 and Green =<9

Table 4: Microcoding (example)

PR-MOT1	Object			Person		Event			Location	
	Real	Virtual	Transient	Present	Absent	Current	Past	Future	In Centre	Elsewhere

		Computer	Not present	Regular	Once off			Here	Elsewhere	Reported	Known	Class	Therapy	Where

Table 5: Final Coding & Rationalisation (example)

No	Initial Code	ACTION	REASON	NEW CODE
1	PR –MOT1	Combine	Underlying rationale for action is the same	PR-M
2	PR-MOT2	Combine	Underlying rationale for action is the same	
3	PR-OR	Combine	Too much similarity	PR-O
5	PR-OR	Combine	Too much similarity	PR-O
6	PR-OR-OB	Combine	Too infrequent	PR-O
7	PR-OR-Task	Combine	Not clear	PR-O
8	PR-OR-Event	Remove	Too much variations in examples	REIN
9	PR-REIN	Combine		
10	PR-MOD	Consider Keeping	Seek new examples	NO DECISION
11	PR-CON	Remove	Confusing in multiples	
12	PR-PHYS	Remove	Too infrequent	
13	PR-PHYS-OB	Remove	Too many 'one-off' examples	
14	PR-ENCOUR	Combine		REIN

Table 6: Final Coded Examples: Isolated Source

Prompt	Example [Source: Design Workshop 1 - Video Transcript]		Emerging Proposition (to be refined)

241

PR-M	". [Child 1] now it's your chance to pick, do you want to pick your favourite pictures?",	[SLT 1]	Adults provide motivation to confer agency?
	"[Child 2]do you want to do this? Let's do it….."	[SLT 1]	
	… "remember the winner will be the person who picks the best",		
	". how many will you do? Will we do them all?"	[TA 3]	
PR-O	"…okay, can we look here now please",	[DESIGNER 1]	Task orientation by adults facilitates impact through increase content generation?
	"……let's have a look at the iPad, can we?"		
	"….the picture is here (points to the screen), can we start with this"	[SLT 1]	
PR-E	"…… [Child 3] ……. can we listen to…."	[TA 3]	Attention engagement by adults facilitates impact through increase content generation?
	"come on, we are not going to play over there until we finish our work here"	[SLT 1]	
	"…we are ready to start, are you ready to start"		
	"…. will be begin now, [Researcher] wants us to look back at the screen now"	[TA 2]	
		[SLT 1]	
PR-R	"…. okay [Child 3] let's get back to what we were doing"	[SLT]	Attention restoration is required by adults to facilitate impact through increase content generation
	"…please [Child 6] over here (points to screen)"	[SLT 1]	
REIN	"…. well done you, you picked that one",	[DESIGNER 1]	Reinforcement supports the conferring of agency?
	"that's very good, well done to you",	[SLT 1]	
	"great job, you're doing great"	[TA 3]	
	"great choice, that's my favourite too",	[DESIGNER 1]	
	"I think that's the best one",	[TA 1]	

.
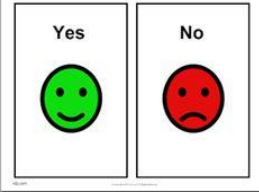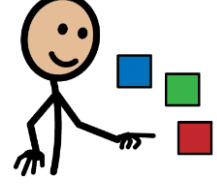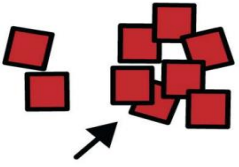
Arabic and Language neutral symbols set for decision making cards

Arabic Symbols

International Symbols

Switch Accessible Camera: Description and Instructions

Adapted Digital Camera & Tripod (Model 5155)

