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The Use of Proxies in Designing for and with Autistic Children: Supporting Friendship as a Case Study

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Abstract

Participatory Design (PD) is an approach for designing new technologies which involves end users in the design process. It is generally accepted that involving users in the design process gives them a sense of ownership over the final product which enhances its usability and acceptance by the target population. Employing a PD approach can introduce multiple challenges especially when working with autistic children. Many approaches for involving autistic children and children with special needs were developed to address these challenges. However, these frameworks introduce their own limitations as well. There is an ethical dilemma to consider in the involvement of autistic children in the design process. Although we established the ethical benefit of involving children, we did not address the ethical issues that will result from involving them in these research projects. Among other issues, the nature of design workshops we as a community currently run require working with unfamiliar researchers and communicating with them while social and communication differences are one of the main diagnostic criteria for autism. When designing for autistic children and other vulnerable populations an alternative (or most often an additional) approach is designing with proxies. Proxies for the child can be one of several groups of other stakeholders, such as: teachers, parents and siblings. Each of these groups may inform the design process, from their particular perspective, and as proxies for the target group of autistic children. Decisions need to be made about what stages in the design process are suited to their participation, and the role they play in each case. For this reason, we explore the role of teachers, parents, autistic adults and neurotypical children as proxies in the design process.

To explore the roles of proxies we chose friendship between autistic and neurotypical children as the context we are designing for. We are interested in understanding the nature of children's friendships and the potential for technology to support them. Although children themselves are the ones who experience friendship and challenges around its development and peer interaction, they might find it difficult to articulate the challenges they face. Furthermore, it is unrealistic to expect children to identify strategies to help them overcome the challenges with friendship development that they are facing as it assumes children have the social skills to come up with these strategies in the first place. Hence, it is necessary in this context to consider proxies who can identify challenges and suggest ways to overcome them.

Lay Summary

Participatory Design (PD) is a way of designing technology with the help of the users who this technology is designed for. For autistic children, involving them in the design process is beneficial to understand their needs and how to support them. However, their involvement can be challenging. This research aims to find ways to involve children in the design process by exploring different methods. First, it explores the use of proxies, these are people close to the children who may be able to provide input on their behalf, and evaluates their involvement and how it may facilitate the involvement of autistic children themselves. In addition, it evaluates conducting design activities with autistic children online to overcome some of the challenges of autistic children's participation in the design process. In order to evaluate these two solutions, friendship between autistic and non-autistic children is used as the context to design for. Recommendations on how to design a technology to support friendship between autistic and non-autistic children is also provided as a result of using this topic as the context.

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Declaration

I declare that this thesis was composed by myself, that the work contained herein is my own except where explicitly stated otherwise in the text, and that this work has not been submitted for any other degree or professional qualification except as specified.

(Aljawharah Alabdullatif)

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1 INTRODUCTION

Participatory Design (PD) is a method for creating new technologies by engaging users in the design process in different stages of development. The benefits of adopting such an approach are widely acknowledged. These include providing users with a sense of ownership, improving the product's usability and acceptance by its target users. (van Rijn & Stappers, 2008). However, employing a PD approach may introduce a number of difficulties, particularly when working with autistic children. Some of the known autism characteristics may contradict the traditional expectations of PD approach. For example, known differences of autism may cause a lack of consideration for, or disinterest in, the ideas of others during design sessions. In addition, participating in reciprocal interactions and turn taking may be a source of difficulty when working within a design team (Frauenberger, Good, Alcorn, & Pain, 2013). Furthermore, the lack of structure and unpredictability inherent in the design process can cause anxiety for autistic children. Moreover, rigidity of thought may present difficulties in understanding that there is no 'right' answer within the design process. Aspects of the design may be ignored if they are outside an autistic child's area of interest. Furthermore, working in unfamiliar settings, with unfamiliar researchers that they have no previous relationship with, can be especially challenging for autistic children.

To overcome these challenges, many approaches for involving autistic children and children with special needs have been developed, such as the IDEAS Framework (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012), Diversity for Design Framework (D4D) (Benton, Vasalou, Khaled, Johnson, & Gooch, 2014) and Child in the Centre Framework (CiC). These frameworks introduce their own limitations. D4D for example requires the involvement of a number of researchers from multiple disciplines equal to the number of child participants, which is often not feasible. Moreover, it has been exclusively tested with autistic children without intellectual difficulties and the results do not necessarily apply when autistic children with intellectual difficulties are involved: these represent a significant proportion of autistic children.

The call within the research community to involve more autistic children in the design is ethically rooted and comes from the idea that the people who are most affected by the technology should have a say in what and how it is designed. However, in order to advance in this direction, the research community needs to address the issues around participatory design with autistic children. The inclusion of autistic children in the design process presents an ethical dilemma. Although the ethical advantages of including children have been established, the ethical issues around it are yet to be discussed and addressed. As Alcorn (2016) states, "children with autism are a scarce resource" - many research projects invite children with autism to participate which takes time away from other learning activities in school.

The nature of design workshops currently run by the research community require autistic children to work with unfamiliar researchers and to communicate with them, while it is known that social and communication differences are one of the main diagnostic criteria for autism. Although it is ultimately for the benefit of the autistic community, the children involved may not get the chance to directly benefit from the results of the research project they participate in, as research projects will take years to become mainstream and participating

children might grow out of the age group the research project is targeting. To summarise, we expect children to miss school to participate in design workshops which may or may not induce anxiety for them so that another generation of autistic children can benefit from the results of this research.

Furthermore, we have established multiple times the benefit of involving the children in the research process from an ethical view but we have not yet demonstrated the value of their involvement from a practical point of view. Answering questions such as "Would an autistic child prefer to use a technology designed by other autistic children rather than one designed by practitioners or parents of autistic children?" would help improve the way we currently design technologies. The use of participatory design is rarely directly related to evaluation of the popularity or efficacy of the finished product (DeSmet et al., 2016). Understanding the practical impact of PD in general, and with autistic children specifically, is needed in order to involve them in the best possible way.

In designing for autistic children and other vulnerable populations an alternative (or most often an additional) approach is designing with proxies. Proxies for the child in the design process can be one of several groups of other stakeholders, such as: teachers, speech and language therapists and other practitioners; parents and siblings; experts in various related disciplines (e.g. autism, educational technology design, Human-Computer Interaction, etc.); adults and older autistic children who can reflect on their own experience and may be able to take the perspective of a younger autistic child, and neurotypical children. Including slightly older children allows researchers to take advantage of the ability of this age group to articulate their ideas and provide justifications and foundation of where they come from and work with others to engage more fully with design activities (Druin, 1999). From their unique point of view, and acting as proxies for autistic children, each of these groups may contribute to the design process. It must be decided at which stages of the design process each are appropriate

for their participation, as well as what role they should play in each context. For this reason, we explore the role of teachers, parents, autistic adults, and neurotypical children as proxies in the design process.

In addition, to increase autistic children's participation and reachability, it is important to overcome the problem of their participation being 'a scarce resource'. Using distributed participatory design (DPD) approaches expands the reach to children who are not physically co-located with the research team. However, research on conducting DPD with children is very limited with no published work on conducting DPD with autistic children specifically.

To explore the roles of proxies the topic of friendship between autistic and neurotypical children was chosen as the design context. The focus was on improving understanding of the nature of children's friendships and the potential for technology to support them. Although the friendship experience and its challenges are relevant to the children themselves, it might be difficult for them to articulate the issues they encounter. Furthermore, expecting children to identify solutions to help them overcome their challenges with friendship development is unrealistic as it assumes children have the social capacity to produce these solutions. Their being able to identify solutions contradicts the fact that they are facing these issues in the first place. Hence, it is suitable in this particular context to consider proxies who can identify observed challenges and suggest solutions to overcome them.

Teachers as proxies have many advantages over others who may play this role. Firstly, teachers are normally trained to deal with their students' challenges and are taught strategies to support their needs. Their first-hand experience applying these strategies in a real, uncontrolled environment is very valuable in understanding what would truly be applicable in a real context and what challenges may arise. Another advantage is that, unlike parents, teachers have access to a larger number of autistic children with varying needs which makes them a good source for a general understanding of what strategies work for supporting friendship and how to adapt

these strategies for each individual child's needs. In addition, teachers in an autism-specific school work directly with autistic children and deal with a smaller number of children in each class, which allows them to have deeper understanding of their pupils' needs and ways to support them. In addition, children spend most of their day in school where they interact with their peers which means that most children's friendships develop at school (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011). Hence, teachers can observe the development of such relationships and the challenges their students face, since they are at the heart of where such relationships are usually made. This makes teachers an important proxy to consider for problems relating to peer relationships.

There are two main characteristics of parents as proxies. Firstly, unlike teachers and practitioners, they have a close and individual relationship with their child. They can also observe their child in different contexts. This means that their input, although specific to their individual child, can take account of their behaviour in multiple contexts. Secondly, compared to adults with autism, their contributions about their child's experience are current and deal with present day situations rather than reflecting on past experiences. Hence, involving parents as proxies would be beneficial when the context of the problem is current and novel to present times. Findings from our interviews with parents further illustrate their important role as proxies in this specific context since parents of autistic children indicated that they are more involved in their children's friendships compared to parents of neurotypical children. This gives them the ability to directly observe the dynamic between their child and their friend, what type of activities they engage in, which aspects are difficult for their child and the characteristics of peers they get along with. In addition, parents are able to identify personal traits that make it difficult for their child to make, interact or maintain friendship. Furthermore, parents might have tried different strategies to help their children overcome challenges they have which the child might be oblivious to.

Autistic adults on the other hand provide a unique prospective given that they have been the target population at some point in their life. They can reflect on the challenges they faced and are perhaps still facing and identify what strategies they tried and what worked for them. Being an adult allows them to better articulate their ideas as their experiences in life have allowed them to develop the capacity to do so better than their younger selves. However, they do not necessarily have the same experience and challenges autistic children currently face in the present time.

Like autistic children, neurotypical children experience friendship and may or may not face challenges they can identify. Friendship is not an experience exclusive to autistic children hence neurotypical input may be valuable as well. In addition to informing the design in terms of identifying challenges and possible solutions, neurotypical children can inform the aesthetic of the design and provide input on what would appeal to children and what are their expectations from their interaction with the design, which is a different perspective from what an adult can provide.

COVID-19 lockdown occurred while this research was ongoing which initially led to resorting to using asynchronous remote communities (ARC) which is a DPD approach to continue conducting design workshops with children online. The distributed nature of this approach opened up the possibility of recruiting participants who are not physically co-located therefore increasing the potential participants' pool. COVID-19 lockdown created novel circumstances offering the opportunity to explore friendship online like never before. Because of these circumstances, most children moved their social life online. Since we wanted to design a technology to support friendship for children, now we can observe children's social interactions online and ask them to reflect on them and suggest better ways to design technology to serve this purpose. Nevertheless, since many aspects of children's lives moved online, it may have resulted in online fatigue which led fewer participants to voluntarily sign-

up for research studies conducted online. Furthermore, previous efforts to recruit participants and to build on established relationships and agreements with schools and autistic children's groups prior to COVID-19 lockdown were lost as everyone was trying to adapt to this sudden shift. In addition, many research activities needed to be revisited, creating redundancy and consuming the time previously allocated to conducting this research. For example, conducting studies online required reviewing ethical considerations and reapplying for ethical approval. In addition to managing the research activities, researchers had to manage issues related to their own personal lives such as the absence of childcare facilities, food shortages and mental health problems caused by COVID-19 lockdown. Although COVID-19 circumstances may have created some opportunities for this research, it also introduced many challenges which are further discussed in later chapters of the thesis.

Finally, while studying how to improve PD for autistic children using the friendship context, the potential for a technology to support friendship was established. This represents an initial step towards building such technology.

1.1 Research Aim and Questions

The aim of this thesis is to enhance autistic children's involvement within the design process by exploring the role of their proxies and how they can improve their participation. In addition, the research described evaluated the use of different participatory design approaches including distributed participatory methods in the form of asynchronous remote communities. Studies included in this thesis attempt to address the following research questions:

RQ1: What role can proxies play in the co-creation process of technologies to support friendship?

RQ1.1: How can teachers inform the design process in the context of supporting friendship?

RQ1.2: How can parents inform the design process in the context of supporting friendship?

RQ1.3: How can autistic adults inform the design process in the context of supporting friendship?

RQ1.4: How can autistic and neurotypical children inform the design process in the context of supporting friendship?

RQ2: How can autistic and non-autistic children be involved in designing technologies for supporting friendship?

RQ2.1: How might design workshops be used, with neurotypical children, to inform designing for supporting friendship?

RQ2.2: How can remote methods be used to best provide accessibility for autistic and neurotypical children

1.2 Research Contributions

This thesis makes the following three contributions:

1. Providing an in-depth exploration of the supporting role proxies can take in the design process for autistic children.
2. Evaluating the use of different modes of design workshops with autistic and non-autistic children.
3. Exploring the potential of using a technical solution for supporting friendship between autistic and neurotypical children.

1.3 Thesis Outline

This thesis makes contributions in two main areas. Firstly, it contributes to the body of knowledge on adopting a participatory design approach with autistic children by exploring the

roles of proxies and evaluating different formats for design workshops. Secondly, it contributes to the context of friendship establishing evidence of the potential of a technical solution to support friendship between autistic children and their neurotypical peers. Hence, chapters within this thesis address previous research in both these areas. Firstly, Chapter 2 begins by reviewing literature related to participatory design, identifying challenges within current practices and introducing participatory design with proxies as a possible solution. It also introduces distributed participatory design, discussing the limited research available on its use with children. In Chapter 3, literature on friendship for autistic children and efforts on supporting it is reviewed. It identifies a key limitation of the current approach to supporting friendship which is not explicitly addressing friendship in both traditional and technology-based intervention but rather targeting social skills as a means to eventually support friendship. The following four chapters explore the role of each of the different proxies which are teachers, parents, neurotypical children and autistic adults through semi-structured interviews. Chapter 6 also involve interviews with autistic children where they are asked about their experience with friendship. Chapter 8 reports on three different sets of workshops conducted with autistic and non-autistic children. These include pilot workshops, physical design workshops and asynchronous online workshops. Finally, the results of this thesis are summarised in Chapter 9 in relation to the thesis research questions, identifying the main limitations of this research and highlighting its contributions. It also suggests possible directions for future work derived from the results of this thesis.

2 PARTICIPATORY DESIGN AND AUTISTIC CHILDREN

2.1 Introduction

This chapter reviews literature relevant to participatory design specifically with autistic children. It begins by briefly introducing Autism Spectrum Condition (ASC) and clearly specifying the language used to describe autism and autistic people throughout this thesis. Discussion of autism in this chapter is limited to general information about the condition and its prevalence while more in-depth discussion of autism and friendship specifically and theories around the topic are provided in Chapter 3.

Participatory Design (PD) is then introduced as a design approach for involving users in the design process, with discussion of different methodologies developed to involve children across the autism spectrum specifically. Participatory Design with Proxies (PDwP) and Distributed Participatory Design (PDP), which are variations of PD each addressing different challenges to this approach, are also introduced.

2.2 Autism Spectrum Condition

Autism Spectrum Condition (ASC) is a neurological condition which affects the brain's functionality characterized by a difference in relating to people, things and events (American Psychiatric Association, 2013). It is identified by differences in communication and social skills and by repetitive body movement or behaviours (American Psychiatric Association, 2013). Social and communication differences are characterised by social-emotional reciprocity differences such as failure to engage in 'typical' turn-taking during conversation, differences in non-verbal communicative behaviour such as body language, and difficulties developing and maintaining relationships. Restricted and repetitive behaviours are identified by the presence of at least two of typical ASC behavioural indicators. These include intense fixation on specific objects/areas of interest, repetitive movement or speech and inflexibility to routine.

It is described as a 'spectrum condition' to indicate the variation in the severity of the condition and its effect on the experiences of individuals living with it (Murphy, 2017). Although understanding of ASC characteristics and required support have grown, causes of the condition are still unknown (Dinishak, 2019).

Nowadays, ASC prevalence is much more than it was previously believed. most recent data shows that 1 in every 100 children is diagnosed with autism globally (Zeidan et al., 2022) .It is estimated that 700,000 people in the UK are autistic (Brugha et al., 2012) and more than 50,000 of them live in Scotland alone (Murphy, 2017). Increased awareness, improved diagnostic tools or a true increase in the number of cases are all possible factors for the dramatic increase in the rate of ASC (Koegel, Koegel, Harrower, & Carter, 1999).

2.3 Terminology and Language Used

The language used to describe autism, autistic individuals, and autistic traits is constantly evolving as understanding of the condition evolves. For example, before 2013, Autistic Disorder, Asperger's syndrome and Pervasive Developmental Disorder, Not Otherwise

Specified (PDD-NOS) were three separate diagnoses in the DSM-IV (American Psychiatric Association, 1994). All subtypes were removed and included within the diagnosis of autism spectrum condition in DSM-5 (American Psychiatric Association, 2013). As a result, earlier research on autism may describe their target population as having an Asperger's diagnosis which no longer exists and would be known as having an autism spectrum condition according to the most recent DSM.

Some changes to the language are not necessarily due to change in the definition of autism and its characteristics but rather follow the preference of the autistic community themselves and how they prefer to be identified. For example, previously, it was viewed as more appropriate to use person first language (i.e. person with autism) when addressing individuals on the spectrum since it is an indication that they are a person first and are not defined by their diagnosis (Blaska, 1993; Foreman, 2005). However, recent views argue that this separation between the person and their diagnosis suggests a stigma around autism implying that an autistic individual would want to distance themselves from their diagnosis (Kim, 2014). Hence, the autism community is now calling for the use of identity first language i.e. autistic person (Autistica, 2022; Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2021). However, it is important to note that this is not the preference of all individuals on the spectrum. Recent research on the matter shows that autistic individuals have mixed opinions on which terminology they prefer (Kenny et al., 2015).

When choosing the right language to use, it is important to recognize both what the most recent research about autism yields in terms of what autism is and how the target community prefers to be addressed. In this thesis, due to its inclusive and participatory nature and to ensure accurate description of autism, when describing other research on autism, the terms used by the researchers relevant to what terms were acceptable during the time their research was conducted will be modified to reflect our current understanding of autism. Occasionally, a

footnote further explaining how this terminology changed relevant to our current understanding will be used when necessary. When describing autism and autistic participants in the studies conducted for this thesis the language guidance from Autistica, a UK charity funding research on autism, will be followed (Autistica, 2022).

2.4 Participatory Design

Participatory Design (PD) is an approach for designing new technologies which involves end users in the design process. This technique is especially valuable when the target user group come from different cultural or social backgrounds from the designers or when designing for users with specific skills/limitations (e.g. designing for children or for people who have additional needs) (Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, 2016). Involving users in the design process gives them a sense of ownership over the final product which enhances its usability and acceptance by the target population (van Rijn & Stappers, 2008). User involvement in the design process varies from taking the role of a co-designer who works with the design team throughout the project cycle to a tester who only gets involved to evaluate the design and give his/her feedback (Druin, 2002). Conducting a participatory design session requires careful design of activities that promote creativity and help users express their ideas (Frauenberger, Makhaeva, & Spiel, 2017). It is important to provide a clear structure of what is required and scaffold creativity tasks to avoid overwhelming the participants (Benton et al., 2012). Hence, planning the design activity is crucial to achieve the goal of adopting a participatory design approach.

Apart from the actual technology designed, using Participatory Design methods benefits the participants involved as it empowers them and helps them develop social and academic skills (e.g. problem solving) (Guha, Druin, & Fails, 2010).

Interface Design Experience for the Autistic Spectrum (IDEAS) is a method for supporting autistic children in a participatory design team (Benton et al., 2012). This method is designed

to tolerate communication and collaboration differences that might arise when working with this specific group by building on the TEACCH interventions approach (Mesibov, Shea, & Schopler, 2005). The process is organized into six sessions; each supports a specific characteristic designed by TEACCH. The first session is dedicated to team building where children agree on a team name, team rules and drawing each other pictures to develop social and emotional empathy. The second session supports the concept of meaning and generalization by introducing existing similar technology to aid their understanding of the design topic. The idea generation session requires the presence of an adult (e.g. a teacher) who knows the children and understands the design task to prompt the children when required. Subsequent sessions are dedicated to developing and evaluating prototypes and improving their design. Other TEACCH characteristics are supported throughout the sessions such as using a whiteboard to display session tasks and group rules to support visual learning.

Despite the promising results of using IDEAS to include autistic children in the design process, adopting such an approach requires the involvement of a number of researchers from multiple disciplines equal to the number of child participants, which is often not feasible. In addition, it is unknown whether similar positive outcomes will be achieved when the aim of the project does not appeal to the participating children. Moreover, it has been exclusively tested with autistic children with less severity of autism traits who require minimal support and results do not necessarily apply when autistic children who require more substantial support are involved¹.

The Diversity for Design (D4D) framework was proposed to extend the applicability of the IDEAS approach to include children who have ADHD, Dyslexia and other neurological

¹ Participants were described in this study as having a diagnosis of 'high functioning autism' which is no longer accepted as a diagnosis.

conditions. This was achieved by structuring the environment and providing support for each group based on their specific needs (Benton et al., 2014).

Child in the Center (CiC) is a framework to facilitate successful participatory design for children with special needs in multidisciplinary research projects (Kärnä, Nuutinen, Pihlainen-Bednarik, & Vellonen, 2010). More specifically it is intended to facilitate collaboration between computer science and special education research. It requires the participation of children, their parents and researchers from both computer science and special education. All participants are involved in every step of the design process and are treated as design partners which allows the early discovery of unsuitable design, avoiding expensive modifications. CiC is inclusive of all children who have special needs regardless of their condition. This diversity within participants requires flexibility and adaptation in the design activities. In the core of the CiC structure are the children, their interests and needs (see Figure 2.1). This framework illustrates the value of inclusion in the design process and its effect on the child and the technology designed. However, it does not suggest ways of developing activities to encourage children.

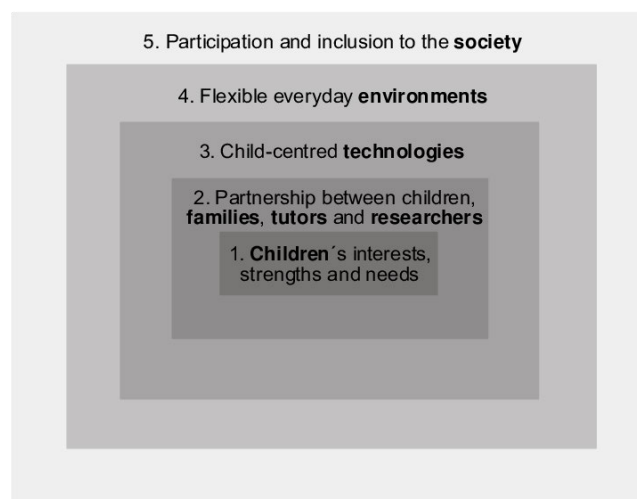


Figure 2.1: CiC Framework (Kärnä et al., 2010)

Frauenberger et al. (2017) built on previous methods of including autistic children in PD by proposing a visual tool which allows planning design sessions by combining different

methods and techniques such as building blocks. This allows the sessions to be customized to the individual needs of the participants, the design goal and designer expertise.

Although researchers generally agree on the benefits of involving users in the design process, there are some conflicts between the roles of the users within the process and degree to which they should be involved. Some literature uses the term ‘Participatory design’ to describe the approach of involving users in the design process but not necessarily as design partners (e.g. DeSmet et al., 2016) while others define PD as involving users as co-designers throughout the design process and do not consider Informant Design, where participants involvement is limited to commenting of low-fidelity prototypes, as a PD approach (Druin, 2002).

Druin (2002) discusses the different design roles a child can take in the design process. These are **user** of the technology while other designers observe, **tester** of early prototypes, **informant** who gives input on low-fidelity prototypes or a **design partner** who has equal responsibility similar to other adult designers (see Figure 2.2). While involving children as design partners offers the most powerful role providing children with the maximum opportunity to contribute to the design, it does not come without its costs as children can feel overwhelmed with responsibility (Frauenberger, Good, & Keay-Bright, 2011).

The Child as...

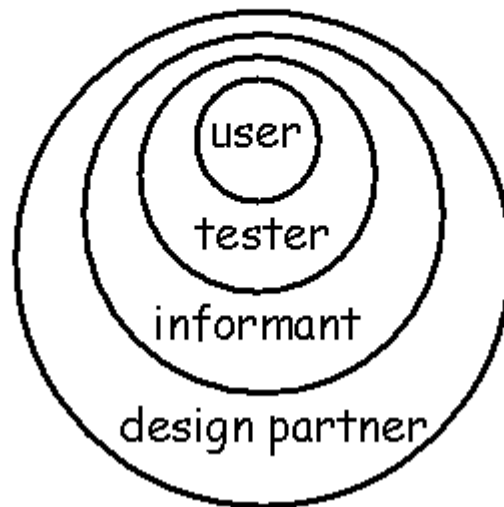


Figure 2.2: Children's Roles (Druin, 2002)

DeSmet et al. (2016) explored the role of PD on the effectiveness of serious games that were designed using this approach to promote a healthy lifestyle. They concluded that PD does not necessarily increase the effectiveness of the game designed, especially when user involvement was limited to the design aesthetic and appeal, as opposed to the game challenge itself. Furthermore, serious games designed with users as informants rather than co-designers were found to be more effective. DeSmet et al. (2016) argued that being part of the target population is not always enough to produce a design that is effective, perhaps subject-domain and design expertise are necessary to improve the effectiveness of the final design. In addition, these results may be due to poor structure of the design sessions themselves where goals are not clearly specified. When designing games with children specifically, they might add elements to the design that would improve the game experience but not necessarily serve the target learning outcome.

2.5 Participatory Design with Proxies

Participatory Design with Proxies (PDwP) is when the needs and requirements of the target user population are represented by people with a close relationship to them (Frauenberger,

Good, & Alcorn, 2012). It is often used when including the target users is a burden on them or when they have a communication difficulty. In this case, proxies are used to communicate the target users' needs. It is important here to distinguish between proxies and stakeholders as stakeholders are often defined as those who have an effect on, or are affected by, the design (Dix, Finlay, Abowd, & Beale, 2003). Although these two terms can be used interchangeably in some fields such as Psychology, there are some important differences to be considered when these two terms are used within HCI. Drawing from the two definitions stated previously, the role of a proxy is to communicate the potential target user's needs and experience, rather than their own. Whereas as stakeholders, the effect on themselves is considered for the design. For example, as a proxy, an individual may indicate that the target users have a preference for a specific colour: however, whether designers use this specific colour or not would not affect this individual. On the other hand, a stakeholder may inform the design by sharing their role in a process involving the target user. Then, designers can automate the stakeholder role hence eliminating their direct involvement in the process. In this case, the design would directly affect the stakeholder themselves. These two terms are not mutually exclusive as an individual can be both a stakeholder and a proxy. The distinction between the two is determined by whether they are providing input on behalf of themselves, or the target users.

Social and communication differences, and repetitive behaviours are all reported characteristics of ASC (American Psychiatric Association, 2013) which can create barriers to the inclusion of autistic children in the design process, since it would require collaborating with others and generating creative ideas (Benton et al., 2012). In addition, it involves working in unfamiliar settings with unfamiliar adults which can be specifically challenging for autistic children (Frauenberger et al., 2013). Fully involving autistic children in the design process require building relationships with them, preparing the environment and structuring the design activities to fit their needs (Benton et al., 2012). Nevertheless, even if every effort is put towards

including autistic children in the design process, specialist schools for autistic children receive a huge number of requests from researchers to conduct their studies in their schools with children. Although some of these studies can be beneficial for the children in the long-term, their constant participation in these studies disturbs their learning without offering significant benefits for the individual child in the short-term.

Researchers have included different proxies in the design process in order to understand the needs and requirements of their target audience. Proxies include parents (e.g. Dawe, 2007) teachers (e.g. De Leo & Leroy, 2008), neurotypical children (e.g. Ruland, Starren, & Vatne, 2008) and practitioners (e.g. Hamidi, Baljko, & Gómez, 2017). In the case of designing for neurodiverse children, adults with the target condition have been used as proxies as well (e.g. Brereton, Sitbon, Abdullah, Vanderberg, & Koplick, 2015; Gillespie-lynch, Riccio, & Sturm, 2017).

PDwP is often used in addition to PD as proxies can provide information on the impact of the design on the target user beyond the context of use (Dawe, 2007). However, input from proxies is vulnerable to its own biases and is not necessarily representative of the target users. This 'indirect input' feature is important to take into consideration when interpreting the results (Hamidi et al., 2017).

The use of PDwP is often criticised within the autism research community and viewed as inferior method to PD with autistic children themselves (Benton & Johnson, 2015). However, the involvement of proxies can enrich the data collected and overcome some of the issues PD with autistic children presents as mentioned above. Nevertheless, not enough research has been conducting on understanding how and when to involve each type of proxy and what kind of data to expect from them. These proxies may not only inform the design of the technology itself, but they can inform the design of the design workshops and tools to use when involving autistic children. It is important to understand what role proxies can play and how to ensure

that their involvement does not overshadow or replace the involvement of autistic children, but rather enhances it and makes it more powerful and fruitful.

2.6 Distributed Participatory Design

Distributed Participatory Design (DPD) is an approach where participatory design is conducted with individuals who are physically distributed (Danielsson, Naghsh, Gumm, & Warr, 2008). Traditionally, PD methods assume the physical availability of co-designers and all participants being co-located physically in the same space. As the trend of software development to be distributed is growing, efforts to explore applying PD methods in a distributed setting were necessary and many studies attempted to explore that space (e.g. Danielsson et al., 2008; Gumm, Janneck, & Finck, 2006).

Asynchronous Remote Communities (ARC) is a HCI group-based method which establishes an online focus group (MacLeod et al., 2017). Although it is not how its creators classified it, it can be considered a form of DPD. It is usually conducted within a private Facebook group and participants are asked to complete a number of activities and to post results to the group. Activities include diaries, scenarios, surveys and others which are completed by each participant asynchronously. The purpose of this setup is to expand the sample size of the research and allow the perspective of underserved populations. It is predominantly used when exploring topics relevant to health, for example miscarriage (e.g. Alqassim, Kresnye, Siek, & Wolters, 2019) and HIV (e.g. Maestre et al., 2018). The predominance within these topics may be due to them being specifically sensitive and more difficult to talk about in person. This method has not been yet utilised with children except for a few studies which explored teen's mental health (e.g. Jenness, Bhattacharya, Kientz, Munson, & Nagar, 2022).