The Adapted Digital Camera and Tripod, model 5155, is a switch adapted camera designed for use by individuals with upper extremity or severe physical disabilities or spinal cord injury. This kid-friendly camera is mounted on a power-driven platform that can tilt up and down and pan left or right to frame a picture before shooting. The motorized platform pedestal has three adjustable feet to level the camera. The panning and tilting function is controlled by the 5-inch orange disc on the black controller center. Use the buttons on the control panel to turn the camera on and to take a picture. This camera also takes movies and downloads easily to a personal computer. This 2.0 Mega Pixel camera has 256 megabytes of memory, an SD memory card slot for memory expansion, and a photo editing program on CD-ROM. The power-driven platform can be mounted on any size tripod (sold separately) by simply screwing the base on the tripod just like any other camera. POWER: Uses 12 AA batteries. OPTIONS: Tripod. DIMENSIONS (HxWxD): The platform is 10.5 x 10 x 10 inches; the controller is 1.5 x 6 x 11.5 inches. WEIGHT: 4.25 pounds. COLOR: Camera colors will vary.

DEVICE CATEGORIES

Made By:

Enabling Devices
Enabling Devices Organization Type:
Distributor
Address:
50 Broadway
10532 Hawthorne , NY United States
Email address: sales@enablingdevices.com
Phone: 800-832-8697
Fax: 914-747-3509
New York US
Phone (U.S. and Canada):
914-747-3070
Web Address:
http://www.enablingdevices.com
Tags:
Controls, Vocational Management, Therapeutic Aids, Blind & Low Vision, Recreation, Personal Care, Computers, Wheeled Mobility

Workshop Environment Set Up and sample visual schedules
Workshop Checklist (Set-Up)

Physical Organisation Checklist Please Complete Before Workshops	
Where will they be seated?	Describe:
Minimising distraction	Describe:
Break-out area	Describe:
Relaxation/Withdrawal area	Describe:
Area for work	Describe:
Area for display	Describe:
Area for collective discussion/presentation	Describe:

Workshop Checklist (Preparation):

Workshop Checklist: Complete Before Commencing Activities

Is there space provided for individual and group work?
Are work areas located in least distractable settings?

Are work areas marked so that a student can find his own way?

Are there consistent work areas for those students who need them?

Does the teacher have easy visual access to all work areas?

Are there places for students to put finished contributions?

Are work materials in a centralized area and close to work areas?

Are all materials easily accessible and clearly marked?

Are break-out/relaxation areas as large as possible? Are they away from exits?

☐

Are the shelves in the play or leisure area cluttered?

☐

Have all Visual Schedule been put in place?

☐

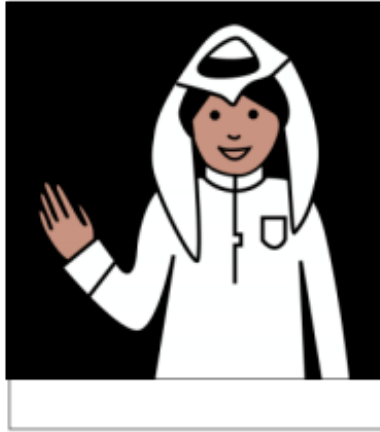Are all of the children ready?

☐

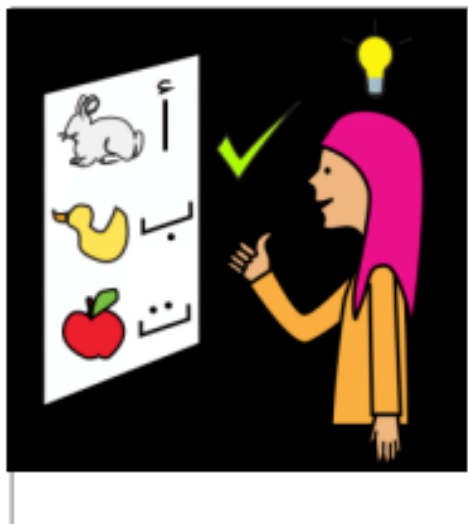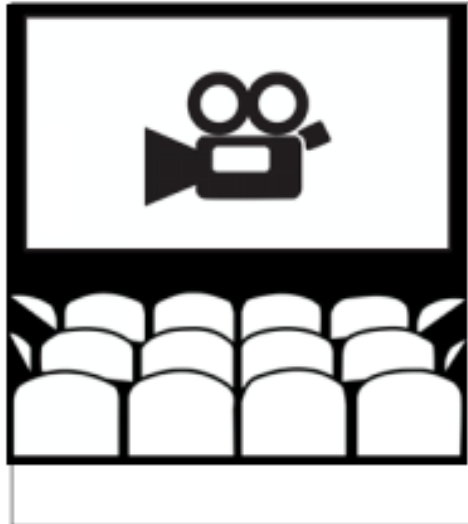Have the activities been explained to the children?

☐

Is all equipment available (including chargers) and fully charged?

☐

Visual Schedule Example 1

Visual Schedule Example 2

Welcome

Break

Group Time

Finish

Computer Time

Accessibility: A fundamental issue regarding accessibility is that everyone should have access to the services provided by ICT, (e.g. computer programs, Email and the World Wide Web), regardless of any visual, auditory, or other physical impairment they might have.

Adaptive living skills: Behaviours necessary for people to live independently and to function safely and appropriately in daily life, such as grooming, dressing, ability to work, social skills etc.

Adjustment: A measure or action taken to assist a student with a disability to participate in education and training on the same basis as other students.

ADOS: Autism Diagnostic Observation Schedule.

Alternative and augmentative communication: Use of sign language, picture communication symbols or speech generating devices to replace or augment the speech of a person with autism.

Application: A computer program or a suite of computer programs that performs a particular function for the user, such as a word-processor, e.g. Microsoft Word, or a range of functions, such as Microsoft Windows or Microsoft Office. Commonly abbreviated to app, especially in the context of Web 2.0.

Applied Behavioural Analysis (ABA): An intervention model based on Skinner's theory of operant conditioning, which reinforces wanted Behaviours, and reduces unwanted Behaviours.

Artifacts: A diverse class of human-created systems, applications, tools, and conventions, including language and mathematics, that mediate human activity. Artifacts are the products of prior human activity; they both enable and constrain current human activity, and their use helps to orient the design of future artifacts. An information artifact (as used in the cognitive-dimensions framework) is an artifact designed to store, create, present, or manipulate

information, whether non-interactive (e.g., a book or a map) or interactive (e.g., a spreadsheet or a heating controller).

Asperger's disorder/syndrome: A form of ASD, characterized by normal IQ but impairments in social interaction and communication.

Assistive Technology: This term describes computer software or devices used by people with special needs to enable them to access the services provided by ICT, e.g. computer programs, Email and the World Wide Web. Technologies under this heading include Text To Speech (TTS) screen readers for the unsighted or partially sighted, alternative keyboards and mice for people who have problems in handeye coordination, head-pointing devices, speech recognition software, and screen magnification software.

Autism: See Autism spectrum disorder.

Autism Spectrum Disorder (ASD): A neurological disorder characterized by social/communication deficits, fixated interests and repetitive behaviours.

Avatar: A graphical representation of a real person, such as used in a MUVE or MMORPG, a kind of "virtual world". Participants in a MUVE or MMORPG choose a name and a visual representation of the character that they wish to adopt as an inhabitant of the MUVE or player in the MMORPG.

Behavior Modification: The use of empirically demonstrated behavior change techniques aimed to improve behaviors.

Behavioral Therapy: The systematic application of behavioral theory, including the use of conditioning and reinforcements, in the treatment of a disorder.

CAI: Abbreviation for Computer Assisted Instruction.

Co-Design: Refers to the act of creating with stakeholders (groups or individuals) specifically within the development process to ensure the results meet their needs and are usable.

CMC: Abbreviation for Computer Mediated Communication (CMC).

CMS: Abbreviation for Content Management System, a software package that makes it possible for non-technical users to publish content (text, images, etc) on a website. Also stands for Course Management System, a type of Virtual Learning Environment (VLE).