KidsTeam is considered the first intergenerational cooperative inquiry design team involving both children and adult members cooperating together on designing various technologies ("KidsTeam: Children & Adults Working as Design Partners," n.d.). The team

meet twice a week at the University of Maryland's Human-Computer Interaction Lab (HCIL) to design technologies to support child development and play. Child participants within this group developed expertise in communicating their ideas, working with others including adults and using various prototyping techniques ("KidsTeam: Children & Adults Working as Design Partners," n.d.). Online KidsTeam (Walsh & Foss, 2015) is an online design environment developed to support DPD. The environment allows participants to share their ideas with others asynchronously by writing, recording their voice, drawings and utilising virtual craft supplies called 'e-Bag of Stuff'. Multiple recommendations for design were identified after the evaluations of the environment with members of the original KidsTeam. The tool needed to be customizable and flexible based on the design problem as different design problems may require different tools or setup. Although it was not used often, an audio recording feature was recommended to overcome the difficulty younger participants may have with typing. The environment should support multiple systems and devices such as laptops and tablets. Having a profile for each participant and a reward system where participants can view their achievements in their profile was recommended, similar to what other online systems usually have. Finally, a balance between allowing each designer to work on their own design separately to come up with a design that truly represents their idea and encouraging the team to collaborate on creating a design that would incorporate everyone's perspective was necessary. Walsh & Foss (2015) suggest that the environment should support forking as a way to allow participant to work on designs independently. However, choosing to fork would require a participant to pay a specific amount of points within the environment. This cost is suggested to encourage participants to evaluate whether the action is necessary.

Walsh & Foss's (2015) work with online KidsTeam remains the only published research on DPD with children prior to COVID-19 pandemic. However, the novel circumstances created by the COVID-19 lockdown forced researchers to adopt a DPD approach for their ongoing PD

research as they found themselves in a distributed state. There have been more publications on DPD with children in the past two years as researchers are publishing results from their DPD projects conducted during the COVID-19 pandemic (e.g. Lee et al., 2021) in addition to various workshops discussing challenges and opportunities of DPD (e.g. Korte et al., 2021). Constantin et al., (2021) provided a taxonomy of DPD differentiating between online PD/DPD, offline DPD, asynchronous DPD and a hybrid DPD suggesting when each is best used. Although online DPD can allow collaboration between participants who cannot collocate, offline DPD overcomes the digital divide problem (i.e. difference in technology access) DPD creates. The online nature of DPD may allow children who previously could not participate in such workshops (e.g. due to not being within physical proximity of a university campus or other locations where these design workshops were conducted) to do so (Antle & Frauenberger, 2020). Nevertheless, it would exclude children who do not have internet access thus widening the digital divide (Antle & Frauenberger, 2020; Camera, 2020; Reddick, Enriquez, Harris, & Sharma, 2020). In addition, DPD allows researcher to establish a connection with the whole household rather than with the individual child participating, including their parents and siblings (Antle & Frauenberger, 2020). However those who cannot get their parents to provide technical support during the process may be disadvantaged: the ability of parents to dedicate time to work with their children is a luxury that not all families can afford (Antle & Frauenberger, 2020). In addition, this need to rely on adults to provide technical support whether they are parents or other facilitators creates power imbalance (Constantin et al., 2021). Furthermore, difference in devices used and software versions available can affect the experience of different participants during the design session (Korte et al., 2021; Lee et al., 2021).

Asynchronous DPD allows participants to work at their own pace compared to online DPD, which is especially important for children who have special needs. Although Hybrid DPD can

be used to address the issues emerging from the other approaches, difference in types of involvement among participants may create inequalities. Nevertheless, Constantin et al., (2021) acknowledge the benefits of any form of DPD to the involvement of participants who have difficulty with social interaction. Furthermore, it offers increased privacy and independence by allowing participants to turn off their camera or microphone (Constantin et al., 2021) or utilise the chat feature to express their ideas and privately communicate with the researcher (Antle & Frauenberger, 2020). However it is difficult to assess participants' engagement and to detect non-verbal cues that may be more evident in a physical design session (Constantin et al., 2021). In addition, there are certain social expectations and etiquette that is specific to conducting these design sessions online, such as using the chat function rather than the microphone to raise questions or add comments to avoid interrupting the speaker, which may not be known to the participants (Kennedy et al., 2021).

Fails et al., (2022) reflect on three case studies of design groups which transitioned from an offline setting to an online DPD setting over 18 months during the COVID-19 pandemic. Over 150 design sessions were conducted collectively among the three design groups. Online sessions' structure mirrored the structure of the physical sessions by using Zoom for circle time and Miro as digital whiteboard to support various design activities which provided a sense of normalcy and familiarity for participants. It was necessary to conduct a technology testing and training prior to the design sessions to make sure participants were prepared in terms of the technology they use and were familiar with how to use it. When introducing a new tool, informing the parents was necessary to make sure it worked as expected and to provide any troubleshooting necessary. In some cases, children themselves were troubleshooting technical problems or collaborating with others to help them overcome technical issues. However, dealing with these technical issues often removed the focus from the design goal and disturbed the ideation process. In addition, children often preferred to turn their cameras off and their

attention was divided between the design activity and distractions at home which affected participants' social connectedness and sense of presence. Children often found it easier to manipulate their physical prototypes compared to their digital ones as they often found the online tools challenging; this was particularly the case for younger children. Transition to DPD also impacted the type of design problems that can be addressed in the design sessions as more concrete problems were required compared to the abstract ideas that were previously discussed in the physical design workshops. This was due to the ease of refining and focusing ideas when all participants are co-located.

Lee et al., (2021) describes another design group which had to move their design sessions online due to COVID-19. After conducting 10 design sessions, a conceptual model for online DPD was proposed. Due to the unpredictable nature of conducting online design workshops with children, their proposed model has improvisation at its core. They extend on Kang, Jackson, & Sengers's (2018) five key features of improvisation in HCI which are (1) Reflexivity, opportunity to explore new ways for collaboration between children and adults; (2) Transgression, intentionally adding disruption; (3) Tension, creating balance between opposing forces; (4) Listening, participants coherently attune to surroundings; and (5) Interdependence, interaction among participants and between participants and technology.

In the context of autism research, there has been little research that explores how to involve autistic children using a DPD approach. Hence, DPD for autistic children remains largely uncharted territory for researchers within this community. It is reasonable to expect, from the multiple frameworks created specifically for involving autistic children discussed in Section 2.4, that the process of conducting DPD with autistic children may differ from how it would be with neurotypical children or adults. Hence, consideration of the children's traits and preferences need to be taken into account when designing DPD workshops. However, as a first

step to exploring this new territory, inspiration from PD frameworks created for autistic children and DPD methods for neurotypical children and adults can be taken into consideration.

2.7 Summary

This chapter introduced Autism Spectrum Condition (ASC) as described in the DSM-5 (American Psychiatric Association, 2013) and discussed appropriate language to refer to autistic individuals and autism traits. The remainder of the chapter focussed on Participatory Design (PD) and its different variations.

Although participatory design is popular within HCI in general, it is specifically encouraged when the target population has special conditions or have different demographics compared to the researcher (e.g. children) as it allows for more involvement with the target group and more understanding of their condition and/or their needs. Hence, many frameworks have been developed to involve autistic children in the design process. Upon reviewing these frameworks, it is evident that applying these frameworks is often difficult and costly. These difficulties were discussed, in addition to the ethical dilemma of providing opportunities for autistic children to have a say and be involved in designs of technologies for them, while restricting autistic children's learning time by involving them in such studies.

Participatory Design with Proxies (PDwP) is presented as a compromise approach, to be used when the involvement of the target population is not possible. Although it is often criticised, it has the potential of benefiting the design process especially when used in conjunction with PD with autistic children.

Distributed Participatory Design (DPD) is an approach used to work with design partners when they are physically distributed. It was first used to cope with the move towards distributed system development and to increase the participant pool making it not geographically limited. However, interest in this approach increased as a result of the COVID-19 pandemic and social distancing restrictions. Many PD research projects switched to DPD

during COVID-19 lockdown and very recent studies are being published on the challenges and opportunities of such approaches. As a result of the novelty of the circumstances, research on DPD with children is very limited while research on DPD with autistic children specifically is non-existent. As a first step to explore DPD with autistic children, accumulating knowledge from DPD with children and PD with autistic children is beneficial.

This thesis explores how participatory design approach can be supported by the use of proxies and how to utilise DPD methods to enhance the reachability and participation of autistic children.

3 FRIENDSHIP AND AUTISM

3.1 Introduction

There have been numerous studies on support for autistic children in different aspects of their lives. However, not enough research has been done on supporting friendship specifically. Recently, more technology-based interventions have been developed for this group due to their general special fascination with technology (Frauenberger, 2015).

This Chapter reviews literature related to friendship and autism first by reviewing three key theories related to friendship and supporting its development for autistic children. Then it explores the nature of friendship for autistic children, highlighting the importance of friendship for the well-being of autistic children. It also discusses the specific attributes of autism which make friendship development difficult for children on the spectrum. Finally, it discusses traditional and technology-based interventions currently used to support friendship, and their limitations.

3.2 Theories of Autism and Friendship

3.2.1 Pair Relatedness Theory

Levinger & Snoek's (1972) levels of pair relatedness theory discuss the formation of relationships which go through four stages. According to their theory, a relationship between two individuals

starts from a zero-contact level where the two individuals are unaware of each-other's existence. The next level is the unilateral awareness level where one individual becomes aware of the other but there is no interaction or much knowledge about the other person. Next, the two individuals may move to the surface contact level where they are both aware of each other and have limited interactions and knowledge about each other. In this level, their interaction mostly follows socially prescribed rules, their knowledge of each other is very shallow and they become what we refer to as 'acquaintances'. Finally, the relationship may progress to the fourth and final level which is the mutuality level. In this level, the two individuals have a deeper knowledge of each other through self-disclosure and multiple interactions. They are no longer necessarily following socially prescribed rules but rather they develop their own interaction style based on their knowledge of each other. Based on this theory, the ability to follow social rules can be a determining factor on whether two individuals' relationship will progress through the levels of relatedness to reach the mutuality level or not. It can be hypothesised that providing support during the surface-contact level by allowing a pair of children to interact within a virtual environment will allow the pair to reach the mutuality level without the need to follow social norms that can be difficult for autistic children. Once the pair have reached a mutuality level in their relationship, social skills will no longer be a barrier to their interaction since they will have developed their own interaction style based on their understanding of each other.

3.2.2 Double Empathy Problem

According to Milton's (2012) Double Empathy Problem, the need to mediate the social interaction and relationships between autistic children and their neurotypical peers is due to the different expectations and social norms each group has. This discrepancy leads to conflicts and misunderstanding between the two groups during interactions. In light of this theory, the social

abilities of autistic children are not impaired but rather they do not match those expected by their neurotypical peers. Hence, we view this problem as a problem of interaction mediation between autistic and neurotypical children rather than a social skills intervention for autistic children. This suggests that autistic children do not have deficits in social communication, empathising and interaction but instead differences in communication and difficulties arise from the mismatch of neurotypes.

3.2.3 The Social Model of Disability

Disability is often viewed as a characteristic of the individual, however, disability is highly context-dependent (Ringland, 2019). From a social model of disability perspective, one's "disability" is not disabling in every context but is created by the lack of accessibility in a specific situation. Hence, when environments are designed to be inclusive these "disabilities" will no longer exist.

In the case of autism and friendship, difficulty in developing friendship has always been attributed to autistic individuals having a 'deficit' in social skills, however, recent studies have shown that some autistic individuals were able to develop friendships despite their social and communication style (e.g. Petrina et al., 2014). This suggests that the 'deficit' is not in the autistic individuals but instead within an entity external to them which makes it difficult for them to develop friendship. Nevertheless, most efforts to support autistic children's friendship has been focused on training the autistic child to improve and change their social and communication style (e.g. Frankel et al., 2010) with only a few looking at improving the environment to enable children to develop friendship (e.g. Wolfberg, 2003).

Autistic children's 'lack of social competence', as defined by social norms, creates a barrier to friendship development with their neurotypical peers (American Psychiatric Association, 2013).

Nevertheless, it is unknown whether developing social skills will eventually allow children on the spectrum to develop friendships. One study examined the characteristics of autistic children who have friends and found that joint attention was the only prominent social skill they have (Bauminger-Zviely & Kimhi, 2017). This finding indicates that the known difficulties of autistic children such as maintaining eye-contact or turn-taking in a conversation might not necessarily hinder the development of friendship. Nevertheless, autistic children's stereotypical behaviour can be stigmatising which may discourage initiation and response by other neurotypical children in natural settings (Underhill, Ledford, & Adams, 2019).

Virtual environments provide an opportunity for designing and testing such inclusive environments. They allow us to understand how such inclusive environments can be designed and how they will affect individuals' accessibility. In social relationships, socialising within a virtual environment allows for asynchronous communication and elimination of social aspects that can be specifically challenging for children on the spectrum such as eye contact and physical touch (Leslie, 1994).

3.3 Friendship and Social Competence for Autistic Children

Friendship is defined as a voluntary and reciprocal relationship between two individuals that is stable across time and involves a compilation of skills such as social cognition and emotion (Bauminger, Shulman, & Agam, 2004). It is identified by a mutual affection and preference which manifest as companionship, intimacy and affection (Petrina et al., 2014; Webster & Carter, 2007). In some studies, an operational definition of friendship is provided that specifies a minimum period a relationship should last (Bauminger, Solomon, & Rogers, 2010) and specific contexts where friendship activities take place (Rossetti, 2011), while others accept the nomination of a friend as an indication of the existence of a friendship (Bauminger & Shulman, 2003; Chamberlain, Kasari,

& Rotheram-Fuller, 2007; Kasari, Rotheram-Fuller, Locke, & Gulsrud, 2012). Similarly, given the exploratory nature of this thesis, a child identifying a relationship as friendship will be accepted as it is since the focus is on understanding the perspective of children and the nature of their friendships.

Children with strong social relations are less likely to develop social and behavioural problems (Hartup & Stevens, 1999). Engaging in positive peer relationships is believed to contribute to the development of important skills such as conflict resolution and emotion regulation (Petrina et al., 2014). This becomes apparent during the transition from primary to secondary school since children with high quality friendships experience smoother transitions unlike those children who have low quality friendships who also reported feelings of isolation (Berndt, Hawkins, & Jiao, 1999; Whitehouse, Durkin, Jaquet, & Ziatas, 2009). Failure to develop such relationships negatively affect the child's self-esteem and increases feelings of loneliness (Bauminger et al., 2004).

Successful social interaction requires the development of basic social skills which typically developing children acquire when they are exposed to social situations using implicit learning such as imitation and modelling (Meltzoff, Kuhl, Movellan, & Sejnowski, 2009). To autistic children, acquisition of such basic skills has been reported as difficult and they often need to learn them explicitly (Klinger, Klinger, & Pohlig, 2007). They may also acquire these skills at a later time compared to their neurotypical peers (Schall & McDonough, 2010).

Although autistic children have fewer friends compared to their matched neurotypical peers, most children on the spectrum reported having at least one friend (Petrina et al., 2014). Nevertheless, these friendships generally lasted for a shorter period of time (Bauminger & Shulman, 2003) and they are often with other children with disabilities rather than neurotypical

children (Bauminger & Shulman, 2003; Locke, Ishijima, Kasari, & London, 2010a). In addition, autistic children do not meet their friends outside of the school setting as frequently as neurotypical children (Petrina et al., 2014). When they do meet their friends, they spend the majority of time playing video games and watching television (Bauminger & Kasari, 2000). Autistic children who play video games with their friends were found to have higher quality friendships compared to children who engaged in other activities such as watching TV, playing or talking with their friends (Kuo, Orsmond, Cohn, & Coster, 2013).

The Friendships Qualities Scale (Bukowski, Hoza, & Boivin, 1994) is often used to measure the quality of friendships of autistic children. Consistent results of the poor quality of autistic children's friendships were reported by several studies (Bauminger & Kasari, 2000; Lee, 2008; Solomon, Buaminger, & Rogers, 2011). More specifically, autistic children scored lower on sub-scales of intimacy, closeness and help compared to their matched neurotypical peers. The only sub-scale where autistic children have the same results as neurotypical children was conflict (Petrina et al., 2014). Lower quality friendships have been reportedly due to a number of attributes such emotion sharing difficulties (Hobson, 2005). In addition, it was previously believed that autistic children have a difficulty with understanding the mental state of others (i.e. difficulty with theory of mind) which affects the quality of their friendship (Bauminger et al., 2010). It is important to take into consideration that the Friendship Qualities Scale (FQS) which is often used to measure the quality of autistic children's friendships was not designed specifically to be used with autistic children and that it was based on the neurotypical view of friendship as the ideal standard. In light of the double empathy theory introduced in Section 3.2.2, the mismatch between neurotypical and autistic individuals' social understanding and communication style may impact how we observe and measure autistic children's friendships.

Despite the common belief, autistic children do not prefer isolation. Bauminger & Kasari (2000) found that autistic children have a desire for friendship and want to be more social. This is identified by measuring their feeling of loneliness, characterized by the difference between desired and actual social state, which autistic children reported more often than their neurotypical peers. This feeling of loneliness increases as individuals become more self-aware of their differences and is frequently experienced by autistic adolescents (Lawson, 2003; Stoddart, 1999; Whitehouse et al., 2009).

Calder, Hill, & Pellicano (2013) studied how autistic children perceived their own social relationships and concluded that although they have generally lower friendship quality than their neurotypical peers, most of them are satisfied with their friendships. These outcomes were later confirmed in Petrina, Carter, Stephenson, & Sweller's (2017) study which took into account the autistic child's nominated friend's (autistic or neurotypical) satisfaction level and reported that the satisfaction with their friendship was mutual. Petrina et al. (2014) argued that despite autistic children having fewer friends compared to their neurotypical peers, their satisfaction with their friendship can indicate that they are sufficient for their individual social needs. However, both studies were conducted with children in primary school with an average age of 10 and 8.5 respectively. Children at this age generally define friendship in terms of companionship only without including notions of intimacy and affection (Rose & Asher, 2000). But as they grow older, more emotional aspects will be expected from their friendships and since autistic children particularly struggle with intimacy it may become challenging to obtain and maintain friendships as they grow (Howard, Cohn, & Orsmond, 2006).

Recently, scholars have been encouraging social integration and the inclusion of autistic children in public and mainstream schools which would create opportunities for children on the

spectrum to interact and develop friendships with neurotypical peers (Grenot-Scheyer, Staub, Peck, & Schwartz, 1998). This is significant for their development since this exposure allows them to engage in social play more frequently and was found to increase their social interaction compared to autistic children who did not have this opportunity (Sigman et al., 1999). Bauminger et al. (2007) compared social aspects of mixed (neurotypical and autistic pairs) and non-mixed (autistic pairs) friendships and found that social initiation and response was more frequent in mixed dyads. In addition, mixed dyads were found to have a more stable and durable relationship. However, autistic children in the mixed-dyads group had better receptive language skills compared to autistic children in the non-mixed-dyads group which might indicate that language ability is a necessary skill to develop a higher quality friendship with neurotypical peers. These findings view friendship from a neurotypical lens judging the quality of friendship based on how neurotypical friendships manifest. Viewing these results using the double empathy problem theory lens, autistic children in the mixed group having higher language skills can explain the difference measured between the mixed and the non-mixed group. In the mixed group, the mismatch between neurotypical and autistic children's expectation from the social interaction is reduced due to the language ability of the autistic children. Nonetheless, this study highlights that interacting with neurotypical peers can be beneficial to autistic children.

3.4 Traditional Interventions to Support Friendship

This section reviews existing research on traditional (i.e. not technology-assisted) interventions to support friendship development and enhance social competence for autistic children. Three manualized intervention models are introduced which are Integrated Play Groups (IPG), the Social Communication, Emotional Regulation and Transactional Support (SCERTS®) and Developmental Individual Differences, Relationship-Based model (DIR®). These three models

were chosen because of their focus on developing social competence and utilization of relationships. The remainder of this section discusses and evaluates other interventions and categorizes them into child-specific or peer-mediated.

3.4.1 Social Play

Social Play is a form of play which involves peers, with early features including joint attention, imitation and emotional responsiveness (Wolfberg & Schuler, 1993). Neurotypical children naturally engage in this type of play when exposed to other peers in preschool years and begin to develop reciprocal social relationships such as friendships (Wolfberg, 2003). However, due to recognized delays in the development of key features of social play (e.g. joint attention) in autistic children, they are unlikely to engage in this form of play without explicit support (Wolfberg, 2003). Facilitating social play is vital as it allows the development and practice of new skills in a controlled and safe environment (Boucher & Wolfberg, 2003). More specifically, social play can teach intimacy, trust and negotiation skills which develop the capacity to form friendships (Parker & M. Gottman, 1989). Play in autistic children is not social in nature (Dean, Harwood, & Kasari, 2017; Kasari, Huynh, & Gulsrud, 2011; Wing, Gould, Yeates, & Brierly, 1977), rather, they tend to engage in a manipulative play where they manipulate a toy or an object with their hands (Kasari et al., 2011; Tilton & Ottinger, 1964). This different form of play and inability to imitate or coordinate joint play activities can result in exclusion from play by peers (Wolfberg & Schuler, 1993). Hence, providing the opportunity to engage with peers alone without offering support will not necessarily improve their social competence (Strain & Cooke, 1976) and relatedly support may be gradually reduced as the child become more socially competent (Bruner, 1981).

Wolfberg, (2003) developed Integrated Play Groups (IPG) which is a model for supporting peer play for autistic children. It facilitates social play by modifying the environment, providing guidance and focusing on child initiation. IPG key features include the following:

- Natural Integrated Setting: include socially competent children as play partners.
- Well-Designed Play Space: accessibility, organization of materials and size are taken into account when arranging the environment.
- Selection of Play Materials: materials are selected based on their interactivity potential, structure and complexity. Constructive toys are an example of toys that can be enjoyed by children with different abilities.
- Establishing Routine: fostering for autistic children's preference for routine and predictability, a consistent play group schedule is established.
- Forming Balanced Play Group: a limited number of familiar peers are included to allow the development of social relationships.
- Focus on Child Competence: child's developmental level is indicated by his spontaneous initiation. As a result, children are allowed to select preferred play activities.
- Guided Participation: the adult's role in guiding the participation is supportive not directive.
- Full Immersion in Play: embedding stereotypical behaviour of autistic children in the play context.

These features are guided by theory, research and practice and have been shown to be effective in improving play behaviours in autistic children such as increasing their responsiveness to other children and initiation of interaction (DiSalvo & Oswald, 2002)

3.4.2 The SCERTS[®] Model

The Social Communication, Emotional Regulation and Transactional Support (SCERTS[®]) model is an educational model for autistic children (Prizant, 2006). It is designed to be used within

multiple settings such as at school or home which requires the collaboration of the child's parents, teachers and caregivers. In addition, its use is not limited to a specific age group and it can be used throughout adulthood as well.

It is based on eight principles and core values which ensure the focus is only on skills that have the most impact on the child's quality of life. Researchers believe that social and communication abilities are one of the key skills which allow autistic individuals to be more independent (Prizant, 2006). Hence, social communication difficulty is one of the three core challenges that this model focuses on in addition to emotional regulation and the need for transactional support. This model emphasizes the critical role social partners play in the learning process since learning is supported by social partners who facilitate successful acquisition of new skills by providing appropriate scaffolding. It operates on eight key principles which are:

- Supporting communication and emotion regulation is the highest educational priority.
- Activities are appropriate to the child's developmental level.
- Different domains of child's development are connected and these relationships should be considered in assessment and education.
- All behaviours are purposeful. Thus, determining the function of undesired behaviours is necessary to provide appropriate support.
- Consider individual child's strengths and weaknesses to provide the right support.
- Measure progress across natural routines in home, school and community.
- Establish positive relationship with children and families.
- Collaborate with families in assessment and educational efforts.

Three decades of extensive research and practice were behind the development of the SCERTS model which makes it a highly reliable and widely used framework (O'Neill et al., 2010).

It provides design guidelines on selecting and organizing intervention activities which have been adapted for designing educational games for autistic children (Porayska-Pomsta et al., 2012).

3.4.3 The DIR[©] Model

Developmental Individual Differences, Relationship-Based model is an intervention approach developed to be used by both professionals and parents to help them understand and help children and adolescents (Davis, Isaacson, & Harwell, 2014). It utilizes human connections to promote the child's development through playful activities. DIR recognizes relationships and emotional connections as a force that fosters social-emotional and cognitive development. This model does not target autistic children only as it can be used with all children with developmental differences.

Floortime is derived from the DIR model and it is an application of the model's principles. Its name is a reflection of its core value of joining the child at their current developmental level and gradually moving forward visiting any missed growth opportunities. Figure 3.1 is a graphical representation of the model where adults on the left side of the pyramid follow the child's lead, engage with them and gradually challenge them to expand their social-emotional and cognitive capacities. On the right is the child's response to the strategies applied by the adult.

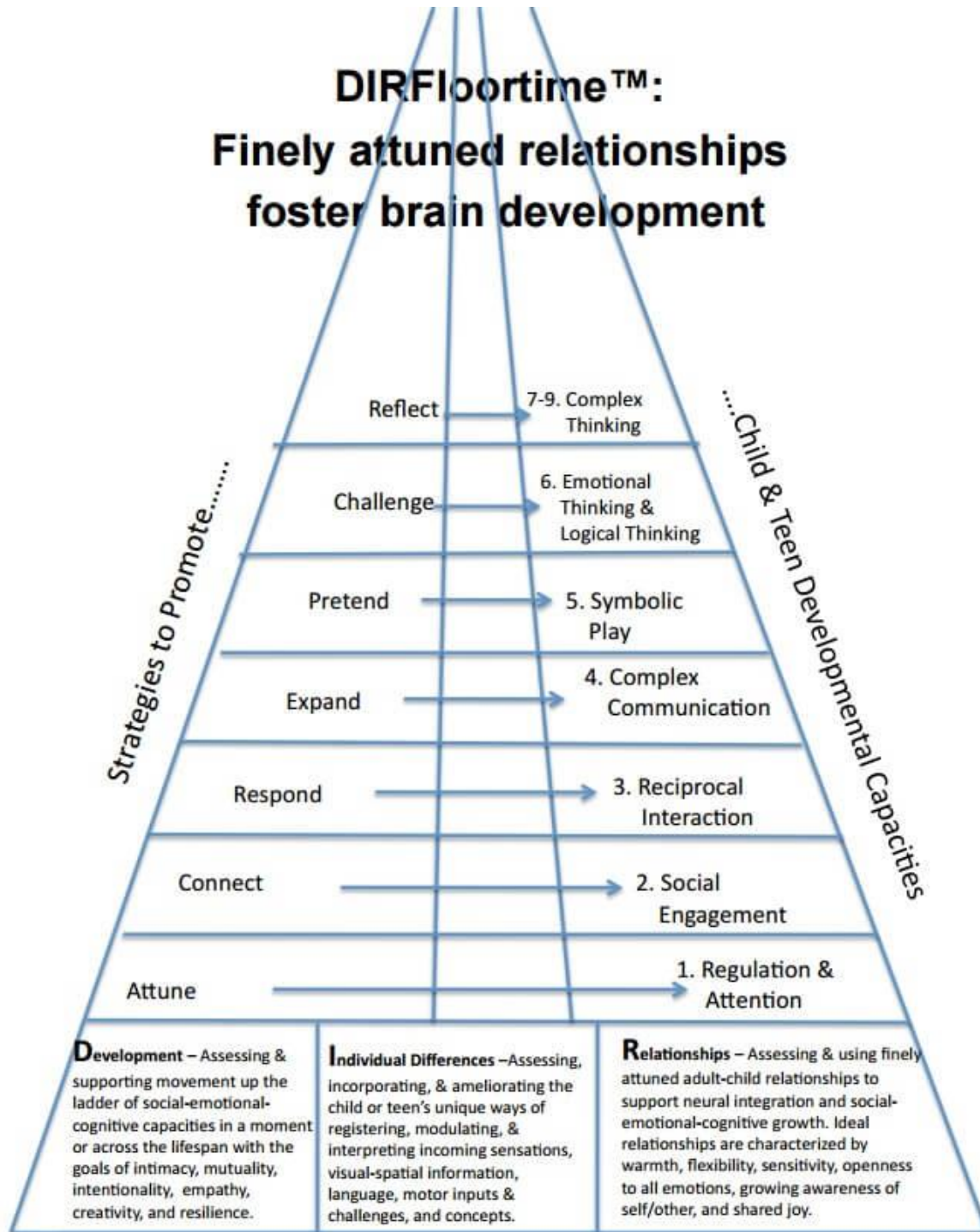


Figure 1 based on description of model in *The Child with Special Needs: Encouraging Intellectual and Emotional Growth* by Stanley Greenspan & Serena Wieder, Perseus: 1998 and *Engaging Autism: Using the Floortime Approach to Help Children Relate, Think, and Communicate* by Stanley Greenspan & Serena Wieder, Da Capo: 2007.

Figure 3.1: DIR Model (Davis et al., 2014)

Although the model is designed to be applied by parents, teacher or practitioners, emotional connection with peers can also be utilized by training peers on this model.

The effectiveness of this model has been evaluated in a number of studies and results have validated this approach (Casenhiser, Shanker, & Stieben, 2013; Pajareya & Nopmaneejumrulers, 2011). However, Mercer (2017) argues that regardless of supporting evidence for this approach, unavoidable design flaws in the studies make judgment on its effectiveness premature at this point. Other models which were built on the DIR model, such as the Play and Language for Autistic Youngsters model (PLAY), have provided evidence of improved social-emotional development (Solomon, Van Egeren, Mahoney, Huber, & Zimmerman, 2014). A key feature of this approach is that it helps facilitate communication and effective response of the parents towards their child as well (Solomon et al., 2014). Zody's World, a collaborative iPad game, was inspired by the DIR/Floortime™ model (Boyd et al., 2015). Details on how the model was adapted into the game were not published. However the positive evaluation results of the game establish the potential for using the DIR/Floortime™ model in developing games to support friendship.

3.4.4 Child-Specific Interventions to Support Friendship

Child-specific interventions are interventions which are delivered to the target child directly whether individually or in group settings (Kasari et al., 2012). This type of intervention is the most common and it is essentially training the child on social skills through direct instruction. This is not usually applied in natural contexts. Intervention agent can be a therapist, practitioner, teacher or parent.

LeGoff (2004) identified transfer as a limitation in the current interventions targeting the development of social skills for autistic children. Children were able to respond appropriately during exercises and demonstrate target social behaviour within therapy settings. but they were

not initiating in natural settings and or making new friends. Building on Wieder & Greenspan's (2003) recommendation of using the child's own interests to promote target social and communication skills, LeGoff (2004) used Lego© as a therapeutic medium to promote social skills. The therapy was organized into an individual 1 hour session, where the child played with the therapist, followed by a 90 minute joint session, where children played as a group. The purpose of the individual session with the therapist is to work on any specific skills or behaviour that appeared to be problematic to the child during the joint session. This pattern continued for a minimum of 12 weeks. Interaction between children is sustained by assigning them to different roles. One child can be an engineer, who describes the model and provides instructions, another can be a builder, who carries out the building of the model. This need for collaborations allows children to practice their communication skills, turn-taking and conflict resolution skills in a natural environment with minimum prompting. Evaluation of this approach yielded statistically significant improvements in the social competence of the children involved. This was assessed by measuring how often a child initiated a social contact, the duration of the interaction, and the impact of the therapy on the participant's behavioural characteristics measured by the Social Interaction subscale of Gilliam Autism Rating Scale (Gilliam, 1995). These positive outcomes were confirmed in other studies too (e.g. Andras, 2012; Owens, Granader, Humphrey, & Baron-Cohen, 2008). Moreover, these gains were sustained and improved six months after the intervention.

Children Friendship Training is a parent-assisted intervention that teaches children social rules (Frankel et al., 2010). It explicitly instructs children on skills such as how to be a good host during play dates and how to develop friendships. In addition, modelling, rehearsal and homework assignments were used to allow children to practice the skills taught. The role of the parent is on

structuring and supervising play dates. This approach was evaluated with autistic children attending second to fifth grade in mainstream schools for 12 weeks. However, improvements in children's behaviour were not significant and were not maintained at a 2-month follow-up.

3.4.5 Peer-Mediated Interventions to Support Friendship

Peer-mediated Interventions (PMIs) are interventions that equip typically developing children with strategies to engage autistic children by training them for this role (Chan et al., 2009; Kasari et al., 2012; Rao, Beidel, & Murray, 2008). Although most studies use this approach to develop social skills such as social initiation and turn taking (S. H. Lee, Odom, & Loftin, 2007; Owen-DeSchryver, Carr, Cale, & Blakeley-Smith, 2008), some studies were aimed at improving academic skills (Hunt, Staub, Alwell, & Goetz, 1994; Kamps, 1995), decreasing challenging behaviour (Ragland, Kerr, & Strain, 1978; Sainato, Strain, Lefebvre, & Rapp, 1987), or teaching specific life skills (Blew, Schwartz, & Luce, 1985). PMIs were found to be one of the most promising social skills intervention approaches by multiple studies which evaluated social skills interventions for autistic children (Chan et al., 2009; Cotugno, 2009; Reichow & Volkmar, 2010; Rogers, 2000). According to Chan et al. (2009), the success of this type of intervention can be attributed to several reasons. First, it enhances the learning process by modelling appropriate social behaviours by peers. Another reason is its accessibility compared to other types of interventions delivered by behavioural therapist or other practitioners since peers are available in the school settings to play their role as an intervention agent. Finally, target autistic children can practice the skills they recently obtained with their peers.

Circle of Friends is a peer mediated intervention to aid the inclusion of children who have additional needs in the school community. It engages peers of the target child to support her/him by understanding her/his needs. Despite its name, this approach aims to facilitate the development

of communication and social skills rather than developing friendships per se (Whitaker, Barratt, Joy, Potter, & Thomas, 1998). Kalyva & Avramidis (2005) evaluated the efficacy of this approach in improving the communication skills of preschool autistic children by applying the intervention with two children weekly for three months then observing the improvement of their communication skills by comparing them to three children in the control group. The results of this study showed significant changes in the communication skills of children in the intervention group compared to those who did not receive the intervention. In addition, a follow up observation was carried out 2 months after the intervention ended and the positive outcomes of the intervention persisted indicating a positive extended effect of the intervention. Although the systematic intervention stopped 2 months before the follow up study, peers may have continued supporting the target child during this time which affected the follow-up results positively. Nevertheless, these results cannot be generalized due to the small number of participants.

Kasari et al. (2012) compared using peer-mediated intervention with a child-specific approach to develop autistic children's social skills in a school setting. Peers were taught to use a range of methods such as role playing and modelling to improve autistic children's social skills. Results showed that peer-mediated methods had a greater impact on the development of the target child's social involvement compared to the child-assisted approach. In addition, these positive outcomes persisted in a post-intervention study conducted three months later. However, reciprocal friendships did not improve for autistic children although more classmates nominated the target child as a friend after the intervention the autistic child did not nominate them as well. This suggests that autistic children did not identify chances to develop friendships. Nevertheless, this study did not particularly target friendship development which might require a greater number of intervention sessions.

Disclosure of autism in children and their need for support to their peers is an inevitable part of PMI methods. This raises a concern regarding increased social exclusion due to stigmatization. In Sasso & Rude's (1987) study, peers were selected based on their popularity and they were trained to engage children with disability. The behaviour of untrained peers was observed to measure the effect of training popular peers on the behaviour of other untrained peers. It concluded that not only did the trained peers interact positively with the target participants, but other untrained peers were encouraged to carry out positive social interaction with the target participants as well. This suggests that careful selection of peers to act as intervention agents can reduce the possibility of negative outcomes, such as stigma. In most studies peers are selected by teacher nomination who take into consideration the nominated child attendance, social skills and social status within the classroom (popularity) (Chan et al., 2009). Harrell, Kamps, & Kravits (1997) present a systematic approach to selecting peers that factors in the selected peer social status and teacher's judgment. The social status of possible peers is assessed using a Likert scale and nominations by other classmates. The resulting list of high status peers is then evaluated by the class teacher based on their compliance, attendance, social and language skill. Although there is no evidence of whether this method can prevent undesirable results such as bullying and exclusion, such methods can be adopted as a precaution.

Selected peers are trained in a number of ways. Some studies provide verbal explanation of the target skill, its importance and ways to encourage it (e.g. Owen-DeSchryver et al., 2008). Another training method is modelling where the trainer carries out the intervention while the peer observes (e.g. S. H. Lee et al., 2007). One similar technique is role playing and rehearsal where the trainer takes the role of the target child and carries out the intervention with the peer (e.g. Chung et al., 2007). In addition, feedback can be provided during the intervention by prompting

peers and correcting their behaviour (e.g. S. H. Lee et al., 2007). Peers are trained to initiate the interaction, extend the interaction by appropriate responses, prompt the other child to engage, model target behaviour, show affection and provide positive reinforcement to the target child on desirable behaviour (Chan et al., 2009).

In addition to the positive outcomes of PMI on target participants, social and academic improvements were observed in participating peers as well (Carter, Cushing, Clark, & Kennedy, 2005). Participating peers reported having a sense of pride and a growing concern for others (Carr & Darcy, 1990). Although PMI shows promise as a method to teach social skills to autistic children, current studies mostly target younger children and do not collect data to analyse the generalizability and maintenance of acquired skills (Chang & Locke, 2016). Targeting older children or adolescents and examining generalizability should be the focus of future research on PMIs.

3.5 Technology-based Intervention to Support Friendship

Technology-based interventions for autistic children have shown potential due to children's attraction to technology. This affinity they have for technology can be attributed to its predictable nature and tolerance for repetitive behaviour (Frauenberger, 2015). Using technology with children on the spectrum allows the creation of an adaptive environment that can present simple and clear goals while collecting data (Kientz, Goodwin, Hayes, & Abowd, 2013). These benefits led more researchers to promote technology-based interventions to support children on the spectrum. Based on the literature review conducted here, developing friendships itself is never a primary goal of technologies developed. However, some studies have focused on developing social and communication capacity to enhance social relationships in general while others worked towards creating virtual spaces where autistic children can socialize.

3.5.1 Collaborative games

Collaborative games represent a large proportion of the literature on supporting social competence for autistic children. In these types of games, a collaboration element is used to enforce interaction between players and allow them to implicitly acquire essential skills that would develop their social competence.

Dyad-Operated Social Encouragement (DOSE) is a collaborative game that collects time-series, audio and event information to be used in interaction analysis later (Wade et al., 2017). The game includes multiple modes, a collaborative game where players can collaborate and help each other, a competitive game where players play against each other and another collaborative game where children play against the computer. The first mode was used as the pre- and post-test in the evaluation of the game's effectiveness. The game was evaluated with NT-ASC pairs and ASC-ASC pairs. Preliminary results show that DOSE increased verbal communication between players, but no results were reported on other social-communication skills.

Boyd et al. (2015) evaluate the effect of the collaborative iPad game (Zody's World: The Clock Catastrophe) on three levels of social relationships: membership, partnership, and friendship. Eight autistic participants were randomly assigned to form four pairs. Each pair played Zody's World three times a week for 2 weeks and shared a set of Lego for another 2 weeks. Analysis of the results showed advantages of the game sessions over the Lego sessions. Participants made positive comments towards each other while playing Zody's World and acknowledged forming a friendship throughout the study during both types of play.

Incloodle is another tablet game designed to support inclusion for children with varying abilities including autistic children (Sobel, Rector, Evans, & Kientz, 2016). Four versions of the game were designed varying in whether it enforces collaboration or not and in the way prompts were delivered. A within-group lab evaluation of the game with mixed pairs of neurodiverse and

neurotypical children revealed that technology-enforced collaboration was useful when collaboration between the children was lacking. However, when children had no problem collaborating on their own, the enforced collaboration rules created tension and was more of a barrier to free play. In addition, no advantage was observed for using in-game character-based prompts over basic instructions.

Holt & Yuill (2017) investigated what configuration of collaborative activities might support the development of autistic children's awareness of others, imitation and communication behaviour. It compared the results of two setups; one where both players share a single tablet and another where each has their own tablet but were connected through a network. Interestingly, the dual tablet setting had a superior effect on children's communication, imitation and awareness of others. These results led them to conclude that the technology alone does not afford collaboration but how it is designed.

Tabletop technology, which is a table with large interactive screen allowing multiple users, has been used for collaborative games in a number of studies (e.g. Battocchi et al., 2009; Gal et al., 2009; Giusti, Zancanaro, Gal, & Weiss, 2011). Its size allows multiple players to share one interface and interact comfortably which can be difficult with smaller screens such as tablets or phones. However, its size and cost limits its usability. Shared Interface to Develop Effective Social Skills (SIDES) utilizes tabletop technology by developing a four-player game for autistic children to practice social skills (Piper, O'Brien, Morris, & Winograd, 2006). Evaluation of the game showed that it was engaging for the participating children and motivated them to perform group activities. However, sustained effects on behaviours were not measured.

Full-body interactive and collaborative games have been used to develop autistic children's social capacities (e.g. Gillespie-Lynch, Riccio, & Sturm, 2017; Porayska-Pomsta et al., 2012).

Lands of Fog is a collaborative game that teaches social interaction behaviours to autistic children but it does not target any specific skill but rather uses collaboration to scaffold the development of their individual social initiation mechanisms (Mora-Guiard, Crowell, Pares, & Heaton, 2016). The technology was perceived positively during the evaluation with children and increased social behaviours were observed during play.

3.5.2 Technology-mediated socialization

Some researchers focus on utilizing technology as a comfortable medium where autistic children can communicate and socialize. Transferability to the real world is not a target for this type of intervention. Rather, the goal is usually to provide an opportunity for socialization through a virtual channel. Technology impacts how people communicate, interact, and behave, thus, Ng (2017) argues sociality should be redefined to include socialization through technology as it is no longer just a tool for learning.

The Lab (Rizzo, Schutt, & Linegar, 2012) is an after school technology club for autistic youth aged 10 to 16. The environment does not have a strict structure and accommodates individual interests. Making games, digital design and competitions are all activities that members participate in. Observations from The Lab reveal that children were able to socialize and develop friendship (Ng, 2017). However, they did not socialize in the typical sense but rather used minimum communication and only when needed.

Zolyomi, Bharadwaj, & Snyder (2017) explored using technology to simulate play dates for autistic children. Using Skype and IllumiShare remote play dates were arranged between children while not in the same physical space. Remote play facilitated play by improving their theory of mind, the ability to understand that others have a mental state different to their own, skills (Wellman, 1992). For example, when in different rooms, children had to explain what they

can hear and see which allowed them to compare their experience to the other player's experience. Although technology has limited the type of activities that can be experienced, it allowed for asynchronous communication and eliminated eye contact and physical touch which might be preferred for children on the spectrum (Leslie, 1994).

3.5.3 Social Tutors

Some studies focus on explicitly teaching specific social skills such as greeting or turn taking. Arendsen, Janssen, Begeer, & Stekelenburg (2010) propose using robots to teach greeting to autistic children. They argue that interacting with robots would be free of social tension. Milne, Powers, & Leibbrandt (2009) developed a virtual agent which was capable of modelling realistic facial expressions. One module of the software aims to teach children to pick up social cues and understand how facial expressions can reflect being bored, interested or wanting to do something. The other module focusses on teaching children strategies to deal with bullying attempts. Preliminary results showed some improvement in the children's abilities in identifying the right action to make based on the tutor's facial expression and recalling what the three-step strategy to deal with bullies was. Without any further studies on the ability of the children to utilize these skills in the real world, it is hard to judge the effectiveness of this approach.

Conversational Trainer is an Android app developed to train users on turn talking without the presence of their speech therapists (Tian, Chuah, & Cappellini, 2015). It allows the user to engage in conversation training sessions with the computer by saying specific phrases back and forth with the computer. Evaluation of the effectiveness of the tool on improving autistic children's turn taking skills was not carried out for this study. Only an evaluation of the design was conducted with four neurotypical children and a speech therapist. Thus, the effectiveness of this approach is unknown.

3.5.4 Minecraft as a tool for supporting autistic children

Minecraft is a virtual world where players can use resources found within the environment to build new objects. In the multiplayer mode, players can collaborate with others to build structures or socialize with them using the chat function. The game's popularity has been growing in general and specifically among autistic children (Bebbington & Vellino, 2015; Ringland, Wolf, Faucett, Dombrowski, & Hayes, 2016) which led to the creation of Autcraft. Autcraft is a Minecraft server created by a parent of an autistic child to provide a safe and bully-free environment for children on the spectrum to enjoy the game. It is a semi-private server where only approved players can join. Ringland et al. (2016) observed children's socialization within this server and concluded that autistic children developed meaningful relationships when provided with appropriate environments. Ringland, Wolf, Faucett, et al. (2016) argue that sharing a space with peers who have similar interests facilitate the development of peer relationships. The virtual environment removes social tension and allows users to socialize comfortably. For example, in typical social interactions, one is expected to make eye-contact during the interaction which is a known difficulty for autistic children. Rather than changing the behaviour of autistic children and forcing them to engage with others in a typical way, a virtual environment allows interaction that is comfortable for the child with ASC and expected for the neurotypical child at the same time. However, children need to learn to extend their social skills beyond this exclusive environment.

Stigma is often a barrier to using an assistive technology (Parette & Scherer, 2004). In order to overcome this limitation, Shinohara & Wobbrock (2011) suggest appropriating existing mainstream technologies as assistive technologies instead of developing new ones. In addition to reducing stigma, adapting existing technologies as an assistive technology is likely to enhance its usability since the user might already be familiar with it. This was observed within the Autcraft community as they have appropriated the virtual world to suit their individual needs (Ringland,

Wolf, Boyd, Baldwin, & Hayes, 2016). For example, holes within the virtual environment were created for players to place their avatars inside them when they feel overstimulated as a sensory regulation mechanism. Virtuoso (Schmidt & Beck, 2016) is another example of a proposed intervention that appropriates Minecraft to teach autistic children social skills while collaborating with others to solve computer programming problems which allow for the development of their computational thinking as well.

3.6 Summary

Autistic children have difficulty developing friendship which leaves them in a state of loneliness that can grow into depression or anxiety in the long-term. Scholars have identified this problem and proposed multiple solutions to help children develop social competence that would help them develop higher quality friendships. However, friendship itself is rarely the explicit goal of these solutions. Rather, it is assumed that by developing the target child's social competence they will be able to develop friendships themselves. Both traditional and technology-based interventions mostly focus on developing social skills and modifying the target child's behaviour to conform to the social norms. However, evidence from evaluations of current interventions suggests that conforming to social norms will not necessarily lead to develop friendships (Rodda & Estes, 2018). In addition, although friendship is a reciprocal relationship, this approach puts all the relationship development load on the autistic child. PMI methods are a possible approach for developing friendships since it also involves neurotypical children and trains them to be more inclusive and autistic aware. Virtual environments are a good candidate for an inclusive environment that allow comfortable interaction for both children. However, designing such an environment should take into consideration target user needs and preferences. Moreover, given their large research base,

existing manualized interventions such as IPG, SCERTS and DIR can be used to inform the design of these environments.

4 DISCOVERING DESIGN OPPORTUNITIES TO SUPPORT FRIENDSHIP BETWEEN AUTISTIC CHILDREN AND THEIR PEERS FROM THE TEACHERS' PERSPECTIVE

4.1 Introduction

Teachers can play different roles when informing design for autistic children. They have the direct role of informing the design based on their experience of what effective strategies they use to support their pupils and how they apply them. They can discuss how successful they are and if they are effective for a subset of their pupils but not others and how they handle these individual differences. In addition, teachers can indirectly inform the design by acting as proxies for autistic children, describing their pupils' experiences based on their interaction with and observation of them. However, when analysing data obtained indirectly from teachers as proxies, it is important to note that these are not often shared with the children directly and are subject to how the teachers

interpret what they observe. Nevertheless, teachers' input as proxies for autistic children is especially valuable as they are more competent in communication and can provide thorough descriptions of their pupils' experiences which can later be approved, denied, or corrected by the autistic children themselves when they are involved. Hence, their input as proxies can structure how to involve autistic children in a way that best suits their communication preferences.

A literature review exploring existing research on theories and intervention on developing social and communication skills was conducted and presented in Chapter 3. Nevertheless, not much is known about how these theories are applied in practice. In addition, few studies have looked at the effect of these interventions on supporting friendship specifically which makes exploring the nature of these relationships vital to understanding the problem.

As an initial step towards understanding the problem space, we conducted interviews with ten teachers and support staff from a special school for autistic children to identify features required in an environment that supports friendship development between autistic children and their neurotypical peers. Although we are interested in friendship between autistic and neurotypical children, we chose to interview teachers in an autism-specific school rather than a mainstream school since these teachers will be especially knowledgeable about autism and encounter many autistic children with varying needs. We believe that the ratio of autistic to neurotypical children in a mainstream school will limit teachers' perspective on autistic children's friendships in these schools, hence this choice was made.

This chapter reports on the results of these interviews and reflects on the opportunities and challenges for a technology-based solution. The purpose of this study was to address the following research questions:

RQ1: What role can proxies play in the co-creation process of technologies to support friendship ?

RQ1.1: How can teachers inform the design process in the context of supporting friendship?

Here we specifically explore the role of teachers as proxies by investigating the nature of friendship for autistic children as teachers observe it and enquire about strategies teachers utilised to support friendship development between their pupils. The strategies identified by the teachers do not only inform the design of a technology to support friendship but they also help structure and inform the design of the design workshops conducted with children which are reported and discussed in Chapter 8.

4.2 Methods

4.2.1 Recruitment

After obtaining ethical approval from the School of Informatics and the local authority, a teacher at the special school who previously collaborated with the primary supervisor was contacted to explain the study purpose and arrange a meeting with the school's head teacher to discuss the study protocol. After meeting with the head teacher, the teacher contacted originally was nominated to coordinate interviews with interested teachers within the school based on their availability.

4.2.2 Participants

Seven teachers and three support staff were recruited from a special school for autistic children. They were invited to reflect on their experience in supporting friendship among autistic children, share strategies they use to facilitate interactions between pupils and to comment on any challenges of applying those strategies. Table 4.1 summarises teachers' demographics.

Table 4.1: Teachers' Demographic Information

Participant ID	Sex	Teacher/Support Staff
T1	Female	Teacher
T2	Female	Teacher
T3	Male	Teacher
T4	Female	Teacher
T5	Female	Teacher
T6	Male	Support Staff
T7	Female	Support Staff
T8	Male	Support Staff
T9	Female	Teacher
T10	Male	Teacher

4.2.3 Procedure

Semi-structured interviews were conducted individually with each teacher. These were aimed at understanding: 1) the teacher's perspective on the relationship dynamics among the autistic pupils; 2) their role in supporting friendship between children and strategies they used, 3) features of an environment or activity that supports the needs of autistic children and improves their ability to interact positively with their peers and 4) technologies currently in use within their class, the teacher's attitude towards their use and their perception of how technology might aid the student learning (see Appendix A for the interview questions). Our goal in the interviews was to get teachers' abstract ideas about what requirements are necessary in any environment and to elicit design requirements from their own practice in the physical world. We use the term 'environment' loosely in most of the chapter. We believe that these requirements can be used to design a virtual learning environment, though this was not explicitly discussed during the teacher interviews. All interviews were conducted in person and audio recorded except for one interview, where the participant did not want to be audio recorded, so notes were taken to record the participants' answers. Interviews were 20 to 30 minutes long and were fully transcribed using InqScribe ("InqScribe," 2022). The data was thematically analysed using NVivo following the process recommended in Braun & Clarke, (2006). Open coding was used to generate initial codes. This

allowed us to freely capture participants' novel ideas without being influenced by predefined codes. These codes were aggregated and organised into preliminary descriptive themes. The themes were then reviewed to produce the final defined themes reported in the next section.

4.2.4 Ethics

Ethical approval by the School of Informatics ethics panel and the local authority where the school was located was sought, and teachers' consents were collected. Parents and children were not consulted in this study as the emphasis of the current research was on teachers' experiences and perspectives. However, respect for the children's privacy was adhered to, and teacher statements have been modified to be more generic, avoiding referring to any specific child in such a way that they might be identified. Teacher statements were also altered in a number of cases where the language used might be considered potentially offensive. For example, terms such as 'low functioning' were replaced with more appropriate labels and descriptions that did not change the meaning or impact the interpretation of the text. All interview audio and transcripts were stored in an encrypted folder on a university-secure server, separately from any identifying information and accessible to the research team only. All audio recordings were deleted after transcription for data-protection purposes.

4.3 Results

Here we report our findings from the interviews with the teachers. Four main themes emerged from the analysis of the interviews: 1) limitation of interaction and need for support; 2) environment and activity features; 3) friendship support as a secondary goal and 4) opportunities and challenges for technology support. Figure 4.1 summarises the themes identified from this study.

Discovering Design Opportunities to Support Friendship between Autistic Children and their Peers from Teachers Perspective

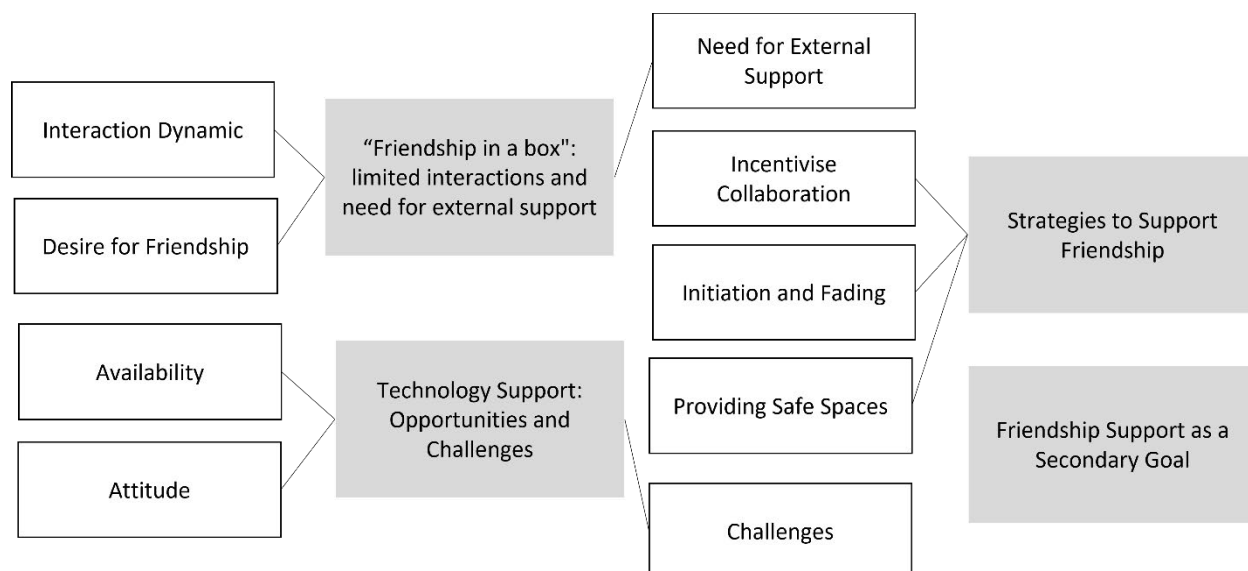


Figure 41.: Thematic map showing the four main themes identified and their sub-themes.

Theme 1: "Friendship in a box": limited interactions and need for external support

Teachers discussed the nature of friendship among their autistic pupils, highlighting their unique characteristics. Here we focus on 1) the nature of the interactions between children, what activities they engage in and where these take place; 2) the children's desire to have friends, and 3) their need for parents and teachers to act as facilitators for their interactions with peers.

Interactions bounded by activity or environment: A recurring theme in friendships between autistic children is that it is often limited to a specific environment or activity. Teachers find that children often associate their relationship with a peer with a specific activity (e.g. playing cards) and did not interact with their 'friend' beyond that activity.

T2: "the ones with lower IQ levels tend to have a relationship which is much like nursery. It is based around the activity. And then probably if that activity starts to fade or they or one of them lose interest there is not much else. There is not much dialogue or anything going on."

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The need to have a shared interest to initiate and maintain a relationship was confirmed by adults with Asperger Syndrome² (Müller, Schuler, & Yates, 2008). They emphasised how having a shared interest would create opportunities for social interaction that may not happen otherwise.

Interactions were also limited to a specific environment. A pair would interact within a specific environment but would not seek to extend the relationship beyond that space. This can be relevant to the children's need for consistency and routine (American Psychiatric Association, 2013).

T4: "From what I have seen, I have not seen them together at lunch time and break time so I think it is only that time of the day and sometimes at the end of the day as well. So, it is very kind of much of friendship in a box."

Teachers often reported that children will only seek peers who are in close proximity to them. Unless they are in the same classes or clubs, it is very unlikely that any relationship between them will develop.

T4: "I think that had they not been in the same register group that friendship might not have developed. In the very beginning, they were not friends and they did not ... I think one of the boys did not particularly like the other boy. I think it wasn't until one day he saw him watching these Youtube videos and they just decided that they were going to... [be friends]."

Some teachers believed that being in the same class allow children to be comfortable and familiar with each other which is especially important for autistic children, given their preference for sameness (American Psychiatric Association, 2013). Establishing familiarity with another peer would create opportunities for friendships.

² Asperger Syndrome was a separate diagnosis but became part of the autism spectrum diagnosis in the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

T9: "Sometimes class groups can be really strong again because they are with each other all the time ... they are comfortable ... they are familiar."

The need for physical proximity was also reported by parents in Bauminger and Shulman's study (Bauminger & Shulman, 2003) as one of the five main features that help autistic children make friends.

Desire to have friends: Many children expressed a desire to make friends, either to their teachers or parents. Some even attempt to initiate interaction with their peers but are not always successful. Some children show their interest in another child by standing in close proximity or following them around. Some children show their interest by teasing their peers.

T4: "The thing with him is, I think, he almost seems like he will shout at people and tease them and with him any kind of interaction, even though it might seem negative, is positive because in his old school he did not speak at all."

Although more often than not others will respond negatively to his attempts he continued to initiate such interactions. According to Dawson & Adams (1984), autistic children's preference for predictability may explain such behaviour as he can predict others' response.

Need for external support: In one case, a child approached their peer and asked him explicitly if he wanted to be friends outside of school. From the teacher's perspective, both children were keen on having a friendship that extends beyond school, but they often needed the support of teachers and parents to achieve that.

T4: "So she approached him and he looked very happy and did not say much just sort of said 'ok' and the next day he came in with this note that his mum obviously helped him to write which said... his address, his mum's phone number and he drew a little picture and gave it to her. So, it is almost like this arranged friendship that now started."

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This pair often seek their parents' or teachers' help to communicate with each other by passing notes or invitations to birthday parties. Even after establishing and communicating the desire to develop a reciprocal friendship, the pair needed further support to maintain this relationship.

T4: "Even though she was capable of asking him 'will you be my friend' and he was capable of saying yes, I think that became the point where it was like .. 'what do we do now? how do we do this?'"

This observation suggests that supporting children with ASC establishing friendships is not sufficient as they may also require support maintaining these new relationships (Long, Brown, Daly, Gibson, & McNeillis, 2018). Children's need for external support was discussed in the work of Calder et al, (2013), where they highlighted the need for parents and teachers to be actively involved in establishing friendship for children with ASC.

Theme 2: Strategies to Support Friendship

Here we identify three strategies to support friendship development; 1) incentivise collaboration, 2) initiation and fading, and 3) providing safe spaces. The first two are related to the activity and interaction between the children while the third is relevant to the environment where the interaction takes place.

Incentivise Collaboration: Teachers identified collaboration as one of the features necessary in an activity to enhance social skills for autistic children.

T10: "Typically having an activity that they will enjoy and it also require them to engage with other people ... at the glee club they need to work together ... sing together ... act together."

However, collaboration between children with ASC can be challenging.

T6: "[Because of] the different needs they can get frustrated with each others' needs "

If given the choice, children often preferred to work on their own.

T4: *"a lot of the kids are actually quite happy to work on their own. There is not a lot of group work that goes on around here and collaboration... again I think that is probably ... the autism ... they do not do well in teams."*

Children often needed support to engage in collaborative tasks. Hence, teachers developed strategies to foster collaboration and increase pupils' engagement with each other. In this case, a support staff member is running a fantasy role playing game based club where each player creates their own character and goes on an imaginary adventure where they can make decisions on what they want to do in different situations. The support staff here manages the game and tells the story. The support staff describes here how he encouraged collaboration with other players by making it necessary for advancing in the game.

T8: *"Well I am trying to get them to do team work, working together, and if they don't team work then I kind of go like 'that did not happen' ... 'that did not work you need to think of another way' or 'ask this person they might have something they can help you with' ... to get them to strategize together and open that dialogue. Sometimes I will just openly say 'alright what do you want to do?' and give them options 'do you want to go to them and ask them for help? or do you want to try this on your own?' "*

Given its collaborative nature, another teacher expressed how participation in sports can be a good way for fostering collaboration. Even in sports which are generally competitive, such as tennis, children need to ask others to join them in order to be able to play the game.

T10: *"Sports are great for that because they got to get up and ask 'do you want to play a game of tennis with me' ... 'should we play football' and while they are playing 'pass to me'*

they got to communicate and work with people even if they are not friends with them they still got to get on with them for the situation they are in so that helps."

Another important feature when supporting collaboration is celebrating the success of the team and sharing pleasure with others. Sharing pleasure motivates children to sustain the interaction and seek others in the future (Davis et al., 2014).

T6: *"When really nice things happen [...] they have a nice moment, so we absolutely jump on that and try to expand on it."*

These strategies focus on providing an incentive for collaboration by making positive results an outcome of collaborating with others. Wolfberg (2003) describes the social play style of aloof autistic children who only approach peers to seek help in achieving their own simple needs (e.g. opening a bag of chips). They appear indifferent to others as if they are unaware of their existence. Hence, making collaboration necessary to achieve one's goal motivates autistic children to engage in such activity (Davis et al., 2014).