Childhood disintegrative disorder: An extremely rare pervasive developmental disorder in which a child appears to develop normally until the age of two and then regresses.

Cognitive: Pertaining to cognition, the process of being aware, knowing, thinking, learning and understanding

Cognitive Behaviour therapy: A type of psychotherapeutic treatment that helps patients understand the thoughts and feelings that influence Behaviours. CBT is commonly used to treat depression and anxiety.

Design: Encompasses activities and actions directed at producing new artefacts. Design work is collective and multidisciplinary. It often includes professional designers, technologists, and future users of the artefacts.

Design rationale: Arguments for why (or why not) a feature or set of features should be incorporated into a design.

Developmental Delay: A slower rate of development in comparison to the majority of children of the same age.

Developmental Disability (DD): A condition that prevents physical or cognitive development.

Developmental disorder: A disorder that interrupts normal development in childhood. A developmental disorder may affect a single area of development (specific developmental disorder) or several (pervasive developmental disorder).

Developmental Milestone: The acquisition of a skill that is associated with a certain age, e.g. sitting up; saying first words.

Diagnostic and Statistical Manual of Mental Disorders: American Psychiatric Association's official manual used by most professionals for diagnosis of ASD. In 2013 the fifth edition (DSM-5) was published.

Discrete Trial Training (DTT): An ABA method which requires the therapists to break down skills into small tasks that are achievable and are taught in a very structured manner.

Early Intensive Behavioural Intervention: An individualized, intensive intervention program which involves the systematic use of ABA techniques.

Echolalia: Repeating words or phrases, often over and over, without necessarily understanding their meaning.

Epilepsy: A brain disorder involving recurrent seizures; sudden changes in Behaviour due to excessive electrical activity in the brain.

Executive function: The cognitive process that regulates an individual's ability to organize thoughts and activities, prioritize tasks, manage time efficiently and make decisions.

Expressive communication: Sending information or messages to other people. This could involve use of speech or augmentative communication.

Graphic elements: An element of a user interface that displays information or can be manipulated by the user to pursue a task.

High functioning autism (HFA): Autism in individuals with normal/ near-normal IQ.

Human-Computer Interaction (HCI): The study of interaction between people (users) and hardware, software, websites and mobile devices. It involves computer science, behavioral sciences, design and other fields of study.

Hypersensitivity: Excessive, often painful reaction to everyday auditory, visual, or tactile stimuli such as bright lights or loud noises.

Hypertonia: Increased tension or stiffness in the muscles.

Hyposensitivity: A marked absence of reaction to everyday stimuli.

Hypotonia: Decreased tension or floppiness in the muscles.

Inclusion: The concept that students with disabilities should be integrated with their non-disabled peers; also referred to as mainstreaming.

ICD 10: International Statistical Classification of Diseases and Related Health Problems.

Individual education plan (IEP): A document that delineates special education services for special needs student

Intellectual disability: An impaired ability to learn, as measured by IQ score (<70) and associated difficulties in adaptive functioning. It is a condition which presents before the age of eighteen.

Intelligence quotient (IQ): The ratio of tested mental age to chronological age, usually expressed as a quotient multiplied by 100.

IT: Abbreviation for Information Technology. Essentially, technology relating to information processing, i.e. computer technology, but see also ICT, C&IT, both of which describe the converging of information technology and communications technology. The term IT is rapidly being replaced by ICT in order to reflect the important role that information technology plays in communications by email, the Web, satellites and mobile phones.

Joint attention: Ability to follow someone else's gaze and share the experience of looking at an object or activity.

Low-Fidelity Prototype: Low cost, illustrated design or concept usually sketched on paper or created as flat images.

Low-functioning autism (LFA): Autism associated with an intellectual disability.

Mainstreaming: The concept that students with special needs should, when appropriate, be integrated with their non-disabled peers to the maximum extent possible.

Neurological: Having to do with the nerves or the nervous system.