Initiation and Fading: Another way that teachers exploit to motivate pupils to engage with each other is through their shared interests. Teachers actively introduce children with mutual interests to each other and encourage them to engage in discussions.

T2: *"I just introduced the two, they are both obsessed with drawings and cartoons and they are both good at them. So I introduced them just now [...] I said '[S1] come in see [S2] work because it is really like yours and you like the same things' and [S2] got really excited about it and [S1] was really pleased to show their work and then I said '[S2] you should show [S1] your work as well' so she did [...] I said 'you know if you want to come in draw in my room at lunch time or when you have free time you can do that'."*

Not only did the teacher introduce the two students using their shared interest but she was also fostering the interaction between the two by suggesting what they can do and how they can meet to discuss their common hobby in the future. Some teachers facilitate the conversation between children by asking questions to get the children to talk to each other. After initiating an interaction, teachers continue supporting the interaction but gradually decrease their involvement while monitoring the interaction and intervening when needed (fading).

T10: "sometimes I will prompt them to ask questions like if one of them says something about a thing that the other is interested in, I would say: 'Oh, you are interested in that, what do you think?' to get them to initiate the interaction that they might not have done."

Providing Safe Spaces: Safe spaces are isolated desks that allow pupils to break away from the group and work independently if they need to. Providing such space is required in all classrooms in the school where we conducted our study. This requirement is in line with Khare and Mullick's (2009) recommendation of including "withdrawal spaces" when designing learning environments for autistic pupils. Teachers realise how important incorporating such space is for providing a comfortable environment for their pupils.

T6: "It is imperative that they have a safe space quiet and dark if that is what they require."

This feature may seem contradictory to supporting collaboration but, as one of the teachers explains, it is vital to provide such a space because, when anxiety levels are high, enforcing collaboration may have negative consequences on all children involved.

T9: "[We need] larger classrooms where you can have a group area and you have areas for people to break away because sometimes we can have a lot of conflict which can be extraordinarily upsetting for other children in the room and if you are feeling anxious like

that you are unlikely to want to be particularly friendly with anyone because you are so anxious."

In contrast, some teachers are concerned about how the availability of such space is not preparing the pupils for the "real-world" where such spaces are not available. They believe that providing such space is not realistic and will obstruct children from developing a coping mechanism that is available for them in every environment.

T2: "I know that some children do need somewhere like that but we should be preparing them as much as we can for the outside world ... and if we are doing things like allowing them to crawl into their own spaces ... in the real world you can't do that."

Theme 3: Friendship support as a secondary goal

For most teachers, friendship is not a primary goal. Teachers are mainly focusing on helping their pupils get comfortable enough to engage with the lessons and do the class activities.

T5: "In terms of the playing and generating friendships that's a path that we are just starting on now that we got them calm and happy. So, I have now managed to get the class happy and responsive. They will engage in their activity, they can maintain their activity for the length of time it takes to complete that activity, they can self-regulate and they can choose on their own between task activity from the selection that I have in the classroom. We worked quite hard to get there."

Teachers struggle to create a comfortable environment where children can learn. Each child is different and has specific needs the teachers must address. An added challenge is that children in the same class can have contradicting needs which requires teachers to adjust the environment to accommodate everyone's needs.

T6: *"Just now, I mean from a teacher perspective what we did, my team and I, was what are the three absolute barriers to learning for these children? One of them was being able to be in the same room as other people. So, we put that at the top of the pile and address that issue and all the rest of the other academic goals can follow."*

Although it is not a primary goal, teachers believed that the Personal and Social Education (PSE) curriculum is where these skills are addressed.

T1: *"we've done a lot of "emotion talks" and stuff during PSE time that helps you sort of identify emotions how to deal with them and that leads them to kind of social confidence and how to make friends and whatnot. So, we've got our PSE curriculum that does that."*

Theme 4: Technology Support: Opportunities and Challenges

Availability: There was a range of technologies available in the school including tablets, PCs and smart boards. Smart boards are usually used to support the lesson (e.g. playing videos related to the lesson) while tablets and PCs are available for the children to play educational games (e.g. Sumdog) or research the lesson topic. However, given children's affinity to technology (Frauenberger, 2015), most teachers use time on the tablet as a reward.

T7: *"we normally find that if we want to get them to sort of work on their own, the way around it is to give them iPads and give them a topic to go and explore themselves. That is very successful and at the end of the lesson they know that they will get free time to do what they want on the iPad."*

Attitude: Overall, teachers had a positive attitude towards the use of technology within the classroom. They often used a range of educational apps to engage their pupils. From this teacher's perspective, children may find it easier to express themselves using the technology.

T1: *"Just trying to use as much as we can. I definitely don't use it to its full capacity and obviously for English I need them for writing. I think it is so important that they use computers and iPads just to get their words out."*

In addition, most teachers saw a great potential for using the technology in the classroom and often expressed a desire to do more with it.

T2: *"It is good ... I would like more please [h]."*

Challenges: some teachers expressed a concern regarding children's reliance on technology

T6: *"My absolute concern is that the modern child, particularly children with additional needs, they are totally invested in their virtual world [...] I suppose an aspiration for me as a teacher is to get them addicted to people .. addicted to conversing with people. and why is that? to sustain them when they are 20, 30, and 40 as opposed to setting at home looking at your screen [...] they end up to be stuck to their piece of technology"*

The teacher who was running a role play game-based club expressed that he intentionally avoids the use of technology during the game as much as possible.

T8: *"The only thing I got was my phone for the dice roller app if we forget them or for like music. Otherwise it is just pen paper and dice. I am trying to keep technology as far away as possible."*

Regardless of teachers' attitude towards the use of technology, they all acknowledge that there are some challenges to their use. A technical challenge was the internet reliability. Given that most of the activities done using technology require an internet connection, having slow and unreliable connection causes problems. Children can get anxious when they see that the internet is not working even if they are not using it.

T10: *"Some of the kids will freak out completely if the technology is not working for whatever reason, you know, certain pupils. Sometime the internet goes down because of some attack or something then you have to keep those kids away from the computers because if they even see that it is not working, they will have a melt-down."*

In addition, teachers expressed a concern regarding online safety for the pupils. Although the local educational council blocks most website which are not suitable for the pupils, some children manage to access content that is inappropriate.

T4: *"You do have to watch a lot of them because in free time if they are using something there is the potential for somebody to try and access things that are not appropriate and there is a lot of kids here that will do that."*

A recurring challenge was the ability of children to transfer from using the technology. Some teachers provide a lot of warnings to help children prepare for the change while others refrain from using technology altogether to avoid causing a disruption.

T10: *"Technology is great but it can be difficult to get the kids to move on from computers. so if they are doing an activity or watching a video then it is time to move, you need to make sure that they are prepared to move away from that and know that this change is happening .. have warnings."*

4.4 Discussion

The purpose of this study was to understand the friendship dynamic for autistic children from their teachers' perspective. Findings from teachers confirm what we previously know about the children's desire for friendship and that they do not prefer to be alone (Bauminger & Kasari, 2000). Teachers have also reported that their students often needed external support from adults around them to develop and manage their friendships. This motivates more research to understand

the type of support needed and how it can be delivered in a way that allows children to be more independent. In addition, the dynamic of the friendship and how it is often limited to a specific environment or activity requires more research to be conducted to understand how these friendships can expand beyond these limits.

Initial design requirements for an environment to support friendship are the main results of this study. Here we discuss how these requirements may be translated into features of games designed for autistic children and provide some examples from previous work. However, these requirements are not restricted to games, but might be applied more broadly.

Designing technologies that support collaboration as a way to teach social skills for children with ASC is a topic explored in previous studies (Battocchi et al., 2009; Piper et al., 2006). However, simply engaging in a collaborative task does not necessarily support collaboration (Giusti et al., 2011). Children will often work independently or even compete with each other. It is vital to provide an incentive to collaborate with others which can be implemented through using different strategies. Hourcade, Bederson, and Druin (2004) provided incentive for collaboration by providing additional features only available when collaborating with others. Another strategy was using cooperative gestures (Morris, Huang, Paepcke, & Winograd, 2006), which are gestures that need to be performed with others to give a single command. This makes collaboration with other a necessity to complete a task (Giusti et al., 2011).

Boyd et al. (2015) evaluate the effectiveness of the collaborative iPad game (Zody's World: The Clock Catastrophe). The game is based on the Developmental Individual Differences, Relationship-Based (DIR) framework (Davis et al., 2014) and its features are designed to reflect different DIRFloortime strategies. DIR utilizes human connections to promote the child's development through playful activities. DIRFloortime is a set of strategies derived from the DIR

model and are an application of the model's principles. Zody's world game adopts some of these strategies as features in the game. For example, to facilitate experience of mutual joy, which is one of DIRFloortime strategies, designers implemented rewards for success in the game tasks. Furthermore, cooperative gestures are also implemented here to reflect the "Being necessary" strategy of DIRFloortime. Participants in that evaluation made positive comments towards each other while playing Zody's World and reported forming a friendship throughout the study. These results are promising and encourage further research in this direction. However, Boyd et al. (2015) state that the question of whether engaging in collaborative tasks will lead to sustained outcomes (i.e. long-term friendships) is yet to be answered. Based on our initial findings, we anticipate that collaboration could lead to friendships, but this needs to be more fully explored in future work.

The initiation and fading strategy used by the teachers is similar to what Collins, Brown, and Holum (1991) define as fading. In the cognitive apprenticeship theory, the master of a skill teaches an apprentice by scaffolding, modelling and providing feedback then gradually fading the support as the apprentice's skill increases. The concept of fading from the cognitive apprenticeship theory can be applied in a virtual environment by introducing adaptation in the environment. This can be by increasing the task difficulty as the skill level of the learner increases or by providing hints when the learner makes a mistake. Both techniques have been used in serious games for autistic children (Mora-Guiard et al., 2016; Schuller et al., 2013). Although fading as a strategy is not explicitly designed in the game, it is implicitly part of the design.

In our study, teachers highlighted the importance of creating safe spaces where they can break away from the group when they need to. Although this may seem unnecessary in a virtual environment where the player can exit the environment at any time, Ringland et al. (2016) show how having a "Safe Space" is a requirement even in a virtual environment. Ringland et al. (2016)

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conducted an ethnographic study of the autistic community of Autcraft which is a Minecraft server for autistic individuals. In the Autcraft world, the players created "sensory regulating spaces" which are holes in the ground that players go to when they are overwhelmed by sensory stimulation. When they go to these holes in the ground, the screen become completely dark reducing the visual stimulation. Rather than simply exiting the game or turning the monitor off, players preferred to create a space within the virtual world where they can feel comfortable. Nevertheless, their research does not address whether providing these safe spaces supports socialising.

These interviews with teachers allowed us to contextualise autistic children's relationships with their peers, and to identify teachers' strategies for supporting friendships for children with ASC. Teachers often facilitated the interactions between the children and played the role of "matchmaker". However, supporting friendship is not often the primary goal for teachers. This is consistent with Calder et al.'s (2013) findings of how teachers and parents prioritise academic and behavioural goals over supporting friendship. Given that supporting friendship is not a priority for teachers and with the availability of a wide range of technologies within schools, designing a tool that support the teachers' role in scaffolding the interaction between children with ASC would be valuable. Nevertheless, design decisions need to be made to address the challenges of the use of the technology within the school. For example, the tool should not require an internet connection and it should provide a suitable way to prepare the child to transfer from the technology to other activities. This can be achieved by using timers or periodic messages that warn the child of the time left to complete the activity and the need to move on.

This study has some potential limitations which need to be considered when reviewing the results. Due to a major incident recently occurring in the school, the interview questions were

extensively reviewed to remove any questions that may potentially be misunderstood as an indication that this study was to evaluate the teachers' performance. Instead, the questions were rephrased to highlight the value of participants' role in this study as informants to the design. Nevertheless, some teachers were defensive during the interviews when talking about how they support their students. Another issue was that one teacher was not comfortable with audio recording during the interview and only agreed to note taking which compromised the richness of the data collected³.

In addition, observing or interviewing children in this school was not possible as teachers were reluctant to ask for formal consent from the children and their parents or audio record the interviews.

Exploring strategies to support friendship and how they can be incorporated in technology to support friendship might have been addressed by conducting focus groups with teachers and brainstorm ideas rather than with individual interviews. However, the changing schedules and absence of staff in some cases led to the decision of using interviews instead and looking for emerging themes among all interviews in the analysis. Nonetheless, it is important to recognise the issues around involving teachers in the design process in order to help designers to develop design methods which fit their target participants' circumstances. Researchers often find themselves in a less than ideal situation where the optimal study design cannot be achieved. This should not stop research in this area but rather it should encourage more research in understanding how to best utilise available sources of data and what can be inferred from them. Next, a discussion of how teachers were used as proxies in this study and how this experience can inform future research design is presented.

³ This is a common issue as teachers often are reluctant to be audio or video recorded (Helen Pain, personal communication, 18 August 2022)

Teachers as a Proxy

Although children themselves are the ones who experience friendship and challenges around its development and peer interaction, they might find it difficult to articulate the challenges they face. Furthermore, it is unrealistic to expect children to identify strategies to help them overcome the challenges with friendship development that they are facing as it assumes children have the social skills to come up with these strategies in the first place. Their being able to identify strategies contradicts the fact that they are facing these challenges. Hence, it is necessary in this context to consider proxies who can identify challenges and suggest ways to overcome them.

Teachers as proxies have many advantages over others who may play this role. First, teachers are trained to deal with their students' challenges and are taught strategies to support their needs. Their first-hand experience applying these strategies in a real, uncontrolled environment is very valuable in understanding what would truly be applicable in a real world context and what challenges may arise.

Unlike parents, teachers have access to a larger number of children with ASC with varying needs which makes them a good source for understanding what strategies work for supporting friendship and how to adapt these strategies for each individual child's needs. In addition, teachers in an autism-specific school work directly with autistic children and deal with a smaller number of children in each class which allow them to have deeper understanding of their pupils' needs and ways to support them. In addition, children spend most of their day in school where they interact with their peers which leads to most children's friendships developing at school (Kasari, Locke, et al., 2011). Teachers can observe the development of such relationships and the challenges their students face since they are in the heart of where such relationships are usually made. This makes teachers an important proxy to consider for problems relating to peer relationships.

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In this study, teachers were able to describe the nature of their students' relationships and share strategies they use to support friendship. Teachers acknowledged their students' need for external support and how they often needed to play the role of matchmakers by suggesting possible friends to their students. They also facilitated the interaction between pairs in order to help them develop and maintain their friendship. Nevertheless, an important finding from this study is teachers considering supporting friendship as a secondary goal and not the main focus when it comes to supporting their students. As designers, we now know that teachers are not the best intervention agent to consider when designing for friendship specifically. However, for interventions to support academic progress teachers may be considered as an intervention agent since they regard this as their main role.

5 EXPLORING PARENTS PERSPECTIVE ON THEIR CHILDREN'S FRIENDSHIP AND THE ROLE OF TECHNOLOGY IN SUPPORTING PEER RELATIONSHIPS

5.1 Introduction

The United Kingdom was in and out of lockdown as a response to COVID-19 pandemic in 2020 and 2021. The first nationwide lockdown began on March 26th, 2020 (IfG, 2021). It was followed by another lockdown on November 5th, 2020 and a third one on January 3rd, 2021 (IfG, 2021). During lockdown, schools closed and moved to online learning and social interaction was restricted (IfG, 2021). These measures limited children's opportunities to socially interact with peers as normal. Consequently, online tools became the primary way for young people to connect with peers to overcome lack of in-person interaction (Quinones & Adams, 2021; Waite et al., 2021). Although social media and online interaction have been used

by adults and adolescents for years, it is new territory for many children as they normally depend on in-person interactions.

During lockdown most businesses moved to remote working, so most parents spent more time at home with their children. This allowed them to be present for most of their child's school time and to have the opportunity to observe their socialising attempts online. This presented an opportunity to explore parents' perspectives on their children's experience with friendship during lockdown and to see how children used technology to mitigate the effects of lockdown on their friendships.

This chapter reports the findings of an interview study conducted with 17 parents of neurotypical and autistic children. The goals were to understand their children's experience with friendships, to see whether they have any concerns about their children's friendships, to determine their views of friendship and neurodiversity and to see how their children used technology to support friendship development and maintenance before, during and after COVID-19 lockdown.

In particular, this chapter addresses the following research questions:

RQ1: What role can proxies play in the co-creation process of technologies to support friendship?

RQ1.2: How can parents inform the design process in the context of supporting friendship?

It explores the role of parents as proxies by investigating friendship between children from their parents' perspective. The data was collected during a time when COVID-19 lockdown and social distancing restrictions were easing down. Hence, the data is highly influenced by the circumstances in which it was collected.

This study was conducted in collaboration with two students, Alicia Smith and Taylor Bartow, studying for an MSc in Psychology of Mental Health. These collaborators were

involved in recruitment and conducted some of the interviews themselves while the thesis author observed them. The MSc students were only interested in exploring the experience of neurotypical children. In addition, they were looking at it from a psychological perspective rather than a design one and they conducted their analysis and disseminated the results in their own MSc dissertations (Bartow, 2021; Smith, 2021). The author of the current thesis conducted their own analysis on the data (collected collaboratively) and included data from parents of autistic children that were collected solely by the thesis author to serve the purpose of this research.

5.2 Methods

5.2.1 Recruitment

Participants recruited for this study had to meet the inclusion criteria below:

1. a parent or a guardian of a child between the ages of 8 to 14;
2. able to participate in an interview using video conferencing software (e.g. Microsoft Teams or Zoom);
3. their child can be either neurotypical, have an autism diagnosis or be in the process of being diagnosed.

We used different channels to recruit parents: below is a list of ways we advertised the study:

1. Posting into multiple Facebook groups that support parents of autistic children.
2. The research team shared the study advert through their personal contacts and social media.
3. Contacting a mailing list of parents who previously participated in similar research studies and indicated that they wanted to be contacted to participate in future studies.
4. After obtaining approval from local authorities, a poster was shared with schools' head teachers, by email, to advertise within their school.

5. Contacting multiple organisations for autistic children to advertise the studies within their communities (e.g. Lothian Autistic Society).
6. Posting the study advert in parenting forums such as Mumsnet.
7. Sharing the study advert on autism research organizations' and charities' websites such as Autism Speaks.

Although multiple channels were used to recruit participants, most parents who participated came through personal contacts.

5.2.2 Participants

Participants in this study include 17 parents, 4 of which are parents of autistic children. Participants PA11, PA12, PA14 and PA17 were parents of autistic children as the 'A' indicates that their child has an autism diagnosis. All participants live within the UK. Table 5.1 shows participant demographics.

Table 5.1: Parents' Demographic Information

Variable	Frequency (<i>N</i>)
Parent Highest Qualification	
School Leaving Certificate	3
Bachelor's degree or equivalent	6
Postgraduate university degree or equivalent	5
Further vocational training for specific industry	1
Unknown	2
Parent Marital Status	
Married	12
Single	2
Partner	1
Unknown	2
Work Situation	
Full-time paid employee	6
Part-time paid employee	5
Homemaker	2
Unknown	4

5.2.3 Procedure

Once parents registered and consented to participate in the study, they were contacted by email to arrange with them a suitable time for the interview. Interviews were conducted online using Microsoft Teams or Zoom depending on the participant's preference. Semi-structured interviews were conducted between April 2021 and January 2022 which was a transitional phase where COVID-19 restrictions were easing across the UK. During this period, children had already returned to schools. Other restrictions regarding social contact persisted but were later removed towards the end of that period.

Interviews were conducted with video cameras of both interviewer and participant turned on however video was not recorded. The interview started with a general discussion about their child's friendships and then it specifically discussed three main themes: 1) friendship between similar (autistic/autistic or neurotypical/neurotypical) pairs and mixed (autistic/neurotypical) pairs; 2) friendship online vs offline and 3) friendship during lockdown. An initial set of the questions was developed by the thesis author and shared with collaborators to ensure that the current set of questions was sufficient to serve the purpose of their independent research goals. Given that the two collaborators were focusing on the experience of neurotypical children and were not considering autistic children, the first theme was irrelevant for both of them and was added for the purpose of this research, while the questions on the remaining themes were agreed among all collaborators (see Appendix B for the interview questions).

By the end of the interview, Participants received compensation in the form of a £10 Amazon voucher for their participation in the study. They were also asked if their children were interested in being interviewed as well and were provided a registration link for the children's interview study. Interviews varied between 20 to 75 minutes in length. Interviews were transcribed using Otter.ai ("otter.ai," 2022) then manually reviewed against the original audio-recording to ensure the accuracy of the transcriptions.

The transcripts were thematically analysed using an inductive approach to identify patterns within the data without specifying predefined themes. Nvivo Version 12 software was used to code the transcripts and produce the themes and subthemes. Thematic analysis process employed followed Braun and Clarke's (2006) guide.

5.2.4 Ethics

Following ethical approval from the School of Health in Social Science Research Ethics Committee, an advert was shared through various channels. Informed consent was obtained from participants using the registration form after providing information (Appendix C) about the study. Furthermore, a verbal protocol (Appendix D) was read aloud before the beginning of each interview and verbal consent was obtained from the participant. A debrief (Appendix E) was read aloud to participants after the interview to allow participants to voice any concerns they might have. Participants' privacy was ensured by privately sharing the meeting link and invitation with the participant by email. Participants' permission to be audio recorded was obtained before the start of the interview and all interviews and transcripts were stored in an encrypted folder on a university-secure server, separately from any identifying information and accessible to the research team only. In addition, names and other identifiable information within transcripts were anonymised using participant identifiers to ensure anonymity and confidentiality. All audio recordings were deleted after transcription for data-protection purposes.

5.3 Results

Three main themes emerged from the analysis of parents' interviews: Properties of Online Socialisation, Impact of COVID-19 and Lockdown and Nature of Friendship Between Autistic and Neurotypical Children. Resulting themes mapped perfectly to the themes of the questions explored. Each question theme explored has a corresponding theme which resulted from the

analysis of the interviews. Figure 5.1 illustrates the thematic map showing the main themes and subthemes identified.

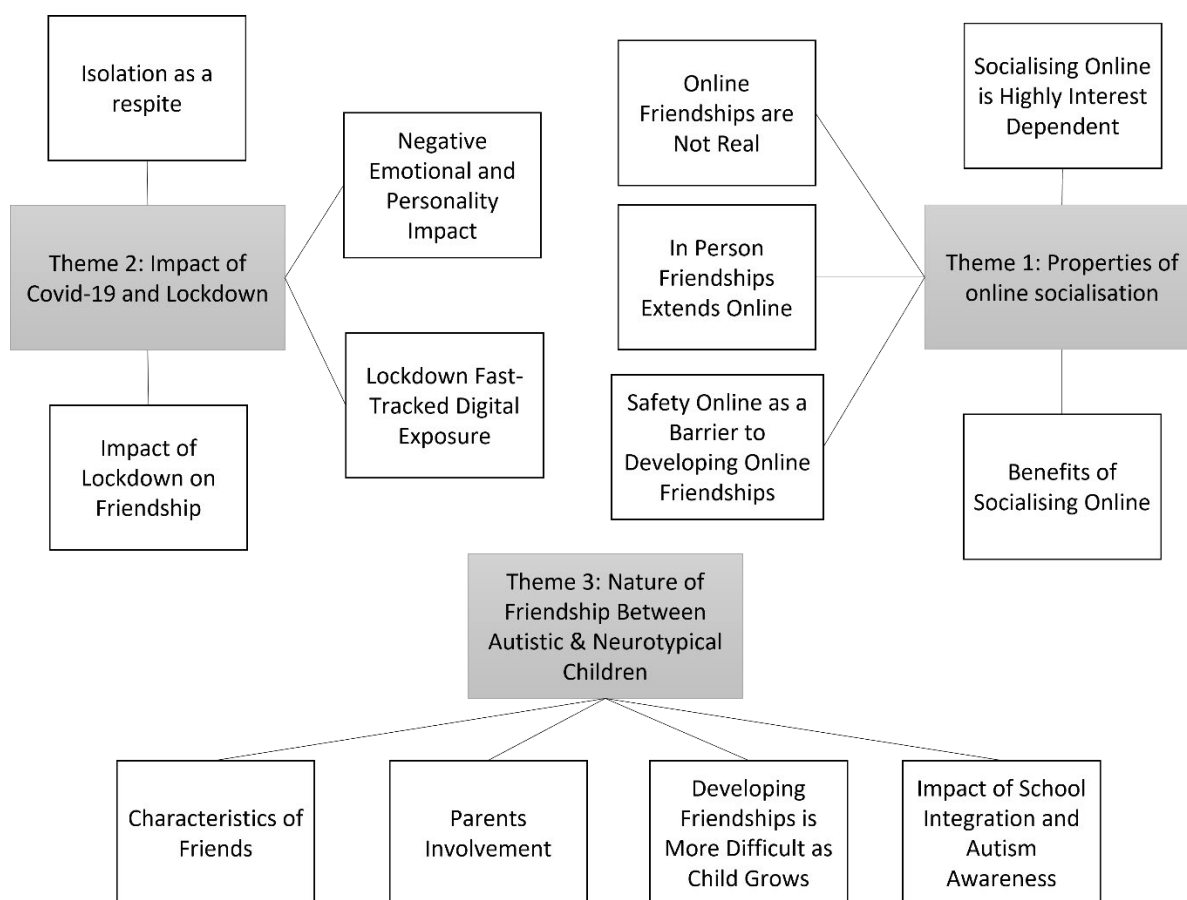


Figure 51.: Thematic Map of Parents' Perspective

Theme 1: Properties of Online Socialisation

Socialising Online is Highly Interest Dependent: Parents believed that their children's success with online socialisation was highly interest dependent. This was especially true for children who were interested in gaming as P1 expressed:

"I suppose he's quite geeky, you know he's into computer games, he's into Minecraft, um and he's into things like The Walking Dead and stuff like that. So um I think that there will be a lot more people online that he can talk to about those kinds of things than there would be in his kind of face-to-face real-life friends".

Children who have 'Invisible interests' would have better chance finding people with similar interests when socialising online as P9 described:

“he'll get to meet other people because he's not really into football and things like that, he's more into computing and things. So I think it's harder to find people who are into those things because it's not so visible, they don't go outside and you can see people playing football”.

PA14 explained how the shared experience of talking to a friend through a Zoom call while playing Minecraft together was the element that allowed her child's friendship to grow online:

"There is a Zoom call, but there is also Minecraft and I would say that their shared experience through the game was what made that different [...] So they get on much better [...] they really developed a very firm friendship over this over the lockdowns [...] he would say I love you when he was hanging up and all this kind of stuff."

However, children who are not interested in things such as gaming may feel excluded when interacting with others online as P10 shared her daughter's experience:

“She had no reference points for those Zoom things [which] quickly turned into let's play Roblox together. But she didn't do all of that [...] I think she was feeling excluded.”

Parents believed that this made the relationship 'one dimensional' evolving around a specific interest but nothing else as P2 states:

"it's fairly one dimensional. They just play Minecraft and shout."

PA14 explained how her child had a difficult time socialising online as they quickly lost interest and could not continue to interact with groups he signed up to meet with online:

" when it was during the lockdown, we tried to do Zoom calls. No, absolutely not. He would just lose interest within seconds [...] He didn't want to engage in the Zoom calls. He tried it a couple of times, it wasn't for him."

When asked whether she believed her child preferred to develop friendships in person or online, she responded:

"he has no patience for sitting still and watching the screen. So, I couldn't tell you what might happen if it did work. What I can tell you is that we tried it and he just left within a minute".

PA14 did not believe that platforms such as Zoom were suitable for making friends especially when the Zoom call had many participants:

"Zoom is a very difficult social space, as you know. And we all modify our behaviour, when we're on Zoom, if there's a big call, you know, it's quite hard to jump in to say something. And for the people who aren't very, very confident, then they just sit there listening for the whole time [...] I think for more than two or three people, I don't think it's a very useful friendship platform."

Online Friendships are Not Real: Parents mostly did not view online friendships as 'real' as P2 was sceptical of his child's ability to develop 'proper' friendships online:

"He claims that he has, you know, transitioned many of his friendships to online. That's his view, but his experience is limited being 12 years old and I believe it's more difficult to make proper friendships in that way".

Parents believed online friendships lacked connectivity as P8 described:

"they need to see each other, you know it's the connectivity you get, which you just don't get online".

Parents believed that engaging in a conversation online was especially difficult for children as P8 explained:

"the conversation doesn't flow in the same way that an adult perhaps would, because children need quite often physical stimulus [...] or being together to play a game or to [...] sit and do a collective activity".

P10 echoed this by stating how engaging in a conversation over Zoom was *"exhausting and [...] ineffective really"*. PA12 shared her concern about her child only interacting with others online illustrating how he needs to be able to do activities with his friend:

"they need to interact, playing, playing football or soft play, or even to go to the cinema. They used to go cinema a lot as well. You know, it's just limited to talking."

Parents also highlighted how people can be perceived differently when interacting with them online. P3 describes the contrast between the reality of her child's friend and how her child imagines him to be:

"I imagine that C3.1 sort of built him up, to be this really amazing character, but he's just a normal little boy is what I mean. But I think because when you're online, you can have like an alter ego can't you."

Safety Online as a Barrier to Developing Online Friendships: In addition to the limitations of online socialization identified by parents earlier, many parents believed that being cautious when interacting with others online would be a barrier to developing strong friendships in this way. As P1 explained:

"I think he's got much more of a relationship with his face-to-face friends, but I think that is mainly because we've always kind of said to him, if you're talking to people online, you don't disclose this information, you don't disclose that information".

Some parents apply strict rules on who you talk to and what to talk about which make it difficult to develop friendships. This was illustrated by P9 rules on online socialization:

"we're quite strict [...] he doesn't tend to chat in public games and things just in case somebody odd. And we don't let them accept friend requests."

PA12 was especially concerned about her child interacting with others online due to his condition as she explained:

"Because of his condition. He trusts everybody. Yeah. And when I asked him, 'Who is the guy you're playing with?' he just gave me the nickname. He doesn't have any idea who he is. So that's my concern."

Concerns about safety online led some parents to limit their children's socialisation to groups known to the parent beforehand. As PA14 explained:

"I don't have any concerns about him meeting people on the internet, because I'm in control of that. And I wouldn't sign him up to anything where there was strangers there. But if it was something within an existing group, like Woodcraft folk or the school, yes, I'd be more than happy for him to do that."

Benefits of Socialising Online: Although parents' view of online socialisation was mostly negative, some parents acknowledged that socialising online may help their children develop their skills and confidence. P8 believed that talking to others online developed her daughter's conversation skills:

"She was quite good at it [...] probably enhanced her questioning of her friends. It probably taught her how to maintain an audio conversation as opposed to a physical".

P9 explained how not getting a reply to your text has a less negative feeling compared to being ignored or rejected in person:

"It's been a kind of a nice way that if you think well, I want to chat to that person, but you don't want to walk up to their face and be rejected. If you sent them a text, it's not so bad".

In Person Friendships Extends Online: Parents believed that their child in-person friendships often extended online. As P5 explained:

"Coming home and going on the PlayStation is just an extended part of their day really, just still hanging out together".

It was just the way to stay connected with their friends as P4 states:

"She spends time facetimeing them in the evening as well. Social media definitely plays a big part in [...] friendships in general, just the way of staying connected at the time".

In some cases, friendship which were originally made in person were only maintained online when it was the only way to stay connected. P4 gave an example:

"we went to Turkey for two weeks and he met two boys from Wales so again they're now online friends".

When asked whether her child had any online friends PA14 replied:

"as an initial meeting, I would say no, for many reasons, but as a development of a sort of existing relationship, then it's worked quite well."

When asked to compare their child's interaction with the same friends online versus in person, parents of autistic children expressed that interactions online can be more competitive and aggressive due to interactions being mostly around gaming. PA17 explained:

"it can get quite competitive and aggressive [...] especially if somebody is letting the team down. when they're in person it's not too [aggressive] unless it goes too long and then they start getting fidgety."

PA14 echoed that comparing her child's relationship with his friend and how their interaction when playing Minecraft online differed from when they were playing together on a camping trip:

"in the summer we went camping together. So we had a week together where he was with her as well. So I would say that they argued more when they were online, but that's because they were in the game, they were kind of hitting each other or getting in each other's way. Whereas in real life, they just kind of went around the woods and hit nettles with sticks, you know, so I think they argued more online. But again, the context of that is they're playing Minecraft. So yeah. Its okay to hit each other with fireballs."

PA12 expressed concern about her child getting overly upset when interacting with friends online which led her to try and limit his online interactions:

"because he doesn't like losing games. Yeah, he can't understand the rules. He's not able to manoeuvre the control and [his friends] don't understand if they're playing a fight. I can hear him say 'don't kill me! don't kill me!' and the other boys are laughing because he's begging them not to kill him. So, because of that, we are trying to limit his time on the internet".

Theme 2: Impact of COVID-19 and Lockdown

Isolation as a Respite: Some parents observed that isolation and lockdown had a positive impact on their child. P4 shared her child's experience:

"she was in a bubble for, obviously, from June through to the end of the summer term. And her bubble was kind of a group of six of them. And I think she found that, she really, really liked to being in that bubble".

When asked how lockdown affected her child's friendships, P10 expressed a positive impact saying:

"It's interesting [...] I think it did provide this respite."

PA17 has also had a similar experience with her child as she believed the lockdown made him happy saying:

"he was quite happy. He was really happy with that".

Impact of Lockdown on Friendship: Parents believed that younger children handled lockdown better compared to teenagers. P8 compares how their positive experience would change if her child was a couple of years older:

"I think we're quite lucky at C8's age of children, most friends seem to have managed to get through it okay. Whereas I think if we had a, potentially an 11-year-old, maybe

year six or going forwards, sadly, I've heard of a lot more problems with kind of, yeah, teenagers".

This idea was echoed by P5 justifying that self-awareness might be the reason why it may be more difficult for older children:

"C5.1 is quite good, but maybe that's a younger thing. Teenagers are a little bit more self-aware."

When asked about their children's experience with maintaining friendships during lockdown, parents' answers varied. P1 believed that having a good foundation for friendships made it more sustainable to such circumstances while casual friendships may fade away. She illustrates by comparing the experiences of her two boys:

"C1.2, I don't think it had as much of an effect on his relationships um and his friendships. Um I think particularly because he was always talking to them over Xbox and things like that, and he used that as a way of keeping in touch. But then he's got a lot more solid foundation in terms of his friendships, whereas C1.1 kind of, you know, flits between people more so".

PA17 confirmed how her child was able to maintain the friendships he made in person online during lockdown:

"Yeah, the friendship continued. But online rather than in person."

P8 believed that, although her daughter managed to keep her friendships going, these friendships would not last if the situation extended. She states:

"you can keep it ticking along. But definitely, you couldn't maintain that for much longer".

When asked whether maintaining friends was easier online, PA14 believed that being able to communicate with friends online was the main reason her child was able to keep his friendships going:

"yeah, absolutely. I mean, we wouldn't have that friendship at all. If it wasn't for us kind of all becoming used to using video calls as a relationship device".

Negative Emotional and Personal Impact: Although the continuous and unexpected change to routine and repeatedly being in and out of lockdown was frustrating for most children and parents, it was especially difficult for autistic children as PA14 explained:

" I think perhaps one thing to say is that the second lockdown, the January one, was a big trigger point for us. CA14.1 had been doing really well in school up until Christmas 2020. And then when he was pulled back out of school for the January lockdown, that's when the major problems started. So, the on again, off again, nature of lockdown has not served kids with behavioural challenges well, and that's been very, very difficult for us."

Understandably, parents reported that lockdown limited the socialising opportunities available for their child. As PA12 explained:

"the only friendships he had were his brother and his friends from the school. So, his friendships were limited to two or three. Before, he would meet a lot of boys."

Some parents reported their children feeling lonely, as P10 expressed:

"she was extremely lonely during the first lockdown".

While others observed a change to their child's personality as P1 states:

"he became quite shy over lockdown."

Some parents were concerned about long-term effect on their children's understanding of socialising norms especially when the child did not go to school prior to lockdown. PA14 shared the experience of her child:

"I think kids like CA14.1, who that's their full experience of school, is having all these rules and that you're not allowed to hug in school, all this kind of stuff. I think he just wouldn't even know that that's the thing that you do. Because he's never had any other

experience of school [...] they probably are quite unsure about socialising with other people, because they have been repeatedly told that it's not [allowed]."

Lockdown Fast-Track Digital Exposure: Parents believed that the lockdown fast-tracked their children's exposure to technology. Allowing their children more 'screen time' and providing laptops, tablets, phones, and other technologies was essential especially since schools transitioned to online learning. Parents also had to allow their kids to socialise with their friends online by allowing them to interact with others through social media, online gaming or messaging and video calling services. P6 explained how they had to provide a laptop earlier than they were anticipating due to lockdown:

"I don't think we would have got her a laptop like this early. Probably. Um you know, until it was like really needed. But um yes, I think it's probably like fast tracked some things".

P9 shared a similar experience of how they had to allow their children to be online more than they used to:

"he wasn't online as much, I think, because of Covid we kind of let them go online more."

PA12 was torn about whether this was a good decision or not and have expressed regret and thought this unplanned early exposure has negatively affected her child as she explained:

"that's why we gave him the Xbox to play but I regret that. but another side is it is good for him to have a relationship. [...] He's growing up. I can't protect him forever [...] I want to prepare him for the world [...] my heart is concerned".

Many parents felt that their children were overwhelmed when the circumstances led them to socialise online more. Sharing her child's experience:

"in the first lockdown, I think it was such a sudden change. C4.1 found the load of messages [...] that she was receiving quite intense and that compulsion to instantly

respond. So, there was a period in the first lockdown where C4.1 decided that she would put her phone away completely".

This was especially prominent with younger children who are not used to socialising online.

P9 had a similar observation with her child:

"I think it just overwhelmed C9.1 [...] having lots of people talk at the same time because they weren't really sure how to negotiate a meeting online [...] before COVID, they didn't really chat online."

Theme 3: Nature of Friendship Between Autistic and Neurotypical Children

Characteristics of Friends: There appeared to be specific characteristics of friends who autistic children tended to approach and eventually befriend. Similarly, neurotypical children who successfully develop and maintain a friendship with other autistic children are likely to have common attributes as well. Autistic children sometimes choose to befriend others on the spectrum although other neurotypical children are available to them. This is what PA17 explained about her child's experience: he had been attending a mainstream school with many neurotypical children, however 'he hunts' for other autistics friends:

"It was about maybe six or seven with diagnosis or with suspected diagnosis as well. So, he hunts. He's got like 5, I think."

Parents have also reported that their autistic children often seek neurotypical peers who are nurturing and take care of them to some extent as PA14 shared:

"he likes to hang out with older children who kind of look after him [he] likes to be looked after. he likes to have somebody who is caring, like with him all the time. So, there's two girls who play that nurturing role for him. And that's, I would say, his two closest friendships, and neither of them are autistic."

Parents of neurotypical children who have autistic friends confirm that their children do hold these characteristics which make their relationship with their autistic friends successful. As P3 explained:

"I think C3.1 knows that they need a little bit more extra help, a little bit of extra patience. And so I think with [autistic friend], and when he started school, I remember [autistic friend]'s mum saying that [autistic friend] was really struggling in the playground, I think that C3.1 sort of took his hand and I think, yeah, I don't even know if C3.1 remembers this because it was a couple of years ago. But back then his mum said that C3.1 was really kind to [autistic friend] and looked after him ensuring he would be okay".

Parents' Involvement: When it comes to developing friendships, parents of children of autism are heavily involved in the process. This was confirmed both by parents of autistic children and parents of their neurotypical friends. P2 explained how the mother of her child's autistic friend was always planning meetings and thinking about activities for the children to do:

"there's one particular friend that I'm thinking of, and actually her, the friend's mother, gets involved a bit, and helps to arrange their meetings and think of things for them to do together sometimes and things like that. So obviously, it's a bit more thought and preparation, gone into that."

PA14 confirmed that by sharing how her involvement during her autistic child's social events made them more successful:

"Anything where I'm there with him is more successful".

Developing Friendships is More Difficult as Child Grows: Parents believed that developing friendships became more difficult as the child grows. PA17 was successfully developing friendships when he was younger, but she is now concerned about him developing friendships. When asked if she believed him growing was the reason she was concerned, she replied:

"Yes, definitely. He did try. now it's more ... [difficult]"

P5 explained how growing into teenagers introduced problems between her child and his childhood autistic friend. She justified this change saying:

"it's such a big period of change in teenagers' lives, isn't it? So much going on. You've got exam pressure, physical pressure, all the pressures."

She also explained how her child meeting his autistic friend during junior high when they were younger made him more accepting of his friend's traits while others who have only met his autistic friend in senior high are less tolerant:

"C5.1's been with [autistic friend name] since junior school. And as [autistic friend name] has got older, it's become more and more apparent that someone like C5.1 and a couple of the other boys understand the issues. But children that have met [autistic friend name] in senior school have had a lack of understanding about his behaviour. So, they don't find it as easy to tolerate."

Because younger children were believed to be more accepting of differences and found developing friendships easier, P10 believed early childhood was a good time for integrating children with autism in mainstream schools. She explained:

"I think children, I do think children of this age are remarkable in their, in the way that they accept exactly what they see [...] It's why the junior school with its mainstream inclusion proved positive [...] they learn to understand difference, but they also don't declare it as difference necessarily. Teaches a lot, I think".

Impact of School Integration and Autism Awareness: Parents believed that integration of autistic children and children with other developmental conditions within mainstream school have definitely increased acceptance of children with these conditions among their peers and made difference part of everyday life. This is what P1 explained:

"because of inclusion and things like that, they've been in classes mixed with children with differing needs. So C1.1 got a wee boy in his class with Down Syndrome, and I guess it's kind of part of everyday life for them."

Parents believed that their children might not feel a difference when interacting with their autistic peers as P7 expressed:

"He probably wouldn't treat them differently. From his point of view, he wouldn't probably feel the difference."

While other parents believed their children would notice a difference, but it would not necessarily change the way they treat others with autism. P1 explained how her work within autism made her children more knowledgeable about autistic traits but it did not change the way they interact with others:

"my area of work is within Autism, so they're reasonably knowledgeable. C1.1, for example, would say 'Oh, I think that boy has Autism' or what have you, because he knows particular traits, but I don't think that they would socialize any different with them."

Nevertheless, some parents felt that their child's needs and abilities are not understood by their peers which leads their child to be emotionally hurt as PA12 explains:

"they don't understand his condition. So they play. For example, make a joke. He doesn't understand. And they don't understand his limitations. they play as normal without taking care, then he can be hurt or most of the time he's upset."

P5 attributed this lack of understanding to autism being an 'invisible' condition where you cannot visually 'see' the difference in someone with an autism diagnosis. P5 explained:

"me and my sister have said, because [child's name] looks different with her Down's Syndrome, children are more likely to understand that she's different [compared to] a child that has autism, who will look perfectly normal like every other child."

She then continued to say:

"They can't see the difference, children are very visual, aren't they? So they don't see the difference. They just think that [autistic child name] is being really irritating."

Autistic children attending mainstream schools sometimes need to spend more one-to-one time with a teacher due to their needs which means they might not have many opportunities to socialise with others. This was the experience of PA14's child as she explained:

"CA14.1 spends very limited time in the classroom. At school, He's very, very disruptive and he tends to be by himself with a teacher somewhere else. So, he hasn't really actually had opportunity to make any friends at school."

5.4 Discussion

This study was conducted to explore parents' views of their children's friendships specifically looking at friendship and neurodiversity, and comparing online to in-person relationships and interaction. This study taking place during a period when COVID-19 lockdown and social distancing restrictions were easing down might have made parents more focused on their children's relationships as they had the opportunity to meet with others and were less distracted by online learning since children returned to school. In addition, schools moving to online learning and parents mostly working from home allowed parents to closely observe their children during social interactions.

Parents believed although some children might be able to successfully socialise online, it was not a suitable medium for all children. It was highly interest and conversation dependent, meaning that if the child was more into active play or was not good at keeping a conversation going they will struggle to start or maintain friendships online. Nevertheless, they acknowledged that when the circumstances made children rely on online interaction and video conferencing technologies to socialise, it allowed their children to develop their conversation skills. It also made children more willing to initiate interactions with others without the fear of

rejection, given it is easier to accept rejection when it is online. However, parents viewed online friendships as 'not real', which supports Valkenburg & Peter's (2011) displacement hypothesis which views online-only relationships as superficial and of lower-quality compared to in-person relationships. Parents have also voiced their concerns about their children's safety when interacting with others online. They believed that rules they put in place to protect their children online and constantly telling their children to be cautious when interacting with others online hinders opportunities of developing friendships online. Although the success of parents' protocols to protect their children online is a desirable outcome from a safety perspective, parents and children being vigilant about online socialisation need to be considered when designing an online tool for children to socialise. It is important for designers to consider how to design tools that are safe for children to socialise within and will also provide assurance for parents.

Parents believed that for neurotypical children to be able to develop a friendship with an autistic child they need to have specific characteristics which include being nurturing and caring. In Peer-Mediated Interventions (PMI) targeting autistic children, criteria for selecting a neurotypical peer to act as the intervention agent include selecting peers with high social status within the classroom (Chan et al., 2009). Although this does not necessarily imply that child popularity was necessarily due to them being nurturing and caring, it suggests that these specific qualities might be relevant to look for when selecting intervention agents in PMI methods. In addition, parents of autistic children observed a tendency for their children to befriend others who are also autistic even when they attended a mainstream school where the majority of available peers are neurotypical. This confirms previous research on the topic which found that autistic children mostly developed friendships with other disabled children rather than choosing neurotypical friends (Bauminger & Shulman, 2003; Locke, Ishijima, Kasari, & London, 2010b).

Parents have also confirmed the important role a parent plays in their autistic child's friendships and the need for autistic children to have their parents involved in their friendships by coordinating meetings with friends and planning and structuring their activities together. This confirms what was reported by Howard, Cohn, & Orsmond (2006) which was a single case study about the involvement of the participant's family in the participant's social life by providing social opportunities and offering advice. This also confirms what teachers observed in their autistic students and how children required external support to scaffold the interaction (see Chapter 4). Results from this study confirm what was previously found by Howard et al. (2006) of how developing friendships becomes more difficult as children grow.

Parents believed that integration of autistic children in mainstream schools was successful in helping spread awareness about autism and normalising neurodiversity and difference. Specifically, exposing children to others who are different from them from an early age can increase the probability of them being more accepting of others. This supports researchers' calls for integrating autistic children within mainstream schools and highlights the benefits of this approach (Grenot-Scheyer et al., 1998; Sigman et al., 1999).

The current study had a number of limitations that may influence the interpretation of the findings. The majority of the parents recruited had a bachelor's degree or above indicating a high level of education and potentially higher level of socio-economic status (SES). This may have been reflected in the child's abilities to access online platforms and be able to continue socialising with their friends. The current study did not recruit many parents who did not have a university qualification and may reflect groups with lower SES. Future research should explore how COVID-19 pandemic has impacted children from lower SES and those children who were digitally excluded to better understand how all children were impacted during the restrictions.

Despite the shortcomings of the current study, the current results show children's experiences during COVID-19 lockdown specifically and their effect on children's friendships. Similar to other studies, results indicated that COVID-19 restrictions had a greater negative impact on younger children as they had less access to technology and their interactions with their friends are mostly activity-based (Cost et al., 2021; Creswell et al., 2021). Scott et al.'s (2021) results show that maintaining friendships was one of the main challenges facing adolescents during lockdown. However, our results showed that older children who were used to interacting with their friends online continued to interact with their friends in a way similar to before the pandemic.

As a result of the restrictions introduced because of the pandemic, many parents felt that they had to allow their children access to various forms of technology earlier than they expected, especially since having these technologies available was essential for their children's education and social life. This effect has not been discussed in previous studies and its implications need to be explored in future research.

Parents As a Proxy

In this study, parents discussed their children's friendships in terms of who they were friends with and the nature of activities they engage in with their friends. In the case of autistic children specifically, results from this study reiterate what previous research has recognised regarding the involvement of parents of autistic children in their social life and how often they contribute to arranging meetings, facilitating conversations, organising activities and providing advice. This close connection parents of autistic children have with their children's friendships allows them to directly observe the dynamic between their child and their friend, what type of activities they engage in, which aspects are difficult for their child and the characteristics of peers they get along with. In addition, parents are able to identify personal traits that make it difficult for their child to make and maintain friendships, and to interact with their friends. Children might

be able to recognise the existence of a difficulty but they might not have the capacity to describe it or identify what it is specifically. Furthermore, parents might have tried different strategies to help their children overcome the challenges they have which the child might be oblivious to. Hence, in this context specifically, and because of the direct involvement of parents in their children's peer relationships, it was appropriate to engage them in the design process as proxies.

Another finding from this study was parents' concern about their children's safety when interacting with others online. Parents often set the rules on who their children can interact with, what platforms they are allowed to use and when they can get access to such platforms. Parents act as gatekeepers to their children's interactions online, making their perspective essential for designers in such context. Designers are not only designing technologies that are suitable for children's needs but they also need to take into account which design features are necessary to make parents allow their children to use the technology in the first place.

In addition, children of parents in this study have also participated in the other interview study we conducted with children themselves (see Chapter 6). Unlike the interviews with neurotypical children, parents of autistic children were always present when their children were being interviewed. They often intervened to explain questions or remind their children of specific instances. Therefore, although parents were interviewed beforehand and asked about what to avoid when interviewing their child, they still felt the need to be present for their child's interviews. Other parents of autistic children who participated in this study did not believe that their children would be able to participate in the children's interviews study (see Chapter 6) themselves and hence did not register for them to take part. Two conclusions can be drawn from this observation: first, parents may question their children's ability to participate in such studies which makes recruitment challenging. Second, interviewing the parents first and them being familiar with the researcher and experiencing the questions their child will be asked first hand can affect whether they choose to allow their child to take part. Parents may hesitate to

allow their children to participate in research studies when they are not familiar with the research team. Interviewing parents first and giving them an opportunity to experience the nature of the interview and discuss any concern they may have regarding their child's participation can be beneficial for recruitment. In one case, a parent of an autistic child requested that any questions regarding returning to school after lockdown should be avoided during the interview with their child as this topic was known to induce anxiety for their child. It is possible that other parents refrained from participating themselves or did not allow their children to participate as they expected triggering topics may come up based on the purpose of the study.

There are two main characteristics to parents as proxies. First, unlike teachers and practitioners, they have a close and individual relationship with their child. They can also observe their child in different contexts as well. This makes their input, although specific to their individual child, informed by consideration of their behaviour in multiple contexts. Second, compared to adults with autism, their contributions about their child experience are current and deal with present day situations rather than reflecting on past experiences. Hence, involving parents as proxies would be beneficial when the context of the problem is current and novel to present times.

6 UNDERSTANDING CHILDREN'S FRIENDSHIPS AND THE ROLE OF TECHNOLOGY IN SUPPORTING PEER RELATIONSHIPS

6.1 Introduction

Nowadays, interaction with friends is not limited to those children who meet in person. Various digital channels (e.g. social media and online gaming) allow children to interact with friends outside traditional environments (e.g. school and playground). How children conceptualise friendship and how they differentiate between online friendships and in-person friendships was of interest. More specifically friendship and neurodiversity were explored, as well as friendship between mixed dyads of neurotypical children and autistic children. In order to be able to support such relationships there is a need for a better understanding of any differences and similarities.

During COVID-19 lockdowns, most children moved their social life online, interacting with friends using social media, gaming, and video conferencing tools. However, available technologies have never been used exclusively to interact with peers nor are they designed for

such circumstances. It is unknown whether this new way of interacting with friends has changed how children conceptualize their friendships and how they view online and in-person friendships. Novelty of circumstances requires rigorous research to understand how children managed their social life and coped with social distancing restrictions. Since the case study of our research was on the role of technology in supporting friendship between autistic children and their neurotypical peers, these circumstances created an opportunity for our research to reflect on how children used the technology and how it affected their friendships.

In this chapter, the results of an interview study conducted with 16 children are reported. The main goal was to understand how they conceptualise friendship, their view of friendship and neurodiversity and how they used technology to foster their pre-existing friendships and possibly make new ones before, during and after COVID-19.

Specifically, this chapter answers the following research questions:

RQ1 : What role can proxies play in the co-creation process of technologies to support friendship?

RQ1.4: How can autistic and neurotypical children inform the design process in the context of supporting friendship?

It particularly focuses on the context of COVID-19 lockdown given the circumstances of when the data was collected.

Similar to the parents' interview study discussed in Chapter 5, this study was also conducted in collaboration with the two MSc students Alicia Smith and Taylor Bartow. They were involved during recruitment and conducted some of the interviews themselves while the thesis author observed. They were primarily interested in exploring the experience of neurotypical children and were taking a psychological perspective rather than a design one. Having gathered the data, they conducted their analysis and disseminated the results in their own MSc dissertations (Bartow, 2021; Smith, 2021). The thesis author collected additional data from autistic children to serve the purpose of this research and conducted their own analysis on the combined data of neurotypical and autistic children.

6.2 Methods

6.2.1 Recruitment

Participants recruited for this study had to meet the inclusion criteria below:

- a child between the ages of 8 to 14;
- who is able to participate in an interview using video conferencing software (e.g. Microsoft Teams or Zoom);
- the child can be either neurotypical, have an autism diagnosis or be in the process of being diagnosed.

We used various different channels to recruit children, including:

- Posting into multiple Facebook groups for supporting parents of autistic children;
- The research team shared the study advert through their personal contacts and social media;
- Contacting a mailing list of parents who previously participated in similar research studies and indicated that they wanted to be contacted to participate in future studies;
- After obtaining approval from local authorities, the advert was shared with schools' head teachers to advertise within their school;
- Contacted multiple organisations for children with autism to advertise the studies within their communities (e.g. Lothian Autistic Society);
- Posted the study advert in parenting forums such as Mumsnet;
- Sharing the study advert on autism research organizations and charities such as Autism Speaks.

Although multiple channels were used to recruit participants, most children who participated came through personal contacts.

6.2.2 Participants

Participants in this study include 16 children between the ages of 8-14, two of whom were autistic. All participants live within the UK. Table 1 shows participant demographics. The numbering convention of the participants relates to the parent participants in Chapter 5. The format Cx.y is used where the x refer to the parent number while y refer to the child number within this family. In case the child is autistic an 'A' is added to indicate their diagnoses (e.g. CA12.1)

Table 6.1: Children's Demographic Information

Variable	Frequency (<i>N</i>)
Child Age Range	
8-10	7
11-14	9
Child Sex	
Male	9
Female	7
Autism Diagnosis	
Yes	2*
No	14

*CA11.1 and CA12.1 have an autism diagnosis while all others do not have a diagnosis and are not in the process of being diagnosed.

6.2.3 Procedure

Semi-structured interviews were conducted within a transitional phase where COVID-19 restrictions were easing across the UK (between April 19th and July 5th 2021). During this period, children had already returned to schools but other restrictions regarding social contact persisted. Interviews were mostly conducted following an interview with the child's parent (results of the parents' interview study are discussed in Chapter 5) with the exception of two interviews where the child was interviewed first to accommodate both parents' and children's availability. Before interviewing the child, and after finishing the interview with the parent, the parent was asked if the interviewer needed to know anything about the child beforehand or if any specific topics might be upsetting for the child in order to avoid them during the interview. Interviews were conducted online using Microsoft Teams or Zoom depending on the

participant's preference. An ice-breaker activity was carried out before the start of the child interview, where researchers and participants talked about their most and least favourite foods. This was done to allow the child to feel more comfortable answering the interview questions. This was followed by a general discussion about the child's friendships and what was special about their friends. Next, five main themes were discussed during the interview 1) friendship definitions and what makes a good friend; 2) friendship between similar (autistic/autistic or neurotypical/neurotypical) pairs and mixed (autistic/neurotypical) pairs; 3) friendship online versus offline; 4) friendships during lockdown and 5) how to maintain friendships during and before lockdown. Similar to the process described in Chapter 5, an initial set of the questions was developed by the thesis author and shared with collaborators to ensure that the current set of questions was sufficient to serve the purpose of their independent research goals. Given that both collaborators were focusing on the experience of neurotypical children, and were not considering autistic children, the second theme was irrelevant for both of them and was added for the purpose of this research, while the questions on the remaining themes were agreed amongst all collaborators (see Appendix F for the interview questions).

Participants received compensation in the form of a £10 Amazon voucher for their participation in the study. Interviews varied between 10 to 30 minutes in length. In one case, the child indicated distress during the interview and the interview stopped and was resumed at a later time. Interviews were transcribed using Otter.ai ("otter.ai," 2022) then manually reviewed against the original audio-recording to ensure the accuracy of the transcriptions. The transcripts were thematically analysed using an inductive approach to identify patterns within the data without specifying predefined themes. Nvivo Version 12 software ("NVivo," 2022) as used to code the transcripts and produce the themes and subthemes. The thematic analysis process employed followed Braun and Clarke's (2006) guide.

6.2.4 Ethics

Following ethical approval from the School of Health in Social Science Research Ethics Committee, an advert was shared through various channels. Informed consent was obtained from participants within the registration form after providing information sheets (Appendix C) for both parents and children. Additionally, a verbal protocol (Appendix D) was read aloud before the beginning of each interview and verbal consent was obtained from both parents and children. A debrief (Appendix E) was read aloud to participants after the interview ended to allow participants to voice any concerns they might have. Participants' privacy was insured by privately sharing the meeting link and invitations with the participant by email. Parents and children were asked to give permission to be audio recorded before the start of the interview and all interviews and transcripts were stored in an encrypted folder on a university-secure server, separately from any identifying information and accessible to the research team only. In addition, names and other identifiable information within transcripts were anonymised using participant identifiers to ensure anonymity and confidentiality. All audio recordings were deleted after transcription for data-protection purposes.

6.3 Results

Three main themes emerged from the analysis of children interviews: children's conceptualization of friendship, nature of children's friendship, and the role of technology during the pandemic. The first theme maps directly with the theme of questions asked as the purpose was to understand how children define friendship and what constitute 'a good friend'. The second theme encapsulate more than one theme of questions as it focuses on understanding the current experience of children whether it was during the pandemic, before the pandemic, between similar (autistic/autistic or neurotypical/neurotypical) pairs or between mixed (autistic/neurotypical) pairs. The final theme is a merger between more than one theme of questions as it focuses on the impact of technology during COVID-19 and what role it played

in facilitating social connection during lockdown. Figure 1 illustrates the thematic map showing the main themes and subthemes identified.

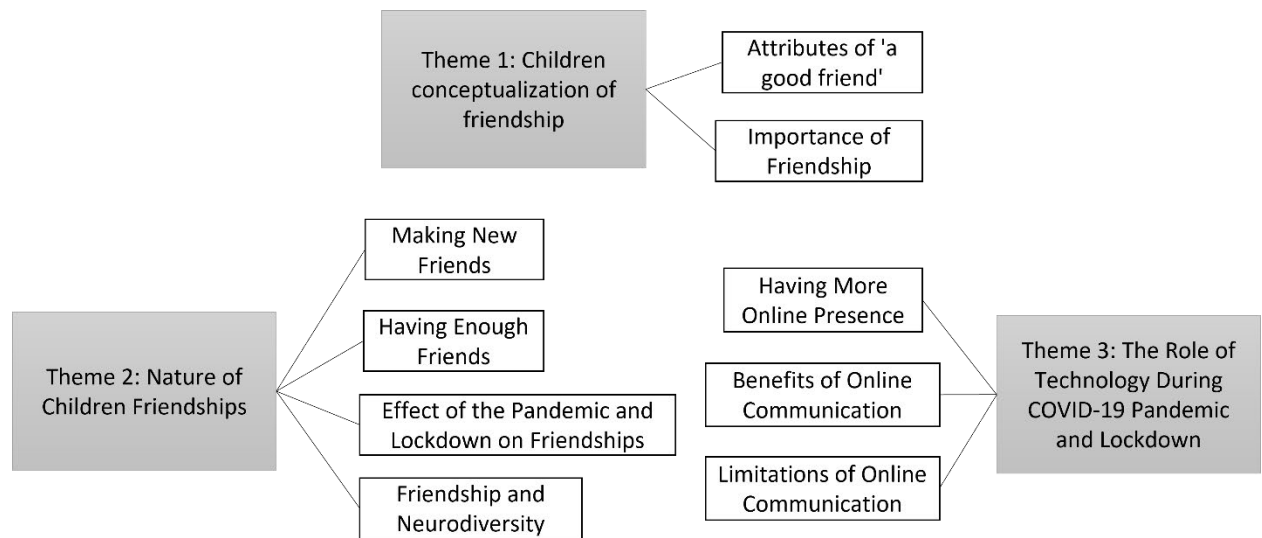


Figure 6.1: Thematic Map of Children's Perspective

Theme 1: Children's Conceptualization of Friendship

Attributes of 'a good friend': Children described 'a good friend' with many positive personal traits such as being kind, polite, supportive, and trustworthy. This is how CA11.1 described his best friend:

"He's caring. He's a very nice friend .. That's it."

C4.1 stated:

"Someone who like trusts you, kind to you, doesn't like, make stuff up about you".

C1.1 Gave a more elaborate description by contrasting how a bad friend would be:

"A good friend would be there for other friends to help them out and have their back.

Well, an example of a bad friend is like not trusting them, being a bit selfish".