Neurology: The medical science that deals with the nervous system and disorders affecting it.

Neurotypical: commonly abbreviated as NT and meaning having a neurocognitive functioning that is considered typical. The term NT is often used to describe people who are not autistic also referred to as "allist."

Obsessive compulsive disorder: Disorder where a person has recurrent unwanted ideas (obsessions) and an urge (compulsion) to do something to relieve the obsession.

Occupational therapy (OT): Therapy which focuses on improving development of fine and gross motor skills, sensory integration and daily living skills.

Participatory design (PD): A design movement primarily associated with Scandinavia, in which future users of the artifacts being designed participate in the original design work.

PDD-NOS: See pervasive developmental disorder — not otherwise specified.

Pervasive developmental disorder — not otherwise specified: An ASD where a child presents with impairments in social communication and Behaviour, but symptoms are not severe enough, or of sufficient number, to qualify for a diagnosis of autistic/Asperger's disorder. It will cease to exist as a diagnosis under DSM-5.

Phenotype: The appearance of an individual, which results from the interaction of the person's genetic makeup and his or her environment.

Picture Exchange Communication System (PECS): A visual augmentative communication system.

Pivotal Response Training (PRT): A contemporary ABA intervention.

Pragmatics: Use of language in the social contexts.

Receptive Language: The comprehension of spoken and written communication and gestures.

Rett's disorder: A rare genetic disorder, usually only found in females, in which a child appears to develop normally for a period and then regresses. Removed as a PDD from the DSM-5.

SCERTS: Social Communication Emotional Regulation Transactional Supports Model.

Self-stimulatory Behaviour: Commonly referred to as a 'stim'. Any kind of repetitive or stereotypic Behaviour (for example, staring at lights, flapping hands, rocking etc), which is believed to provide some form or sensory stimulation.

Sensory integration therapy: Therapy which aims to improve the way the brain processes and organizes the senses.

Social communication disorder: New language disorder in the Diagnostic and Statistical Manual of Mental Disorders, 5th Ed. (DSM-5).

Special Education (SPED): Specialized and personalized instruction of a disabled child, designed in response to educational disabilities determined by an evaluation

Stereotypy: Persistent repetition of body movements, ideas, or words.

Stimming: Engaging in self-stimulatory Behaviour.

Storyboard: A visual representation of how a user will interact with an application or interface.

Syndrome: A group of symptoms or traits that indicate a particular condition or disorder.

TEACCH: Treatment and Education of Autistic and Related Communication - Handicapped Children. An early intervention model which emphasizes structured teaching.

Theory of mind: Ability to attribute mental states to oneself and others and to understand what another person thinks, feels, desires, intends or believes.

Tic: A repetitive movement that is difficult, if not impossible, to control.

User Interface (UI), or Graphical User Interface (GUI): What the user sees.

User-Centered Design (UCD): An approach to designing a product or service (e.g. user interface design), in which the end user is placed in the center of the process.

Virtual Learning Environment (VLE): A VLE is a Web-based package designed to help teachers create online courses, together with facilities for teacher-learner communication and peer-to-peer communication. VLEs can be used to deliver learning materials within an institution or within a local education authority. They may even address a wider constituency and can even be used on a worldwide basis.

Virtual Reality: The simulation of an environment by presentation of 3D moving images and associated sounds, giving the user the impression of being able to move around with the simulated environment. Users wear helmets and visors that convey the images and sound and gloves that give them the experience of touching objects.

Virtual World: A type of online three-dimensional imaginary world or game in which participants and players adopt amazing characters or avatars and explore the world, engaging in chat or playing complex games.

Visual supports: The presentation of information in a visually structured manner to make it easier to understand, for example, a daily schedule may be shown by photographs or cartoons.

Weak Central Coherence: A theory suggesting that a weak drive for coherence may be relevant to understanding aspects of autism. The theory is based on an understanding of how information processing typically occurs in most people.

Wechsler Intelligence Scale for Children: An IQ test.