Sharing a similar sense of humour and having 'inside jokes' was another attribute that children

mentioned often as something they look for in a friend. As C2.1 described:

"you can have inside jokes that just make sense to you, but they're not to make sense to everyone else"

Children mostly chose their friends based on having mutual interests such as football or gaming. And they often indicated having similar interests as the main reason of becoming friends with their closest friend. When asked why he became friends with his best friend, C1.2 justified:

"Just because we have the same interests. We've always liked the same stuff really"

Importance of Friendship: Children believed that having friends is a need. When asked why he became friends with his best friend CA12.1 replied:

"I need to .. I need a friend.."

When asked about how having friends is different from not having any friends, C10.1 highlighted the importance of friendship and how not having any friends will make one feel lonely:

"It's quite important because it's a bit, you get really lonely if you don't have any friends".

C2.2 thinks that friends can help someone who has mental health conditions:

"it's more like nowadays, mental health is more of a thing, I think ... and friends help a lot with that stuff".

CA11.1 said that his friendship brings him joy and he feels a lot of good feelings because they have a friend as he expressed:

"If you have a friend it's very good. happy, excited and everything".

Besides the positive feeling you would have from having friends, C2.2 believes that having friends would help one develop their social skills:

"they can work into social skills too because later on in life, you obviously need more social skills".

C10.1 explained how friends can also bring new expertise and different perspectives which you can learn from, such as the time when she wanted to try whittling and her friend who is an expert helped her pick the right piece of wood:

"she told me actually this wood isn't that good for whittling with. How about you try that wood?".

Theme 2. Nature of Children's Friendship

Making New Friends: Children constantly identified starting a conversation as the first step to developing a friendship. C1.1 explained his way of making new friends:

"I try to start a conversation, like small conversations. And I'm hoping we could talk more and hopefully become friends."

In addition to starting a conversation, CA11.1 ask others if they want to be his friends:

"Just talk and ask them if they want to be a friend".

As having mutual interests was one of the main attributes of "a good friend", children felt that knowing someone's interests was key to becoming friends with them. C1.2 explained how knowing someone's interests would help start a conversation with them:

"just try to have conversations with people, get to know what they're interested in, keep

talking to them".

C9.2 explained how he usually become friends with others who have similar interests:

"I just talked with people. Like interesting, and if they have similar interests, we usually become friends."

Children explained how making friends is more difficult as you get older. C10.1 compares how she used to make friends when she was younger to how she makes friends now:

"Well when I was younger, I just went up to people and said, 'do you want to be my friend?' And then for instance they said, 'yeah sure do you want a Dorito or something?' But now, [...] you don't just go up to somebody and say [...] 'do you want a Walkers crisp?' [...] And you instantly bond [...] I have to know them well, or if they're new I have [to] show that I like their personality and I'm satisfied with how kind they are."

C9.2 reiterates this idea by giving an example of how he used to make friends when he was younger:

"It's easy when you're younger, because I've had stories of when I was younger, I just like, there was one time I was on a big cruise ship [...] going out to an island or something and there was this child's play area on it. And I just walked in and knew, just bashed open, I just walked in and just said, 'hello friends'. I wouldn't make that sort of mistake nowadays."

He then elaborates on how, as he aged, he became more afraid of rejection which may have discouraged him from approaching other children to make more friends:

C9.2: "I'm not interested in making any more. There's risks involved in that."

When asked about what risks, C9.2 went on to say, C9.2:

"Uh being disappointed, yeah. Or just not being able to find any friends and realising just how lonely you are."

Having courage to ask others to engage in social activities and not being afraid to be rejected was important to develop friendships as C2.1 explained:

"I'm not afraid to ask people if they want to do something, I'm not like afraid that they'll say no [...] what's the worst that can happen? they'll just say: 'actually, no'."

Having Enough Friends: Most children who were interviewed indicated that they are satisfied with the number of friends they have and were not interested in making any new friends. C5.1 explained that even as a sociable person, he is happy with the number of friends he has:

"I've always been quite a sociable person, but I feel like that the group I've got is probably where I like it to be honest".

C2.1 indicated that she is more interested in making few high-quality friendships than having many friends who are not as close:

"I prefer to have less but closer friends, than more but less close friends."

C2.2 explained how having many friends would be a liability for having to talk to them all:

"I wouldn't really want more because then they'll just be people talking to me all the time."

This was also confirmed by CA12.1 as he felt maintaining many friendships would be a liability. However, although CA11.1 said he was happy with how many friends he has he still said he wanted *"More friends"*.

Effect of the Pandemic and Lockdown on Friendships: Different areas in the UK have been in and out of lockdown since March 2020. For some children, each time they went into lockdown there was a different effect depending on how strict the guidelines were at the time. C2.1 explained:

"Well, I mean, lockdown one and three affected my friendships [...] two didn't really affect me because we still went to school, so it didn't really affect me."

When asked about whether the pandemic and lockdown affected their friendship in any way, children gave varied answers where some felt that their relationships did not change at all and that they were able to pick up where they left off before lockdown.

When asked if the child's friendships had changed because they were no longer to see their friends C1.1 said,

C1.1: "Um no, [...] they all came back as the same before lockdown."

When asked whether he believes the lockdown and pandemic in general was good or bad for his friendships C1.2 said it was both:

C1.2: "I think that since lockdown we just stopped being able to do as much. And see each other as much. Yeah."

When asked how the pandemic impacted the child's friendships in a good way the participant responded,

C1.2: "I think it's definitely brought us closer together in a way. [because] we're all going through the same thing at the same time."

This torn position on the effect of the pandemic and lockdown was shared by many of the

children interviewed. CA11.1 justified:

"it's good because I can talk to [my friends] and It's bad because I can't see them."

In C1.1's experience, it was good for some friendships but bad for others:

"It was good for my online friends and my in-person friends, but my school friends [...] it wasn't good for that [...] because [...] I could get to see my in-person friends a lot and [...] I get to talk to my online friends".

Children reported having increased appreciation for their friendships as a result of lockdown.

C2.1 explained:

"I guess it made me appreciate how [...] easy it was to just feel able to go to someone's house and talk to them [...] it made me appreciate my friendships, being able to see people more"

In person friendships were more difficult to maintain when trying to keep in touch online. This was especially prominent when online communication was not part of their daily interactions before lockdown. Children expressed how keeping such friendships often required extra effort. C1.2 explained how there was always a risk of losing his friendships if he were not talking to his friends often:

"just don't stop, talk to them or anything, they'll probably just drift away really. Just not really speaking anymore so".

In addition, due to the limited ways children were able to connect with their friends, they often had to pick which friendships they are going to invest the time to keep in touch with. When asked about whether she was able to maintain her friendships during lockdown, C6.1 explained:

"only my like, really, really close friends. Otherwise, [...] I didn't".

As a result, many friendships were lost during the lockdown period as C1.2 expressed:

"Some of us drifted away. Some [...] have just not been in contact. Some have been speaking, just haven't been doing as much stuff as we used to".

Friendship and Neurodiversity: We discussed with children their relationships with other autistic/neurotypical friends. When asked whether they felt any difference when they are interacting with autistic friends, many children said there was no difference and it feels very natural. They also engaged in similar activities as they would with their non-autistic friends.

C5.1 expressed:

"I feel pretty fine to be honest. Just another person sort of thing."

When asked whether their relationship with their autistic friends is similar or different to their relationship with other non-autistic friends C9.2 replied:

"Similar, mostly done through playing video games [...] he's not any different."

C10 explained how she does not care if her friend has a diagnosis as long as they are good friends:

"I really don't care what friends I have as long as I can trust them to keep a secret or something like that. Um and they're kind and loyal to me."

Some children embraced the difference between them and their autistic friends. As C9.1 explained:

"because he's different than me. Can think of different things that make it more creative and enjoyable."

C2.1 also appreciated her autistic friend's honesty:

"she doesn't feel pressured to like, lie to you anything. She won't lie to you about things she'll just listen to you and she'll say what she thinks, which I find a very good trait because I hate it when people are playing mind games."

Nevertheless, neurotypical children found some autistic traits difficult to understand or deal with. C2.1 shared her thoughts about her autistic friend lack of eye contact saying:

"she doesn't really make eye contact with you which when I first saw it, it kind of miffed me, because you're having a conversation and you feel like she's not listening. But then, when I understood her, I knew she was listening to me, she just didn't look at my face."

C2.2 gave another example saying:

"he acted different, I can tell due to autism, he got angry a little easier."

Neurotypical children also noticed that their autistic friends' parents are often more involved within the friendship and they usually engage with their autistic friends in more structured activities. C2.2 shared how a typical meeting with her autistic friend would be:

"we would go for a walk. But her mum would be there which was actually okay, because I've had friends who their parents are very overprotective, and it's an issue, but it was fine that her mum was there, and her mum would normally arrange something for us to do, so like if we went back to her house, then we'd do painting or something. I wouldn't just meet her we'd normally always decide what we're going to do."

She continued to compare it to how it would if she met one of her non-autistic friends saying:

"whereas with my friends who aren't autistic, I just might invite them over and hang

out, talk and do a little bit of homework or whatever we would do."

As for autistic children interviewed, their experience with friendship with other neurotypical children was limited. CA12.1 was not aware of what his diagnosis meant and he found it difficult to answer whether he had non-autistic friends or not. CA11.1 acknowledged there was a difference he felt when interacting with others who are non-autistic but he was not able to explain what that difference was. CA11.1 said:

"I think I play with them differently."

When asked to explain how they played differently he said:

"Like playing with toys".

Theme 3: The Role of Technology During COVID-19 Pandemic and Lockdown

Children used a variety of tools to connect with their friends during lockdown. Video-communication services mentioned included Microsoft Teams, Zoom, FaceTime and Google Meets. In addition, they were able to connect with friends through video gaming consoles such as PlayStation and Xbox. Very few participants were using social media platforms such as Facebook Messenger, Discord, Snapchat, and Instagram. This may be due to the young age of children in this sample.

Having More Online Presence: Children reported that they have "more online presence" due to the pandemic and lockdown as C2.2 described:

"we have more online presence. [...] [we] are more online "

C6.1 also said that he was more online during lockdown, and he was introduced to new platforms to socialise with friends:

"I think I've used online a lot more when I'm talking to my friends and Discord a lot more than I would use because before I would just use WhatsApp".

This was echoed by C2.2 who believes that he will do more online activities with friends even after lockdown:

"I would usually meet them out of school [...] for like, certain events and stuff, but I really like [to] meet up more online because we just do more online stuff".

This appeared to be strongly influenced by the fact that schools moved to online learning and that communicating online was the only way to stay connected with others during more strict stages of lockdown. Many children believed that using technology for socialising with friends was essential during lockdown regardless of whether they liked it or not as C2.2 explained:

"I think most people just [...] use [...] messaging like WhatsApp or Discord, a lot more when lockdown started just to keep in touch with their friends [...] I think most of them if they didn't really know anything about Discord, I might have persuaded them to actually get it or something [...] that was [the] way that I sort of kept in touch with them. So any that didn't really have Discord, it was hard to even make friendships with them".

Benefits of Online Communication: Many children believed that interacting with their friends online made their relationship grow stronger. C2.2 said:

"No. I think it strengthened them because most of [...] my friends [...] are more online. And [...] I know how to be online. And I can use it to an advantage not as a fault. And it's much easier to communicate, much simpler".

However, C2.2 clarified that this might not be the case for everyone as it would depend on your

interests and what you usually do with your friends:

"I think, other friendships may have been weakened by it. Because I know a lot of people who are like sporty and they [...] don't communicate with their friends online a lot".

This was especially during COVID-19 lockdown when most people were sharing a similar experience. As C5.1 explained:

"I feel like it just sort of made it more enjoyable being, like, stuck inside having everyone online at the same time doing the same thing."

Children expressed how making new friends was easier when interacting online compared to in person. C2.2 said:

"I quite like being online. It's a lot easier and simpler than real life".

CA11.1 echoed that saying he felt it was easier for him to make friends online rather than in person. There were multiple reasons why children found it easier to develop friendships online. Some were related to self-consciousness and not being shy as C1.2 explained:

"if you're self-conscious of your body or anything, they won't know that, so I think it is easier to make friends online".

C1.1 said:

"I'm quite shy, well I'm not really shy online, so for me it's a bit easier to make friends online".

Others believed that the way technology is used makes it easier to find people with similar interests which increases the potential of becoming friends. As described by C2.2:

C2.2: "I think it's a lot easier to find people because they're all bunched up in different

places. And you can easily start conversation. because when you're near someone in game, they're usually doing the same thing [...]"

C2.2 elaborated, confirming how having similar interests was a key attribute that allows individuals to bond.

C2.2: "[...] Yeah, it's very easy to like, be friends with them through that"

Another reason was the flexibility of meeting friends online.

C5.1 explained: "It was because everyone was together. We didn't really have to organize anything. It was just sort of you join in when you wanted, and just had a good time."

Limitations of Online Communication: Interacting with friends online mostly revolves around gaming and children rarely find the chance to get involved in conversations with the other players to get to know them better. C7.1 explained how he prefers making friends in person since he does not get the chance to know the other person when playing online:

"you don't actually see them and have a proper conversation, because you're also focussed on the game that you're playing."

When asked what they would like to change about playing with friends online using Xbox, CA11.1 replied:

"you can see our faces."

When asked to explain more CA11.1 clarified:

"So you will say how are you today and stuff. Mostly have more to say".

Most children had a preference for in person friendships. When asked to choose which one

they preferred to spend more time with CA11.1 replied:

"I have to say... In person."

When asked why she preferred in person friendships C6.1 justified:

"because like, you can properly interact with them. And like, you can get to know them a bit more than online."

Children felt that interaction online was very limited especially when you are not interested in online gaming. They believed that interactions online were very conversation driven. When asked why she preferred interacting with friends online or in person C4.1 explained:

"In person you can actually do stuff more. On, like, FaceTime or zoom, you can just like talk, you can't like, do anything else really".

Children felt they often ran out of things to say as C6.1 stated:

"when I did see them on Zoom calls, I just didn't really know what to say".

Although communicating online was the main way they maintained their in person friendships during lockdown, many stated that it got boring over time as C4.1 expressed:

"it just got a bit boring after a while, like FaceTime with friends every day".

Children identified key attributes to social interaction which were missing when interacting with friends online such as eye contact. C2.1 explained:

"You can't make proper eye contact with them [...] I find when you're having a conversation with someone, if you can't make eye contact with them, it changes the whole conversation".

She elaborated further on how it lacked an emotional connection:

"Being able to have that connection, emotionally. Like, you can't [...] they're just not there".

Conversations online did not flow the same way they do when talking in person as the communication is often asynchronous. C9.2 complained about his experience texting his friends online:

"It's useful. I did have problems, it's not WhatsApp's fault that this happened but it sometimes takes a few hours for your friends to get back to you".

Children discussed how talking to people online is different from talking to them in person. As C10.1 explained:

"if I met them on something like Animal Jam, or Club Penguin, which are two online games, I wouldn't get to actually see their faces and actually know, know if they were lying that they're my friend or not [...] and the faces, you can edit the screens um so you're not actually seeing their real faces".

Some believed that online friendship are not "real" as C9.2 states:

"It doesn't count if it's only online. It's just someone, that's just a person you know, not a friend".

C2.1 explained how it is important to meet someone in person to be able to call them a friend:

"Well they're not really your friend if you haven't met them"

This distinction was mostly rooted in being aware of predators online as C2.1 justified:

"we've had enough teaching at school, watching freaky videos where somebody ends

up being a middle-aged man [...] you're wary in the back of your head you know? I think this is a real person. But it could just be someone very odd".

This caution can be a barrier to developing friendship online as many kids are careful when disclosing personal information online compared to in person. When asked about his interactions with his online friends C1.1 replied:

"they introduce themselves. Like not too much [...] of their personal information. But like they [...] talk to me and say stuff, normally game progress. But sometimes we talk about how was your day and stuff".

There was also variation of what they are willing to do with their online friends as C1.1 elaborated on his relationship with an online friend:

"he said are you comfortable to share your voice? and I said no [...] but he shares his voice. I don't, no. And we don't see each other".

Although they may trust their online friends, meeting them in person was not something children considered doing. When asked what would happen if he met his online friends in person C replied:

"I think I could trust them [...] but I wouldn't meet them [...] offline, you know. I wouldn't meet them. But [...] I don't think they're dangerous".

Many children did not have any friends who they have only known online and never met in person. C10.1 was not interested in making such friendships as she was worried about how much time she would be spending on screen to interact with her friends if she had any:

C10.1: "Yes, because I'd probably be spending way more time on the screen"

C10.1 explained how spending so much time in front of the screen would be "a bad thing" and carried on to justify why they thought it was "bad":

C10.1: "Well, it just, it just sort of stops me from thinking about anything else"

There was an array of technical problems that children complained about, that they faced when they were communicating with friends online such as glitching C7.1:

"sometimes the computer like, auto left the meeting, and then you missed a bit, and then just you glitched out or something",

and voices of others sounding odd. When asked about what she would change about Zoom meetings to make it better C10.1 suggested:

"I could [...] find a way to make the voices sound less robot"

6.4 Discussion

The purpose of this study was to explore children's experiences with friendships and neurodiversity in general. Due to the circumstances of when this study was conducted, it specifically focused on the children's experience with friendship during COVID-19 pandemic and looked into the role of technology in nurturing these relationships by comparing online and in-person relationships. Results from this study suggest that children might find it easier to develop friendships online. Children's ability to easily connect with others online who may be physically distant has been reported in previous literature (e.g. Boyd & Ellison, 2007; Wolak, Mitchell, & Finkelhor, 2003). The current study has shown that this has also been the case for the children during COVID-19 restrictions. Participants attributed this ease of meeting new people to the increased confidence one feels when interacting online and not being afraid of rejection. Previous research has established that introverted or socially-anxious children can utilise social media and online gaming to strengthen their existing friendships (Grunander,

2016), benefiting from online platforms which reduces reliance on social-cues (Baker & Oswald, 2010; Massing-Schaffer, Nesi, Telzer, Lindquist, & Prinstein, 2020; Suler, 2005).

It is worth noting, however, that research on the quality of online friendships shows that these relationships are generally less intimate than in-person relationships as they lack social cues necessary in social interactions (Amichai-Hamburger, Kingsbury, & Schneider, 2013; Mesch & Talmud, 2006). Participants indicated that interactions online are more prone to conflicts as it is difficult to fully understand other's intentions without observing their facial expressions and body language. Similar to results from Sherman, Michikyan, & Greenfield's (2013) study, children in the current study showed a preference for face-to-face communication compared to audio-calls or messaging when interacting with friends.

Rather than using a digital medium to develop friendships, many children used it to maintain their in-person relationships. This suggests that children in the current study do not see their online and offline interactions with their in-person friends as two separate entities but rather a blend between the two, which supports findings of previous studies (Mesch & Talmud, 2006; Valkenburg & Peter, 2009; Yau & Reich, 2018). Furthermore, their ability to reach their friends at any time of the day may even strengthen their friendships (Valkenburg & Peter, 2009).

Livingstone, Haddon, Görzig, & Ólafsson (2011) interviewed 25,142 children and one of their parents from 25 different European countries and found that children between the ages of 9 to 12 were able to form reciprocal online friendships with unknown individuals. Nevertheless, other research in this area established that those online interactions were mostly useful for maintaining existing friendships (Blais, Craig, Pepler, & Connolly, 2008; Clarke, 2009). In this study, although some of the participants felt more connected to their friends during COVID-19 lockdown when they interacted with them online, this was not the case for

others who felt their relationships were negatively affected when interacting online was the only option they had. We can conclude that although online communication can be beneficial for meeting new people and extending interactions with in-person friends, it does not eliminate the need for offline and in person interactions with friends (Ellison, Steinfield, & Lampe, 2007).

It is important to take into consideration that children in this study have used generic mainstream platforms which were not specifically designed for children. However, when Inkpen, Du, Roseway, Hoff, & Johns (2012) evaluated VideoPal, a platform designed for children to allow them to share videos asynchronously, results showed that such a platform allowed children to engage in rich conversations which helped maintain and strengthen existing relationships. This suggests that designing platforms specifically for children may change their experience.

Online friendships may also be impacted by children's awareness of online risk. Sullivan's (1953) interpersonal theory of friendship identifies companionship, trust and support as key characteristics of friendships (Roach, 2019; Rubin, Fredstrom, & Bowker, 2008). Increased trust is often linked to consciously intended self-disclosure (Wheless & Grotz, 1977). This combined with parents reminding their children to be cautious when interacting with others online can hinder opportunities to strengthen the relationships made online. Participants in this study identified online safety as one of the main concerns when interacting with others online. Joinson (2001) and McKenna, Green, & Gleason (2002) examined the relationship between self-disclosure and forming close relationships online in adults and found that increased self-disclosure resulted in stronger relationships comparable to those developed in person. However, previous research has not explored whether children were disclosing intimate details when interacting with others online. Results from this study illustrated that

children are often cautious about disclosing personal information when socialising online due to concerns about online safety. These results contribute to the literature comparing online and in-person friendships as research in this area has not considered that online safety is constantly taught to children nowadays. While adults can assess the safety of disclosing personal information online and choose if they want to do so, children often follow the directions of their parents and schools about how to interact online. This difference may explain the different experience children and adults have with online relationships. These results are encouraging for online safety campaigns and show that the children recruited in the current study were aware of online risk and employed strategies to protect against this risk.

Neurotypical children interviewed mostly felt natural around their autistic friends however this feeling was not necessarily mutual as one autistic child felt that something was different when they were interacting with neurotypical peers but did not quite express what it was. Furthermore, some children acknowledge the difference between themselves and their autistic friends. However, they were accepting it and even viewed this difference positively believing specific autistic traits can be beneficial to the relationship such as honesty. Nevertheless, neurotypical children found some autistic traits difficult to deal with such as not making eye contact. Similar to what was reported by parents (see Chapter 5), children also noticed how parents of autistic friends are often involved in the relationship and that they often need to plan and structure meetings with their autistic friends. This suggests that although neurotypical children may be accepting of their autistic peers and can see the value in some autistic traits for friendship, the friendship dynamic can still feel different compared to friendships with other neurotypicals. It requires specific adjustments such as planning and structuring meetings and involving parents. This might be difficult since parents of autistic children might be willing to invest the time to support their children's friendships however this is not necessarily the case for parents of neurotypical children who are used to their children

being able to manage their friendships on their own.

This study has a number of limitations which need to be taken into consideration when assessing its results. Similar to the parents' interview study and because these interviews were conducted with the children of the parents in the previous study (see Chapter 5), most children interviewed have parents of a higher level of socio-economic status (SES) which may have affected the experience of the child during COVID-19, specifically by having access to online platforms to continue socialising with their friends. In addition, although the small sample size in this study was deemed sufficient for its exploratory nature, it is difficult to generalise the results to a wider population. Furthermore, observing differences between different variables such as gender, age and socio-economic status would require a larger sample.

Additionally, fewer autistic children were interviewed when compared to the number of neurotypical children interviewed. Consequently, the results presented dominantly reflect the views and experience of neurotypical children. Nevertheless, the difficulty experienced in recruiting autistic children to participate in this study itself motivates the need to conduct more research on how to involve autistic children in such research.

It is evident that the COVID-19 pandemic had a significant effect on children's friendships and how they socialize. Future research needs to investigate whether these effects will have lasting impact on children's friendships and ultimately their mental health and wellbeing as we continue to transition out of lockdown.

7 UNDERSTANDING AUTISTIC ADULTS' EXPERIENCE WITH FRIENDSHIP AND THE OPPORTUNITIES TO SUPPORT IT

7.1 Introduction

Autistic adults provide a unique perspective when they are acting as proxies as they themselves once were autistic children similar to the target population. Nevertheless, choosing to include the perspective of autistic adults utilises the years of experience an autistic adult has in two different aspects. Firstly, due to experience they have not only faced challenges around friendship and are able to identify them, they might have also overcome these challenges as they grow to become more competent and have gone through different programs and interventions targeting autistic children and are able to comment on its effectiveness. Second, as adults, they had the chance to change their communication skills or find alternative ways of communication which allow them to participate in studies which require them to articulate their ideas and perspective. Moreover, as adults, they have autonomy which allows them to freely participate in such studies without requiring a parent's or guardian's consent. Nevertheless, their

perspective cannot and should not replace autistic children's and the limitations of their perspective need to be considered when reviewing their input. Many things change over time which may impact the view and experience of children today compared to the experience of children over 15 years ago. These include advances in technology, available support provided and our understanding of autism itself.

This chapter reports on the results of 20 semi-structured interviews with autistic adults and reflects on their experience with friendship among neurodiverse communities and with neurotypical individuals, and considers the potential of technology as a medium for friendship support. The purpose of this study was to partially address the following research question:

RQ1: What role can proxies play in the co-creation process of technologies to support friendship ?

RQ1.3: How can autistic adults inform the design process in the context of supporting friendship?

Here we explore the role of autistic adults as proxies by investigating the nature of friendship for autistic adults and reflecting on their experience as children. We also explored ways to support friendship from an autistic adult perspective.

This study was conducted by Dr Karri Gillespie-Smith and collaborators. These interviews were carried out in two different periods of time. The first 10 interviews were in 2019/2020 and involved verbal autistic adults only, while the other 10 interviews were carried out in 2020/2021 and involved both verbal and non-verbal participants. Dr Karri Gillespie-Smith and collaborators designed the study and prepared the interview questions. They also conducted all interviews and later conducted their own analysis of each set of interviews separately. The analysis was specifically looking at it from psychological perspective rather than a design one. The data collected was made available to the thesis author, who combined the two sets of

interviews and conducted their own analysis on the combined data, which will be presented in this chapter.

7.2 Methods

7.2.1 Participants

Participants were eligible to take part in the study if they met the inclusion criteria: (1) were an autistic adult (≥ 18 years old), (2) proficient in English, and (3) able to provide their own consent.

Two set of interviews were conducted in two different time periods but both with the same interview questions and procedure. Participants in the first set of interviews were not invited to participate in the second set of interviews. For the first set of interviews conducted in 2019/2020, researchers gathered a list of various autism charities to contact them for recruitment purposes. These charities were emailed with information and a link to the registration Qualtrics (“Qualtrics,” 2022) page requesting if they could share it with their members. This method of recruitment had a low response rate which may be due to not having established relationships with these charities who act as ‘gatekeepers’ as Sullivan, Gibson, & Riley (2012) suggest. Researchers also shared the link on their own social media pages and on different social media groups with information and a QR code. After interviewing some participants, they volunteered to share the study with friends who met the criteria: this is a commonly used approach known as snowballing (Robinson, 2014). Ten participants were interviewed in total during the first set of interviews.

Recruitment for the second set of interviews conducted in 2020/2021 was considerably more successful as researchers advertised the study on their own TikTok account and gained an overwhelming interest in the first 24 hours ($n=18$) which led them to close the registration form to control the number of potential participants. After removing participants who did not meet the criteria, were known to the researcher, were ill or participants who requested to be

withdrawn from the study, 10 participants remained. The participants were interviewed using their preferred method of communication. Six were verbally interviewed, two used some speech but mostly used textual communication, and two used text-only. This variation in communication preference demonstrates a more accessible study design which accounts for autistic narratives which are chronically under-represented in qualitative research (Nicolaidis et al., 2020; Nind, 2008; Yergeau, 2018). Participants demographics are illustrated in Table 7.1.

Table 7.1: Autistic Adults' Demographic Information

Variable	Frequency (<i>N</i>)
Age Range	
18-24	8
25-34	8
35-44	2
45-54	1
55-64	1
Gender	
Male	4
Female	7
Not Disclosed	2
Other	7
Employment Status	
Unemployed	2
Part Time	4
Full Time	4
Self Employed	3
Student	7
Highest Level of Education Achieved	
Postgraduate	2
Undergraduate	3
Higher National Certificate	2
High School	13
Region of Residence	
Scotland	8
England	7
Ireland	1
United States	4

7.2.2 Procedure

Due to social distancing measures in response to COVID-19 restrictions, interviews were conducted online via Skype. The thesis author was not involved in the process of developing the interview questions or conducting the interviews with participants (See Appendix G for the interview questions). The interview questions discussed four main themes; (1) perception of friendship; (2) forming friendship; (3) maintaining friendship and (4) COVID-19 and social isolation. Since the aim of the collaborators' research for which these interviews were conducted was to capture the experience of the autistic adults themselves, rather than asking them to reflect on their experience in childhood, a pragmatic approach had to be adopted during the analysis. Instances where participants spontaneously reflected on their childhood were coded and focused on in order to be able to utilise the data in the context of this research. In addition, although there were no main themes focusing on friendship between similar (autistic/autistic) and mixed (autistic/neurotypical) pairs, or social interactions online vs offline, participants were asked to discuss these topics as follow-up questions to some of the main themes discussed, which was beneficial for the purpose of this analysis.

The thesis author received the transcribed interviews for the purpose of conducting her own analysis based on the research goals of the thesis. In addition, a cumulative analysis that aggregated the results from both sets of interviews was carried out and provided to Dr Karri Gillespie-Smith and her collaborators for the purposes of their own research.

All interviews were thematically analysed following Braun and Clarke's (2006) guide on conducting thematic analysis. An inductive data-driven approach was taken when generating the initial codes as it fits with the exploratory nature of this study. Nvivo 12 software ("NVivo," 2022) was used to code transcripts and aggregate them into themes and subthemes.

7.2.3 Ethics

Ethical approval was sought and obtained from The University of Edinburgh before recruitment began. Several ethical considerations were taken into account including taking extra care when wording participant information sheets and consent forms to make sure they were clear, providing text-based sources of support to address the needs of non/semi-verbal participants and clearly stating the participant's right to withdraw their consent both verbally and non-verbally at any time. In addition participants were asked to indicate any adjustments they might need to be able to complete the interview. All identifying forms went through a de-identifying process where all identifiers are removed and stored in a password protected encrypted file on the university's secure servers. Participant's right to withdraw their consent and delete all relevant data were also repeated to participants during the interview process and on the debrief form.

Although the subject was not considered distressing, there was still potential for participants to become distressed while discussing personal lived experiences related to friendship. Hence, the researcher would conduct regular check-ins with the participant throughout the interview.

7.3 Results

Four main themes emerged from the analysis of the interviews: perception of friendship, friendship with NT vs. ND, the role of technology in socialising, and the impact of COVID-19 on socialisation. The resulting themes do not directly map to the themes of questions asked during the interview. Rather, the resulting themes fit more with the goals of this research. For example, the role of technology in socialisation did not correspond to a main theme of questions. Nevertheless, instances where participants discussed their use of technology while answering other question were coded and analysed. Similarly, the generation of the theme

friendship with NT vs. ND followed a similar process. Figure 7.1 illustrates the thematic map showing the main themes and subthemes identified.

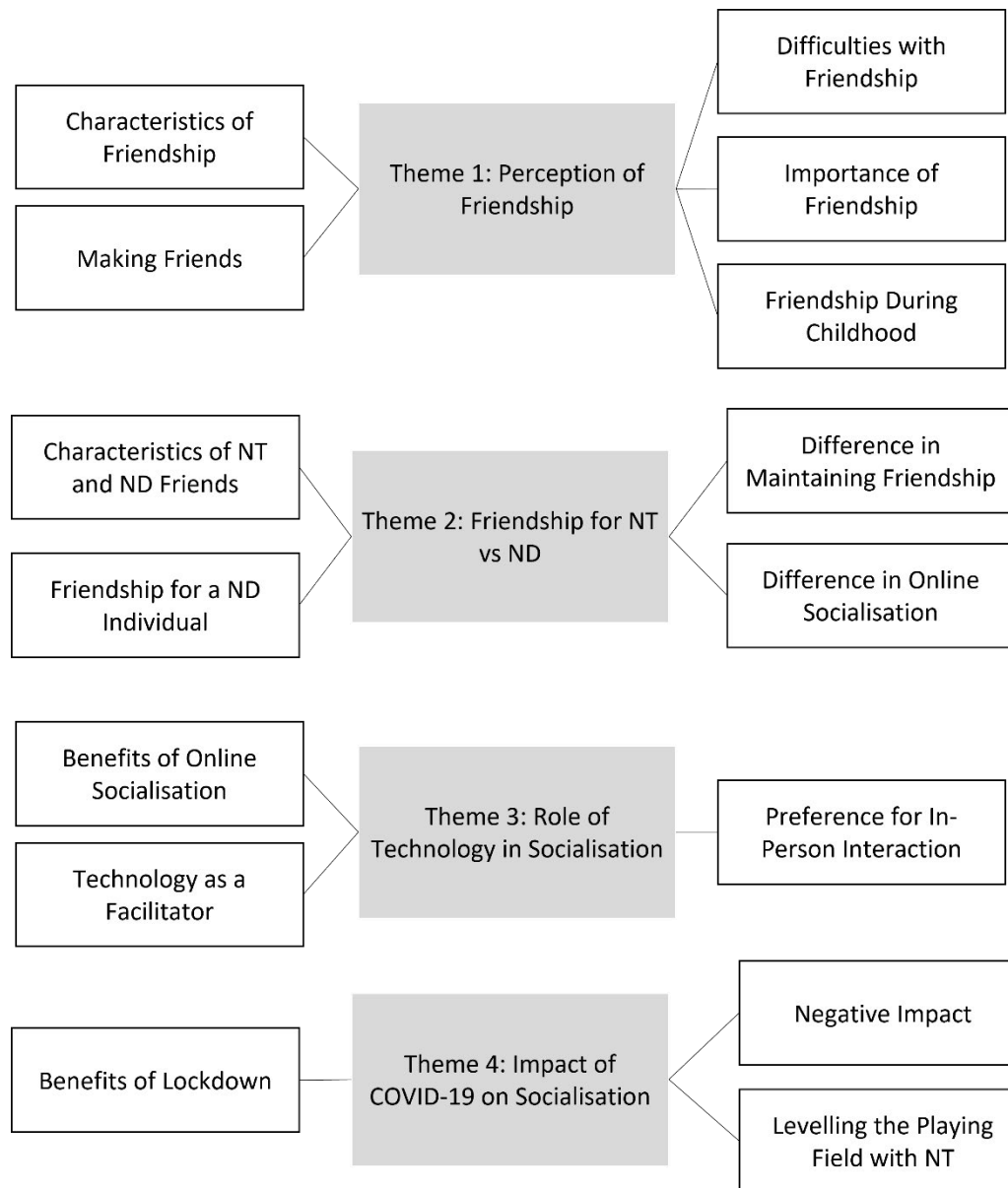


Figure 7.1: Thematic Map of Autistic Adults' Perspective

Theme 1: Perception of Friendship

Importance of Friendship: Participants expressed the importance of friendship to them and how they have been actively seeking friends even though some of these attempts have not been very successful. As Participant E explained:

"I've had trouble with friendships a lot in the past but they're very important. I guess I struggled to make and maintain friends but it's something that I really want and strive for".

Participant B expressed the necessity of friendships saying:

"I very much need that kind of companionship and someone to bounce ideas off of for me to function pretty much at all".

Participants believed that friends are important for different aspects of one's life, whether it is providing support, self-validation or a sense of security. Participant K described self-validation acquired from having friends by saying:

"in a way [they] validate that you're an 'okay' person in some respect."

They then elaborated on friendship's relationship to self-worth:

"An affirmation that you belong, that you're worthy of interaction with other people, that you're worthy of friendship".

Friends also provide a sense of joy and happiness which makes going through life easier as Participant D described:

"having friends makes the day-to-day easier, you know, it shows that there is happiness in the world and there is joy that can be had and there are people that care about you".

Some participants believed that having friends can especially help with autism specific challenges. Participant K shared their experience with that:

"I feel that my friends support me physically with my autism, you know. Some of my closest friends have supported me when I've had meltdowns in public spaces, they've helped me get to events and manage things".

Participant O summed up the importance of having friends by expressing how friendship improved their quality of life in general:

"the quality of my life is so much higher for having that".

Friendship During Childhood: Continuing from the previous subtheme, participants explained how they have always valued friendships even as children. Participant O expressed:

"Just that it is really valuable to me".

Although as children they valued friendship and wanted to have friends, they often preferred to not seek out others and stay within their comfort zone. Participant Q share their experience:

"I always want to be part of the group, but I'm quite happier standing back. Sort of I'm not noticed. I want to have friends, but it's just really complicated for me so it's best not to have friends".

Some believed that their view of friendship as adults changed from how they used to view it as children because of all the experience they have had and that their childhood perception of friendship was mostly influenced by what they saw on TV and read in books which was often idealistic. Participants C explained this discrepancy in understanding by reflecting on their own experience:

"When I was younger, I had this very idealistic idea and concept of what friendship was supposed to look like so I took a lot of my cues from TV but mostly from books, you know, and how friendships were described there but what I found was that in practice friendships were rarely that way".

They then elaborate on how this affected them as a child saying:

"I experienced a lot of putting more energy and emotion into my friendships than maybe were necessary because I wouldn't get the same amount back. and so that was really disappointing as a kid".

Learning the rules of friendship and trying to befriend others required effort and many failed attempts. Participant K shared their experience where they used to mimic behaviours they see on TV and from other kids around them in order to establish friendship:

"I used to try and figure out how to make friends by, you know, I'd watch tv shows so I tried to mimic the things I saw on tv or tried to mimic the things that my friends would do, but then people can tell what you're doing in a sense, I think, you know, neurotypical people would pick up on that, and so they'd be like, 'Oh, you're just copying me.'"

They then explain how this approach kept them from being their 'authentic' selves and thus kept others from wanting to become their friends:

" they want somebody to be authentically themselves and when you don't know how to do that it's really difficult to make connections".

Characteristics of Friendship: Participants were asked to express what they think about when they think about friendship, and they gave a variety of answers describing the characteristics of this relationship. They described it as a reciprocal relationship where both parties actively want to be in each other's life and are accepting and trusting of each other. Participant F defined it as:

"A bond or relationship between you and another person that is reciprocal, beneficial to both of you, and built on trust".

They differentiate a friend from an acquaintance by the intimate details they would share with a friend and the ability to ask a friend for favours. Participant K explained this difference:

"I wouldn't ask an acquaintance to maybe support me to go into an event or, you know, or maybe I wouldn't share how I feel about having an argument with a partner with just an acquaintance".

Shared interests and values were important characteristics for most participants as Participant M expressed:

"[friends are] like-minded people, people with similar interests, that kind of thing".

Difficulties of Friendship: Participants expressed how friendship was always difficult for them even as children. Some believed that it was most difficult in their childhood as Participant L said:

"Childhood is when it's most difficult".

However, it gets easier with experience, and they have more success making and maintaining friends as adults. Participant P compared their experience interacting with adults and teenager with autism saying:

"it's a lot easier to talk to young kids with autism and adults with autism as opposed to like, teenagers with autism [...] talking to adults with autism is also good because they're just more advanced and they have more experience of the world whilst talking with teenagers with autism can be slightly challenging because [of] anxiety".

Another reason participants attributed the difficulty to was not being diagnosed at a young age and hence not understanding themselves and not being exposed to proper coping techniques that will help them in their early years of socialisation. Furthermore, awareness about neurodiversity positively changes the experience of ND children. Participant P shared their experience by saying:

"I had no friends in primary school...at all, but because autism wasn't known at the time it wasn't fair in the school because they didn't know anything about [it] at the time. But then when I progressed into secondary school, the school already had people on the spectrum, and I felt like a hero in secondary school in terms of how respectful and how nice all of the students were towards me because I was that bit different people treated me with such dignity and respect".

Some participants are overwhelmed by the difficulty of friendships that they prefer not to have any friends. This was the choice for Participant Q who explained:

"It sounds harsh, but I prefer not to have friends. Friendships are complicated. I've tried hard in the past with friends, but I just get confused. So I tend to hold back".

Some also struggle to distinguish between a friend and an acquaintance as Participant P expressed:

"It still is extremely challenging to know the difference between an acquaintance and a friend and that's actually something I am still working on".

This was echoed by Participant I who often find themselves in a relationship where they believed the other person was an acquaintance while the other person considered them a friend:

"I've had people that considered me friends that I considered just classmates".

Nevertheless, once a friendship was established, participants still find some difficulties maintaining these friendships. Managing expectations was a challenge for many participants as they were not certain what was expected from them in a relationship. Participant I explained how inability to predict what others want from them might lead them to stress and withdraw from the relationship:

"I get really stressed out (I'm insecure about my friendships) so sometimes I just disappear for a bit, sometimes I get overwhelmed with talking to so many people, etc. I'm scared I'm clingy, so I'll ghost people, stuff like that. I find it hard to predict what people want/need from me".

Participants have lost friends for a variety of reasons; some were due to moving away, some were due to differences in circumstances which makes arranging activities together difficult, and others have difference of opinions which they cannot resolve. Participant K shared how they lost their friend due to a difference of opinion which they could not get over:

"Friends are very valuable to somebody who struggles to make them and somebody [...] when you feel close to somebody it's not the type of thing I want to just throw away, but also, because of how strongly my views are held...and I think that is due to my autism. How difficult it is for me to change my moral opinion on things and to just bend the rules, even for a close friend to go, 'Well, you know what I really hate those opinions but I am gonna just ignore them for this person' I couldn't do it. And so I lost this really important person to me".

In addition, falling out of contact made connecting again difficult as participants did not know what to say after their long absence. Participant H explains how they lost some of their friends:

"They just kind of drift away from me. I just forget to contact them, or don't have anything that I specifically want to talk to them about, so why would I talk to them, but that sounds really bad when you say it though. So, yeah, just that, just not really having anything to say to each other, so don't end up talking and I think talking is really necessary for a friendship".

Making Friends: Most participants made friends through people they already know whether they were family or other friends. Some made friends by chance rather than by actively seeking

the other person's friendship. When asked about how they made friends, Participant I replied: "by accident" they then further explained:

"I've never really looked for friends or rather, when I've looked for friends I haven't succeeded, I've only made friends by chance".

Participants expressed how hard it was to make friends especially overcoming the first interaction with an individual. Participant L compared their experience to NT saying:

"They don't have this like confusion and panic and stuff about early stages of friendship and things like that".

Participants attributed the difficulty of this initial interaction to a number of reasons. Participant P did not know what to say to someone they did not know anything about as they explained:

"Making friends can be hard at first if you don't know the first thing about the person".

Participant N explained how the necessity of interaction can be a good way to get to know the other person and overcome the difficulty of initiating as they explained:

"So you've got a reason to talk to somebody I suppose and then you can kind of pick up what kind of person they are and they can pick up what kind of person you are and then you can sort of chat more informally other times".

When there is no reason to talk to someone, Participant N suggests having a set of scripts about general topics such as the weather or family which they accumulated over the years and they can use whenever they are interacting with others. They explained:

"Have got a collection of scripts I can go through, and use depending on the situation, that I didn't have when I was younger".

Some participants were aware that if they talk too much about their interests this can discourage others from continuing the conversation. Participant P shared how they have come to realise that they need to speak less and listen to others' interests more:

"It's important to start off in what they are interested in and that's how people become interested in someone on the spectrum".

Theme 2: Friendship for NT vs. ND

Participants believed there were differences in how they socialise and maintain their friendships compared to other NT individuals. In addition, they see differences in their relationship with NT friends compared to ND friends. We discuss these differences in the following subthemes.

Friendship for an ND Individual: Many participants reported that they have a tendency to befriend other ND individuals. Participant C explains how they find themselves developing friendships with other ND people without intentionally seeking them out:

"Not on purpose I'm not like asking people 'Are you autistic?' - but every time I've made a good friend it turns out they are autistic".

Participant B said that even when they have a NT friend, they suspect that these friends may have an undiagnosed neurodivergence:

"My friends that are probably closer to neurotypical are probably just also autistic without having a diagnosis".

Participants discussed how their diagnosis changed their friendships. Their diagnosis often allowed them to understand themselves better and have the correct terminology to describe their needs and address them. Participant D compares friendships they had before and after the diagnosis:

"I have all these little scenes of autistic friendship from pre-diagnosis in my head which look different from the ones I have since the diagnosis, you know, because I have that label, that way of understanding myself and how I relate to others better".

Participant E explains how the diagnosis helped them understand their needs and get over the negative view of themselves when they were not able to act the way others around them are acting:

"I feel like this is actually one of the ways that understanding myself as autistic has really helped me because it's not just me feeling like deficient that I need that time or can't be as spontaneous as other people. You know, before I had the words for it, I just felt very like, 'why can't I do this?'. And having the label actually gave me a little bit more of like the understanding for myself to say, 'it's okay that I need that'".

Participants believed that when they are making new friendships, they have the added need to disclose their diagnosis. When asked about how they make friends Participant R replied:

"I'd say quite like normal people except of the added, 'By the way, I've got Asperger's, if I say or do anything odd, that's the reason', kind of explanation".

Participants felt that they can be more open and 'authentic' when they have disclosed their diagnosis to others. Participant D shared their story about when they felt comfortable and safe enough to start unmasking in front of their NT friends but unfortunately this led their friends to feel that they cannot cope with their behaviour:

"I stopped masking around them because I felt very comfortable with them and I thought that they were safe people that I didn't have to mask with, so to hear not long later, you know, a month or two, that it was too much for them just really really hurt because I'd opened up to them, I guess, and I had let the mask down and they just weren't having

it, which I guess is fair enough cause it is a lot for a neurotypical person who hasn't ever dealt with someone who is autistic before".

Characteristics of ND and NT Friends: Participants noticed differences in their relationships with others depending on whether they were ND or NT. They generally felt that ND friends understand them better and can relate more to them. Participant T explained:

"They know what you are going through and if you say something they know that sometimes it doesn't mean how you said it... and they understand".

This is often not the case when interacting with other NT friends as Participant G shared her experience with both saying:

"With NT friends, I constantly feel like I am playing a game without knowing the rules and I could get thrown out at any moment. I am hyperaware, ultra-masking, over analysing everything. With Autistics, it just comes naturally. I say things without filtering and they just understand me. The first time I experienced it I was so stunned. I didn't know what it felt like not to have to translate myself for other people".

This feeling of being misunderstood when interacting with NT people was reiterated by Participant J as they share their experience in school:

"I was living in a neurotypical world and didn't understand how to make friends there. It's like being in a foreign country, unable to speak the language fully, like enough to buy food and water and book a room in a hotel and all the things you'd need to get by, but not enough to make any connections or meaningful friendships".

This makes talking and interacting with ND friends easier as Participant G explains:

"It is easy to get caught up talking about stuff we like. This is what I mean about how much easier it is to interact with a fellow ND".

Their ND friends understanding their needs, how they tend to explain things, and how important their interests are to them, helps tremendously when interacting with each other. Many examples were shared by participants, Participant F gives an example of how the need to withdraw from a social gathering will be dealt with differently among ND and NT friends:

"Boundaries are communicated and respected considerably more in neurodiverse friendships. Many things can go unspoken – e.g. someone is withdrawn or leaves a meetup early with little explanation will often be given a free pass or an understanding message/check in later, rather than an interrogation/questioning the behaviour".

Participant N gave another example of how their ND friends usually appreciate their honest way of expressing their opinion especially compared to their NT friends:

"I feel like a lot of autistic people tend to just state facts and say how they feel, whereas neurotypical people often seem, at least to me, to dance around the subject and sugar coat things because they don't want to upset anyone which is understandable and both ways of doing friendship are entirely valid".

Participant J explains how NT friends usually do not appreciate their friend constantly speaking about their interests as they do not understand how important it is to them while ND friends will be supportive even they did not share the same interest:

"Neurotypicals just don't get how important they are, they think we are weird and they get fed up with us talking about it, but an important part of autistic friendships and generally what makes autistic spaces so healing is that we can just talk about them to people who will be supportive you know, like they will actively appreciate it".

Participants believed that their ND friends have similar expectations from the relationship and are generally more loyal and invested. Participant J compared her friendship with ND and NT friends saying:

"I feel like autistic people are more loyal in their friendships. That we have certain standards that we expect of people. Because I think autistic people have quite structured views of things, They have definable characteristics [...] to fit in with neurotypicals we have to sort of create these rules and boundaries so otherwise we tend to cross them. I grew up with being told that loyalty was a big thing in friendship and that you have to support your friends. So, I tend to go above and beyond for my friends, my neurotypical friends, and then I often felt let down when I feel like they're a lot more flippant and not so caring or thoughtful".

Participant C reiterates this by explaining how ND friends do not "keep score" and will remain loyal to each other and understand others' behaviour:

"There's not a checks and balances system, there's not this, you know, expectation of I did these five things for you and you have to do these five things for me. It's like nobody is keeping score, there's not a barrier there for us to navigate – we know if the other person does something a little silly why they're doing that silly thing".

Participants also felt that they become friends with other ND individuals much faster compared to how fast they make NT friends. Participant C explained this difference:

"When you get two autistic people in a room who know each other are autistic it's almost like immediately like 'Uh, do you want to form an alliance with me?' like it's – you can say 'Hey do you want to be my friend?' and like 'Yeah!' [...] I have friendships that I've made like [this] that has lasted me for years and years and been very healthy with autistic people, versus you know the slow gruelling kind of, almost currency system where it's like a piggy bank that you have to keep making deposits into in order to build up something that resembles a functional, in your mind, a friendship [with NT]".

Nevertheless, some participants believed that friendships with NT are necessary and beneficial to them. As Participant P explained:

"I personally don't socialize with other autistic people because, the only reason is, if I stayed with people with autism my sense of confidence won't grow, so I'll be stuck [...] So that's why I constantly mix with neurotypical people, to help me grow and to help me flourish and I just find going up to people is good".

In addition, Participant Q believed that their NT friends help them make sense of others' behaviour:

"Because sometimes even now I'm messaging someone, like [friend name] or [another friend name] or my daughter on like Facebook, I've got to get her to check what I've put or the reply. I say: 'I don't really understand what that means', and she'll help me go through it".

Moreover, some participants expressed how they can get frustrated by their ND friends' needs and way of communicating as much as other NT people would. Participant N explained:

"The things that a neurotypical would find annoying or frustrating with an autistic, I will find that annoying or frustrating with that autistic person too"

When asked to give an example they said:

"I know one person and they talk a lot, [...] they keep on going on a subject and they won't pick up that – ok I don't need you to go into that much detail, I am not that [into] it [...] it's just frustrating sometimes".

Participant P gave another example of how important eye contact was to them and how it makes interacting with people on the spectrum difficult for them:

"I do find many people on the spectrum have very poor eye contact [...] so that's why I just don't mix with people on the spectrum because of eye contact. It's just so hard to talk to people when they don't look at you".

However, friendships with NT people usually revolve around a specific activity or a shared interest that they do together while friendships with other ND people go beyond that. Participant H talked about what types of activities they do with their NT friends:

"With neurotypical people, I think we do 'things', we watch films, we go shopping".

While Participant G shared the type of things they do when they meet their ND friends:

"With other autistics, it is a meeting of minds, a feeling of coming home, being able to use our own shorthand - which is probably similar to NTs with other NTs. But we also use it as a way of exploring ourselves, learning new things and expanding our horizons. It's not just to waste time, I have hobbies for that".

Difference in Maintaining Friendship: Participants believed that NT and ND people maintain their friendships differently. It is like they have a different set of rules on how to keep a friendship going and what they expect in order to maintain the relationship. Participants believed that within ND friendships they can go out of contact for long periods of time and come back without affecting the relationship. This was a recurring event in many participants' relationships as Participant C explained:

"I've noticed my friendships with neurotypical people they want to talk all the time which is fine but it's a lot of energy and if they don't talk to me in a couple days or if I don't talk to them then they think I'm ignoring them or being selfish whereas with my autistic friends and my neurodivergent friends long periods of time can pass and then we'll get to together again or we'll message each other and it's like no time has passed at all".

Participant G reiterated that by giving a thorough explanation of the difference in expectations when comparing NT friendships to ND friendships:

"We don't have the same rules to our friendships. We can be out of contact for months and then just pick up as if there hadn't been a break. We aren't expected to remember about if the other's child was trying to get into the local football team or had a ballet recital. With NTs, it is a mortal sin not to remember to ask about every little thing that they told you before and you must check in on a regular basis, even if it just to say hey".

Difference in Online Socialising: Participants have noted multiple differences to the way they socialise online compared to their NT friends. Participants believed that NT people will prefer in-person interaction as it is more natural to them. Participant N expressed:

"I think it's easier for NT to make friends face to face because they understand all the 'rules' so much better (like 'how are you' doesn't actually mean how are you). They're also more relaxed".

This leads participants to believe that most NT individuals use the technology to find people to befriend rather than to develop the friendship and maintain it online as Participant G said:

"I think we form friendships using tech and use tech to build the friendship and keep it more. I think NTs use tech to find people to then socialise with IRL [in real life]".

Participants believed that the absence of body language and social cues which NT people usually rely on in a social interaction makes online interactions difficult for them. As Participant N explained:

"I think a lot of neurotypicals don't like doing it online and they find it difficult and they would much rather be face to face with someone [...] Whereas, online it's really tricky for some."

Participant D explained how NT people will often edit themselves online to cope with the lack of social cues they are used to which can be beneficial when interacting with a ND person:

"Neurotypical people when texting know that they have to change the way that they communicate to accommodate for the lack of body language and facial expressions, et cetera. So, they do that when talking to everyone online, and as someone who is autistic that is really quite convenient".

Theme 3: Role of Technology in Socialising

Participants use multiple social media platforms including Facebook, Twitter, Tumblr, WhatsApp, Reddit and Discord. They also use video conferencing technology such as FaceTime, Zoom and Skype. Participants acknowledged the important role technology and social media has in their social life which we discuss in the following subthemes.

Technology as a Facilitator: In many ways, technology has acted as a facilitator to social interaction for our participants. This role starts early in a relationship when the social media platform's algorithms suggest other people's accounts. In many instances, these algorithms were successful in suggesting someone who eventually became a close friend. This was the experience of Participant C, who shared how they met one of their closest friends:

"An algorithm showing the same content over and over again until you decide '[...] let's hang out in person' and then you like that person so, you know we went from casual internet friends a little over a year ago to now like, they're a part of my family [...] they have keys to get into my building, to get into my house".

In addition, the necessity of having another player when playing online games created opportunities to develop friendship. Participant D explained their experience with making friends through online gaming:

"Looking at World of Warcraft, which is where I have made a number of friends online. I have mainly found it when I have been looking for a guild or something, you know, just people to run dungeons or raids with or people to role play with, for example [...] it is just a place where you can find people that you can relate to and because you have that thing that everyone is there for, it is an easy conversation starter because you all have that common ground".

In addition, participants felt that when the initial meeting was made online, it made meeting in-person much easier as Participant N explained:

"It's a lot easier. There's a sort of [...] I suppose an online breaking of the ice"

they then continued to say:

"Because to them I am probably really weird, and they don't know what's going on. So, they know I am ok and I know they are ok, so it's a lot easier to talk when we meet face to face".

In addition to the role technology played in helping with the development of friendship, it also helps with maintaining this relationship. Participants believed that following their friends on social media and being up to date with what they are doing through what they post would help them remember to contact their friends and keep the relationship going as Participant G explained:

"I am friends with some of my senior school friends on FB and the sharing of posts is enough to keep that emotional memory present".

Moreover, these online posts can be a conversation starter when they are unsure what to talk about with their friends. Participant P shared how beneficial Facebook was for that:

"Facebook has been very beneficial in that sense [...] you can carry on the conversation from a post that you saw on Facebook. So, I would have met someone on the street by total random or in a restaurant and then someone would wave at me and then they say, 'I can't believe that you're mixing with the Downton Abbey cast' [referring to an image they posted on Facebook]. But, but that's how Facebook has been very good to me".

Benefits of Online Socialisation: Most participants believed that it is much easier to communicate online and develop friendships. They attributed the ease they feel to a number of factors. They believed that it was easier to find people who are similar to them whether it was in terms of neurodiversity or in terms sharing similar interests and values. Participant G compared their experience now to how it was before using the internet and how it has widened the scope of possible friends they can have and gave them access to communities they belonged to:

"Back in my youth, you could only make friends with the people at school, work, social clubs. I wasn't even surfing the net until my 20s. Now I can find my community so much more easily".

In addition, participants were comfortable communicating online because of the absence of body language and social cues. It also helped them edit themselves and think carefully about what they are saying which makes them feel much more confident. Participant S explained their experience online saying:

"Online I can be a lot more confident and can say what I want to say, I can formulate things I want to formulate, but if we were to meet up in person it would be a lot harder for me to do that".

Participants have found that the use of emojis helped them tone a message and were easy to understand. Since emojis were used by both NT and ND people online it creates an equal experience to the interaction as Participant K explained it:

"There is no tone to read into it and the only way you can ascribe a tone to it is with emojis and emojis are easy to read [...] even neurotypicals can misinterpret the tone of a written message. So, I definitely feel that instant messages and texts levelled the playing field for me and helped with forming those friendships".

Furthermore, communicating online gives a sense of freedom and openness as fear of judgment is reduced. This is what Participant A expressed:

"Online people usually don't know me so well. Except to all my friends. I'm a bit more open about it online than in real life".

Another benefit to online communication was the ability to leave the conversation when feeling the need for a break and come back to it when ready as Participant T explained:

"Online you could say something and you can leave it there and go away like distance yourself for a bit, and then come back to it when you feel right and ready to talk about what you said while face to face you can't have conversation like that, you have to go for the conversation at once you can't go away".

It also makes friends more accessible online and helps maintain the relationship in a much easier way as Participant R expressed:

"I've been able to easily keep in contact with online".

Preference for In-Person Interaction: regardless of the many benefits of online socialising, some participants still preferred in-person interaction. Participant O felt that although online friends are easily accessible these relationships usually lack depth as they explained:

"[online friendships have] a lack of depth [...] It doesn't feel as human either. So that would make the biggest difference. But it's more available, so you're trading in a real authentic human experience for an easy to obtain human experience".

Although some participants believed that the ability to edit self was a positive for socialising online, others viewed it as a drawback since friends made online seem different when they meet them in person. Participant P believed that it was difficult to sense someone else's energy when interacting online which made them prefer in-person interactions. They share their experience of meeting an online friend in person:

"I am very much in tune with energy and it's just a lot easier. For example, I saw someone on Facebook who looked really nice but then, when I saw the person, I felt so uncomfortable around this person and the reason for that is, is just our energies just did not match".

Another drawback was that some participants missed the physical connection as they prefer physical touch. Participant G expressed:

"The only advantage of face-to-face is hugs - I have hyposensitivity to touch, so I love tight hugs".

Theme 4: Impact of COVID-19 on Socialising

Participants had mixed views on how COVID-19 and the lockdown has impacted their social life. Some believed that lockdown had contributed positively to their social experience while others felt it interrupted their social life. These different perspectives are discussed in the following subthemes.

Levelling the Playing Field with NT: some participants believed that social distancing and lockdown levelled the playing field with NT people in different ways. For many ND individuals, social distancing is already a practice and now that everyone has to do it they

communicate with others in a way more suitable for their needs. This is what Participant G shared about their experience with lockdown:

"It has been wonderful. I know that is a bad thing to say, but people's expectations have changed, and they are having to maintain relationships in the way I find more comfortable. Skype, WhatsApp, text, email and because I have a condition that affects my voice, I have almost got everyone to stop ringing me. I am dreading lockdown ending actually".

Participants also felt that lockdown led more NT people to understand the experience of their ND friends and reach out to them more as Participant K expressed:

"It's just been business as usual. But for them [NT friends], they are like "Oh we need to check in". So, in some ways I feel like they've checked in with me more because they've been more conscious of people being lonely whereas before I feel like they didn't realize how lonely other people could get. And I've been lonely, so I've always known that, but I feel like they have only just realized what loneliness is because of lockdown".

Benefits of Lockdown: participants believed that social distancing and lockdown put more emphasis on socialising and finding alternative ways to connect to others which encouraged socialising online. Participant S compared how frequently they contacted friends before the pandemic to after the pandemic saying:

"I feel like there has been more contact, because beforehand we only contacted each other, even on the group chat, every now and then [...] but after the pandemic happened, we actually started contacting each other a lot more",

they then concluded:

"If anything my friendships have benefitted from the pandemic".

Many participants enjoyed the limited in-person interaction and have found the lockdown as a time to relax since they no longer need to mask as much. Participant G expressed:

"For me the absolutely best bit of the lockdown was I finally unmasked for significant periods of time without being in a shutdown or burn out. Like I have started stimming a lot lot more, which is great".

Negative Impact: Many participants missed in-person social interactions during lockdown and lost many of their friends during that time as Participant J expressed:

"I have been so isolated that nothing seems of interest really anymore, it's hard",

they continued talking about their friendships, saying:

"I've lost them all now through COVID [...] I just isolated myself more and more and more from the good ones and used the lockdown as a way to distance from the bad ones".

Participant E explained how it has been harder to maintain friendships as they were no longer able to carry out their established routine which allowed them to keep these friendships going:

"I do feel like friendships have been harder to maintain. I didn't necessarily have to change my day-to-day much, but I would kind of get myself to go out, make plans fairly regularly just to keep up with that [maintaining friendships] and I've gotten out of the habit of it and just couldn't for a while, so it's definitely made it harder because you don't see people as regularly".

Making new friends in these circumstances was extremely difficult and almost limited to online socialising. As Participant D explained:

"It's hard to make friends because you can't just go out and do things as much, and the things you can go out and do you are strongly discouraged from meeting other people, which kind of impedes everything to do with the friend making process".

Participants struggled with the amount of things they have to do online during the pandemic as many of them worked or studied online and also had to have all their social interactions online which can be overwhelming as Participant D clarified:

"Because everything is online now, I do my entire degree online, it's hard to have all of that be online and then all of my social interactions, cause it just becomes so overwhelming, I guess, to have everything be in my computer or in my phone".

On a different note, although participants were able to unmask and relax due to social distancing and lockdown. Some participants were worried about losing the skill to mask when life is back to normal and they have to socialise with others in-person. Participant O shared their concern saying:

"I do feel like I get out of practice, with masking, with remembering the rules and sticking to behaviours that aren't going to harm other people".

7.4 Discussion

In this study participants described their experience with friendship and how they made and maintained their friendships. They also reflected on their experience as children and how it is similar or different to their experience as adults. They have also discussed the impact of technology and online socialisation on their social life in general and specifically during COVID-19 lockdown which was when these interviews were conducted.

Definitions and models of friendships available in the literature come from a neurotypical perspective and there is a possibility that autistic individuals have a different view of what friendship means or feels to them. However, after specifically asking participants about

how they defined friendship, they incorporated the same core elements of reciprocity, acceptance and trust but did not often mention aspects relating to intimacy or affection. Nevertheless, when differentiating between a friend and an acquaintance they used intimacy as an aspect to separate the two relationships. However some still struggled to distinguish between these two relationships. This is in line with what Brownlow, Bertilsdotter Rosqvist, & O'Dell, (2015) argue about the potential of individuals with autism having a different conceptualisation and expectation of friendship compared to the neurotypical view. Nevertheless, participants confirmed the importance of friendship to them and how it improved the quality of their life which is consistent with results of previous research (Jones & Meldal, 2001). Furthermore, they believed it is especially beneficial for them as autistic individuals as friends can often help them with difficulties related to autistic characteristics or wider issues such as stigma and social isolation. Participants also highlighted how friendships with other NT individuals is especially beneficial as they would support them in making sense of a "neurotypical world". This is consistent with what Bauminger et al., (2008) found when evaluating friendship between mixed dyads of autistic and non-autistic children and found that these relationships allowed the autistic child to develop social and linguistic skills which matched what is expected from a neurotypical peer. These findings suggest that friendship with other NTs can still be beneficial throughout adulthood as well.

Participants described how they had an idealistic view of friendship inspired by TV shows and other media which does not reflect their real-life experience. This can be linked to the rigidity of thought characterised by autism which may lead individuals to strive to achieve relationships similar to what they saw on TV. Participants reported how they often mimic social behaviours they observed in order to socialise and establish friendships with neurotypical people. However, this imitation behaviour was not always perceived positively as it created a discrepancy between their authentic self and what they are trying to mimic to appear more

approachable to other NT individuals. Although imitation is known to enhance social bond and is also often used by NTs (Carpenter, 2006), the difference in how autistic children imitate may be related to why this behaviour is not positively perceived. Marsh, Pearson, Ropar, & Hamilton (2013) described how NTs "overimitate" copying both social and functional aspects of a behaviour while autistic children often omit aspects which are not functional.

Participants believed that authenticity is important in a friendship, however, they are often faced with the dilemma of whether to let their guard down and act naturally around their NT friends which may lead them to behaviours which upset their NT friends, or keep masking and sacrifice being their true self.

Participants highlighted how central their diagnosis is to their social life and the positive impact being diagnosed has on their friendships. Being aware of their own needs when it comes to social interactions allow them to address these needs and access appropriate support to be more successful in meeting their own social goals. Participants believed that disclosing their autism diagnosis is necessary for their friendships and is important for others' acceptance. Hence, a positive impact was observed when communities became more understanding of autism as a result of multiple autism awareness campaigns. These findings confirm how early diagnosis of autism improves an individual's self-awareness and facilitates relationships with neurodivergent and neurotypical friends. It is also encouraging to continue conducting more autism awareness campaigns as it highlights the benefit of such efforts.

Participants identified how some aspects of autism impacted their friendships with others in general and their friendships with NTs specifically. Rigidity of thought made it difficult to maintain friendships with someone who held different opinions or beliefs especially when their views are constantly posted on their social media accounts. However, it was this rigidity of thought that was also believed to be the reason that autistic participants perceived

themselves and other NDs as more loyal friends compared to NTs. In addition, focusing on their own interests was often perceived negatively by other NTs and they needed to consciously try to limit talking about their interests and allow others to speak. Nevertheless, participants found that the way they talk about their interests was accepted and understood by fellow NDs as they understand the importance of these interests to the individual. This is yet another finding in line with Milton's (2012) double empathy problem highlighting how although both ND individuals have a special interest which they want to talk about they are more willing to listen and give others the opportunity to talk about their interests compared to NTs. In addition, being forthright and direct is often appreciated by fellow NDs as it gives clarity which NTs might be offended by. Therefore, the current participants had a tendency to befriend other NDs and found developing friendships with them easier and faster, describing their friendship with them as "a meeting of minds". Friendships with NDs are often more easy to maintain as their expectations of friendship were perceived as being 'similar'. Nevertheless, participants believed that developing friendships with other NTs is necessary as they can help them make sense of an "NT world". In addition, continuing to challenge themselves with making and maintaining friendships with NTs was viewed as an opportunity to grow. Hence, it is important to conduct more research to understand how to support these relationships.

Participants identified two strategies they used to develop friendships. First, there needed to be a purpose for the interaction in order for them to be able to initiate a conversation with others. When this was not possible, participants resort to a set of scripts which they gathered through the years to allow them to find something to talk about with others such as talking about the weather. These strategies are consistent with the finding from the teachers' interviews in Chapter 4 where they identified incentivising the interaction by making it necessary as a way to encourage autistic children to initiate. The use of a set of scripts is similar to the initiation and fading strategy identified by teachers as participants in this study used the

scripts in the beginning of the conversation but then they continued the discussion based on how the conversation was going. These two strategies are inherently available when interacting with others through online gaming as there is a need to communicate and collaborate with others to achieve a shared goal. Also, there is a common ground or focus point to generate discussions which is the game itself. This is among the many reasons participants preferred online socialising.

Participants gave additional justifications to explain why they found it easier to communicate with others online. Online socialising gives them time to formulate and edit themselves which is not possible when communicating in-person. It also gives them a larger pool of possible friends and finding communities they relate to which may not be available physically around them. Participants believed that there was no fear of rejection when approaching others online which is consistent with what our interviews with parents and children yielded in Chapters 5 and 6 respectively. In addition, it is inherently a safe space since they are able to distance themselves from the online interaction when they need. This is consistent with the third strategy teachers identified in Chapter 4 which is "providing a safe space". The absence of social cues was another reason participants preferred online socialisation as it provided equal opportunities with NTs. Social media posts were good conversation starters when initiating an interaction to develop friendship and a visual reminder to maintain an existing one. Participants confirmed that meeting someone online first made it easier to interact with them when they meet them in person. These findings suggest that online socialisation is a good candidate to be used as a medium to support friendship for ND individuals in general and specifically with NTs.

Social interactions being mostly online was one of the main advantages of Covid-19 lockdown reported by the current participants. They believed that it levelled the playing field with NTs in two aspects. First, the social isolation NTs experienced during social distancing

and lockdown is similar to the experience of NDs even before COVID-19. Second, NTs are now resorting to communicate online which is NDs preferred way to communicate. Other advantages of COVID-19 lockdown included how the social distancing guidelines put emphasis on social interaction and finding alternative ways to connect with others, which made people go out of their way to make sure they stay socially connected where before it came as a by-product of their everyday life. In addition, the ability to unmask for an extended period of time was viewed positively by some participants as they found it relaxing while others were worried that they were losing their masking skill and feared this would be a ‘disadvantage’ when life returned to normal. This highlights how important masking is for autistic individuals’ socialising and how letting go of this mask was viewed as a retreat. Allowing autistic individuals to socialise comfortably without masking is an important advantage of online socialisation.

Although participants identified many benefits to online socialisation, they discussed some disadvantages as well. Despite them viewing the ability to edit themselves online as a benefit, it was also a problem when it comes to other people editing themselves and then seeming different when they met in person. Participants found that although online interactions were easy to obtain they lacked depth to make it feel more real. The lack of physical touch such as hugs was viewed negatively by participants who prefer to be touched. These findings demonstrate how online-only socialising solutions are not ideal and a mix of online and in-person strategies need to be considered when providing friendship support.

Autistic Adults as a Proxy

Autistic adults as a proxy for autistic children have a unique perspective that no other proxy can provide. This is due to them being autistic children themselves at some point in their life and being able to reflect on their experience as children. However, it is important to consider

how they are not children now and they do not necessarily have the same experience compared to children who are experiencing the world currently. Multiple factors may create the difference in these two experiences. First, technology has vastly changed from when the adults in the current study were children. Hence, they do not have the capacity to comment on challenges children may experience with technology currently available. However, they can attempt to predict what children's experience might be, relative to their current and previous experience. In addition, our understanding of autism, available support and autism awareness within schools and communities in general has changed considerably. There has been a growth within the autism community and increased advocacy for people on the spectrum. Another important factor to consider is whether the autism diagnosis of the autistic adult was known when they were a child or whether they were not diagnosed until adulthood as the support provided or the lack thereof will change, depending on whether they were diagnosed as children or not. This may impact how friendship was perceived or managed by participants as children. Nevertheless, the accumulated social experiences and support an adult with autism has may have allowed them to better communicate and articulate their perspective in an interview compared to autistic children. Furthermore, they may be able to overcome the challenges they were facing as children and can share the solutions and strategies that helped them defeat these difficulties.

In the results of this study, participants confirmed that they are now more advanced socially and that their experiences allow them to talk about friendship. They have also shared strategies they used to develop friendships which were developed over the years through observations and trial and error and were not known to them when they were children. They also reflected on the benefits of online socialising and how it aligned with their preferred way to socially interact with others. They specifically shared how it gave them equal social opportunities with NTs and allowed them to find communities they identified with, which was

not present for them when they were children. We can assume that autistic children may experience challenges with online socialisation similar to what autistic adults are experiencing currently. Nevertheless, they may still have their own challenges which are not experienced by autistic adults. This may be due to the different platforms adults and children use which may introduce different issues. In addition, adults were not exposed to online socialising until later in their life, when they have already obtained more social experience. Hence, when reviewing results from autistic adults as proxies, it is important to consider how their experience may differ from children currently and investigate these specific potential differences.

8 CO-DESIGNING A SERIOUS GAME TO SUPPORT FRIENDSHIP WITH CHILDREN

8.1 Introduction

In this chapter, we will introduce the co-design workshops we conducted with children to design a serious game for supporting friendship between autistic children and their neurotypical peers. There were seven workshops conducted in total, four of which were physical workshops (conducted prior to COVID-19 lockdown) while the remaining three were online workshops (conducted during lockdown).

Prior studies were needed to design the design activities themselves. In addition to utilizing the literature on participatory design discussed in Chapter 2, two pilot design workshops were conducted to evaluate the suitability of the design activities. Lessons learned from these pilot workshops are discussed here. Furthermore, following the teachers' interviews discussed in Chapter 4, the strategies identified by teachers were incorporated into the design activities of these workshops.

In this study, the second research question is addressed:

RQ2: How can autistic and non-autistic children be involved in designing technologies for supporting friendship?

RQ2.1: How might design workshops be used with children to inform designing for supporting friendship?

RQ2.2: How can remote methods be used to best provide accessibility for autistic and neurotypical children?

Question RQ2.1 was addressed by conducting several design workshops with autistic and neurotypical children and comparing each iteration of the design workshop and observing how the design activities were perceived by participants and how they evolved.

Conducting the design workshops with children was limited by COVID-19 restrictions: conducting face to face physical workshops was not permitted. This created an opportunity to explore other ways of including children in the design process. Asynchronous Remote Communities (ARC), which is a form of Asynchronous Distributed Participatory Design (DPD), was chosen as a way to adapt the physical workshop to an online format. This change allowed RQ2.2 to be addressed. Conducting live DPD online workshops was also considered. In parallel with the research described in this thesis, the author was involved in conducting a live DPD workshop for a different research project (Singh, 2021). The aim of the project was to design an online Dungeons and Dragons tool to help autistic children cope with anxiety. The thesis author involvement in this project allowed her to experience a live DPD workshop with autistic children. In addition, all interested participants in the ARC workshop conducted for this thesis participated in a live warm-up session prior to starting the ARC workshop. These two experiences contributed to the decision of conducting the design workshops asynchronously. While working with an autistic participant in the live DPD workshop, the participant appeared distressed by one of the questions and due to the workshop being conducted synchronously with other participants present, it was necessary to retreat from that

question and move on to the next. It is possible that in an asynchronous approach it would be possible to revisit the question at a later time when the child is less anxious or change how the question was presented. Therefore, for the current research, Asynchronous DPD was chosen. This allowed more participants to take part as they are able to complete the activities in their own time, and at their own convenience. It was also expected that removing time pressure might reduce anxiety for children who are not familiar with design workshops, especially those on the spectrum.

The results of the two formats, Physical and ARC workshops, will be presented separately and the findings will be discussed jointly at the end of this chapter.

8.2 Pilot Design Workshop

Two pilot design workshops were conducted during an early stage of this research. They took place in conjunction with other design workshops as part of related research conducted in parallel with this (Chytiroglou, 2018; Pollak, 2018). The purpose of this workshop was to test an open format of the design workshop where the design problem is explained and the children are left to design anything they choose, without any limitations.

8.2.1 Methods

8.2.1.1 Recruitment

Participants were recruited through a database of families who had previously participated, or showed interest, in similar research projects. Parents were sent information about the workshop by email and interested parents replied with their children's information to register for the workshop.

8.2.1.2 Participants

Fourteen neurotypical children participated in the pilot workshop 7 females and 7 males with ages ranging from 6 to 10 years, with an average age of 8.

8.2.1.3 Study Design

Two design workshops were conducted in two consecutive weeks with very minor differences in the activities and structure. In the first workshop the nine children were divided into two groups, based on their ages, to avoid the problem of older children dominating the discussion. In the second workshop, all five participating children formed one group. Each group session lasted for approximately 40 minutes. The first 10 minutes was for warming up and introducing them to the session's topic and the rest of the time was dedicated to the main design activity.

- Warm-up: children took turns talking about their friends, how they met them, what activities do they do together and how they might include a new student in their class within their peer group. Next, the researcher introduced the research goal and the difficulties some children may have in making friends and moved to the second part of the session.
- Game Design: children were asked to design a game which can be played by two players and can help them become friends. The children were provided with sheets of papers asking them to specify the game goal, rules, rewards and any other notes they might have (see Appendix H) . Children were provided with Lego pieces and characters to physically represent their game. After finishing their design, pictures were taken of the design, and their explanations of the game, and the children were then asked to explain their game further to the researcher. Samples of the children's designs are shown in Figure 8.1. At the end of the workshop, each child was given a laminated participation certificate with their name on it (see Appendix I).



Figure 81.: Sample of Children's Designs

8.2.1.4 Ethics

Ethical approval was obtained from the School of Informatics ethics panel. Given that this workshop was in conjunction with other workshops each with a different purpose and activities, a combined information sheet and consent forms for all workshops was sent to parents and their children to obtain their approval. Parent and child permission to audio and video record the design session was sought before the beginning of the workshop. All video and audio recordings were stored in an encrypted folder on a university-secure server, separately from any identifying information and accessible to the research team only. All physical materials the children created during the design process were stored in a locked cabinet in the researcher's office.

8.2.2 Lessons Learned

Most children were engaged with the workshop, in particular in the game design part where they got to use Lego. However some children played with the Lego in a typical way rather than using it as a tool to express their ideas. Hence, Lego were a distraction from the workshop goal for some children. To address this issue, the researcher paid specific special attention to these children and prompted them, reminding them of the goal of the workshop. Many children came

up with ideas for games to be played by groups of children rather than pairs, which did not address this specific research problem. In contrast, some children produced a one-player game where the other player was more of an object in the game rather than an equal partner. Although the researcher specified that the game should be a two-player game, it was evident that in further similar workshops more attention should be given to the structure of the activity and the form of the questions asked. A modification to the game design sheet might include a section on player 1's role and another section on player 2's role which would emphasise that there should be only two players and each should have a role in the game.

In addition, some participants came up with competitive ideas which contradicts the research aim. Hence, the importance of the collaborative aspect of the game should be highlighted to the participants and the activity should specifically ask them to design collaborative games.

Lessons learned from these pilot design workshops are summarized below, where each problem is identified with its proposed solution:

- Lego can distract participants from the design goal: develop a prompting strategy to keep participants engaged and consider using other materials that are less distracting.
- The children came up with designs which do not directly serve the purpose of the research due to the lack of structure: Design sheets should provide more structure, specifying number of players and their roles, and the activity should specifically ask children to develop collaborative games.

These findings were incorporated into the design of subsequent design workshops in the form of adding reflection activities to provide structure and to act as a prompting aid. In addition, findings from teachers' interviews, discussed in Chapter 4, and the research literature on participatory design were incorporated as well and a discussion of how these were applied is given in Section 8.3.1.4

8.3 Physical Design Workshops

8.3.1 Methods

8.3.1.1 Recruitment

Participants were recruited through convenience sampling from a database of families who have previously participated in similar design projects and shown an interest in the workshop purpose. Parents were emailed with information about the workshop and proposed dates and interested parents replied to register for the workshop.

8.3.1.2 Participants

There were seven boys and seven girls. Their ages ranged from 7 to 12 years with an average age of 9. Four children participated in workshops 1, 3 and 4, and two children participated in workshop 2. Table 8.1 shows participant information and the pseudonym they chose for themselves which will be used throughout this chapter.

Table 8.1: Physical Workshop Participants' Demographic Information

#	Workshop#	Age	Sex	Chosen Pseudonym
P1	1	12	Male	Blackbeard
P2	1	10	Male	Sailor
P3	1	10	Male	Hunter
P4	1	7	Female	George the Pirate
P5	2	7	Female	One
P6	2	9	Male	P.P. Mudd
P7	3	12	Male	Zed
P8	3	8	Female	LA
P9	3	11	Female	NaMeimo
P10	3	10	Female	Alex
P11	4	11	Male	Ninja
P12	4	8	Female	Midnight Hunter
P13	4	8	Male	EB
P14	4	8	Female	Bloter

All children who participated in these workshops were neurotypical. Seven of them had experience designing games for children with autism in previous research projects. A decision was made to work with these neurotypical children first as they were more accessible and were familiar with the researchers and the nature of the design workshops. At this stage, we refrained

from recruiting autistic children. The neurotypical group represent a subset of the target audience and their experience with design workshops allowed us to evaluate the workshop protocol and to consider how to apply adjustments for future workshops with autistic children and for those with less experience of game design. However, the workshop's activities were designed with autistic participants in mind, as subsequent workshops were planned to involve both autistic and neurotypical children. These workshops were scheduled to run in a specialist school for autistic children in March 2020. However, COVID-19 restrictions prevented autistic children participating in these physical workshops and their participation was limited to ARC workshops which will be discussed later in this chapter.

8.3.1.3 Procedure

When parents and their children showed interest in participating in this study, they were sent the ethics booklet by email. Three 3-hour time slots were offered, and the participants were able to choose their preferred time. When participants arrived at the workshop location their consent forms were collected. All session were video and audio recorded and the children were given participation certificates to thank them for their involvement in the design workshop (see Appendix J).

8.3.1.4 Study Design

The purpose of this design workshop was to design a serious game. The aim of the design workshop, designing a game to support friendship between autistic and non-autistic children, was explained to the participating children in the beginning of the workshop. The workshop was organized into multiple sessions focusing on a different aspect of the game design and utilising different design activities. Although each session consists of different design activities, all sessions follow a similar structure. The overall structure for all sessions was as follows:

1. Introduction: at the beginning of each session, the specific purpose of the session was briefly explained. Next, outcomes from previous sessions (if any) were summarised and a visual schedule of the activities of this sessions was presented.
2. Session activities: this part of the sessions varied from one session to the other. It consisted of the design activities of that particular session.
3. Reflection: In this part of the sessions the participants reflected on the overall purpose of the design and discussed how the ideas generated in the session's activities support the development of friendship. The children were given the chance to improve on their ideas to better fit the overall goal.

The theme of the game to be designed was a treasure hunt game, where players gather clues and solve puzzles to find a hidden treasure. The theme was inspired from the ideas of neurotypical children who participated in the initial design workshop discussed in Section 8.2. The theme was chosen to create structure during the design workshops while keeping the game narrative, challenges and environment open enough to allow for creativity. This was chosen in order to achieve the balance emphasised by Frauenberger, Good, & Keay-Bright (2011) "between empowering children and overburdening them with responsibility". Below we describe each sessions' activities and their purpose in detail.

Session 1: Team Building and Identifying Challenges

This session had two main activities. The first activity was the team building activity which was inspired by Benton, Vasalou, Khaled, Johnson, & Gooch's (2014) design framework for working with neurodiverse children. In this activity, the team members were identified by asking each child to draw a portrait of themselves and to choose a pseudonym (used in the dissemination of the study). Children were then asked to write 3 strengths they had as designers and to share it with the group. The purpose of this activity was to allow the children to understand their role and the value of their input. Next, the children were asked to choose a

name for the team and agree on the rules of the team. Team name, members' portraits and team rules were added to a board to be displayed in each subsequent session.

The second activity was a discussion about friendship where the following questions were discussed 1) Do you have a friend? 2) how did you meet? 3) what do you do together? and 4) do you feel lonely sometimes? The purpose of this warm-up discussion was for the children to share their experience of friendship and to understand the dynamic of their relationships. Then, children were asked to individually identify (either by writing or drawing) three challenges of making friends and to share their ideas with the group. Next, the children worked together to create an affinity diagram from the challenges they identified. The three main strategies identified from the Teachers' Interviews Study discussed in Chapter 4 were 1) enforcing collaboration; 2) providing safe spaces and 3) interaction initiation and fading. These were presented as possible solutions and the children were asked to match these solution to the challenges they identified previously. Children were encouraged to add their own solutions as well. The affinity diagram produced was a reference point in all reflection activities in subsequent sessions.

Session 2: Developing Narrative and Environment Blueprint

This session focused on two aspects of the game which are the game narrative and the environment blueprint. For the first activity the children were provided with arts and crafts materials and asked to create characters which are the players in the game. The children were asked who these characters are, what are they doing in this environment and what their relationship is with each other. Next, the children were asked to collaboratively draw the blueprint of the environment of the game and design the interior of the spaces on a large sheet of paper. The children then used the characters they designed to develop the narrative of the game specifying where each character will start and how they move about in the environment.

Session 3: Puzzle Design

The purpose of this session was to develop the puzzles of the game which are the mini challenges the players have to overcome to progress in the game. Using the arts and crafts kit, each child was asked to develop at least 3 challenges (or puzzles), one of each category:

- Collaborative: where the two players need to work together.
- Social: where the two players need to do a social task (e.g. find information about each other).
- Cognitive: puzzles which one player can solve independently.

Next, the children were asked to fit these puzzles to the narrative of the game and specify how each puzzle leads to the next, modifying the puzzle, narrative or environment as they go.

Session 4: Game Design

In this session the focus of the activity was to design the game experience by designing rewards and hints. The children were asked to design what rewards were to be given to the players, how their progress in the game would be displayed and what and how hints should be provided.

Workshop 5: Formative Evaluation of Prototype

In this session, after the children completed what represented the first prototype of the game, they were asked to play the game and comment on their experience as they played.

Figure 8.2 summarises the overall design workshop plan and the activities of each session.

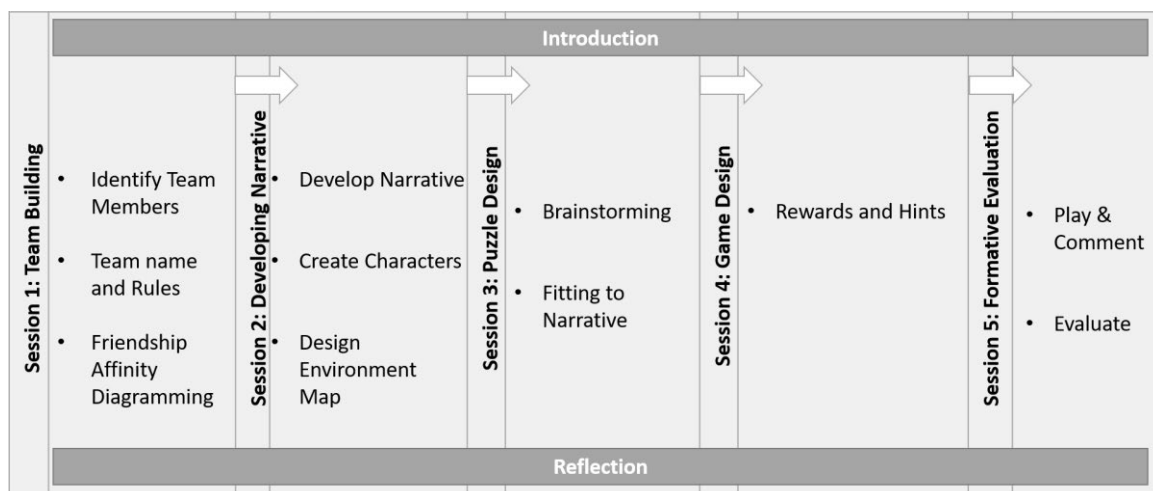


Figure 8.2: Design workshop plan showing the different activities for each session

8.3.1.5 Ethics

Ethical approval was obtained from the School of Informatics ethics panel. Interested parents and children were sent an ethics booklet which contained information sheets for both parents and children along with consent forms for both (see Appendix K). Parents' and children's permission to video and audio record the sessions was obtained in the consent form. All video and audio recordings were stored in an encrypted folder on a university-secure server, separately from any identifying information and accessible to the research team only. All physical materials the children created during the design process were stored in a locked cabinet in the researcher's office.

8.3.2 Results

Team Building and Engagement

Children were very engaged in designing the game but often diverted from the design goals. Children were enthusiastic when completing the workshop tasks and often engaged with each other and built on others' ideas. Given how involved children were while designing different game elements, the reflection stage was necessary to keep the children on track with the design purpose. This was achieved by constantly asking the children how their ideas contribute to friendship development and where they fitted within the affinity diagram they developed at the beginning of the workshop. Figure 8.3 illustrates the children's engagement while testing their game towards the end of the design workshop.



Figure 8.3: Evaluating the early prototype of the game designed in the first workshop*Friendship Affinity Diagram*

A number of challenges to friendship development emerged during the affinity diagramming activity of the design workshops. Figure 8.4 shows affinity diagrams produced from the four workshops conducted.

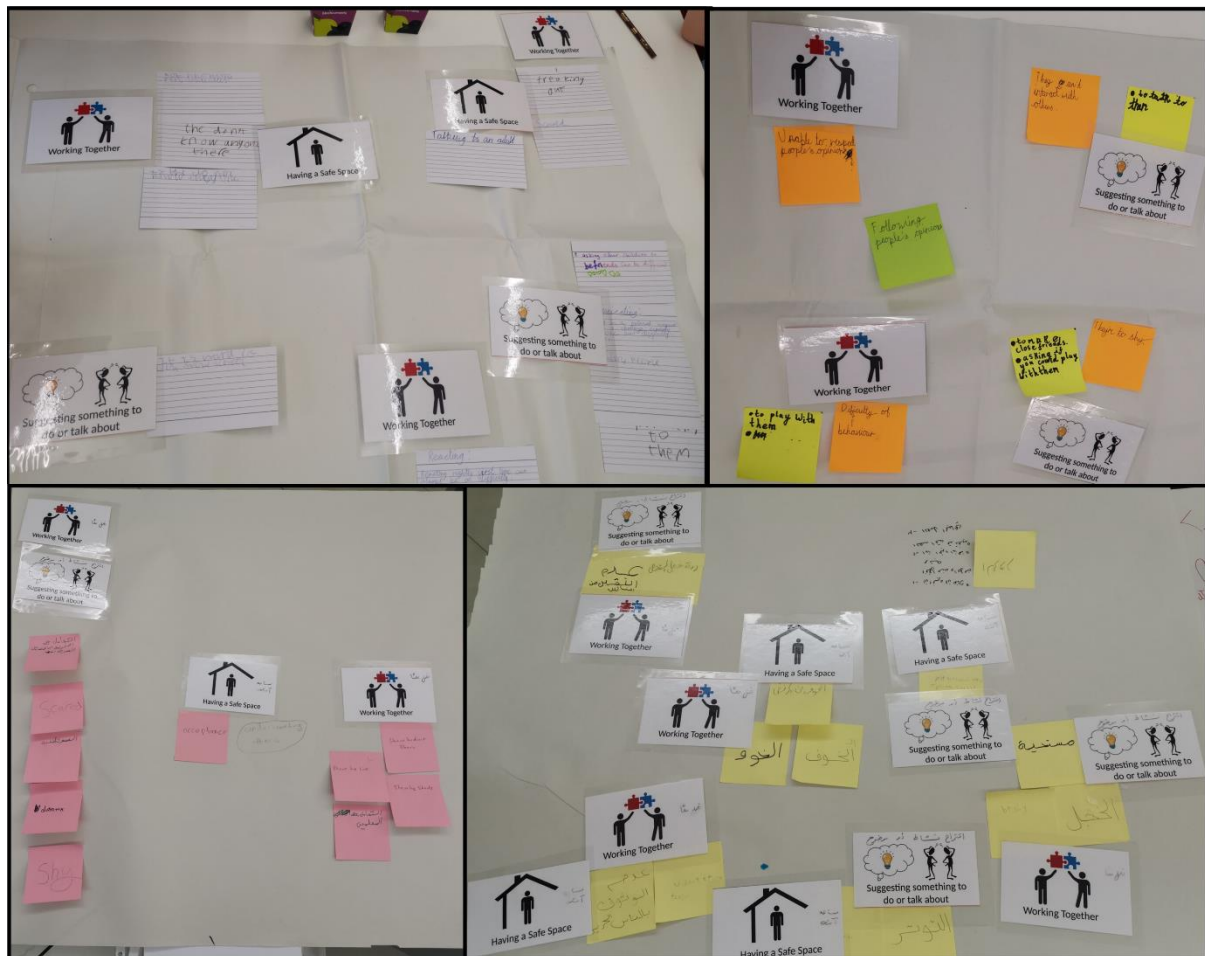


Figure 8.4: the first row from left to right shows the affinity diagrams from workshop 1 and 2 and the second row shows the affinity diagrams from workshops 3 and 4⁴

"Not knowing anyone" was one of the challenges many participants identified. Children believed that providing a safe space and incentivising collaboration were suitable strategies to

⁴ Participants in workshops 3 and 4 were all Arabic speakers and Arabic was used as an additional language for communication

address this difficulty as they would provide comfort and encourage children to work together and provide opportunities for social interactions.

Children also found that "being scared" and "freaking out" and specifically "fear of rejection" could be other challenges to friendship development which can be accommodated by providing a safe space for children to retreat to when overwhelmed. In addition, they suggested seeking external support such as talking to a teacher to facilitate the interaction with other children. Providing support and engaging with others in collaborative activities was another solution children matched with this challenge. Children also suggested talking to an adult when feeling anxious to reduce their anxiety. Furthermore, children suggested being respectful towards others as a means to get others' respect.

Children also identified "being arrogant" as a reason someone might find it challenging to develop friendships. They suggested being humble and working together as strategies to overcome this challenge.

"Being shy" was another challenge children identified which makes developing friendship difficult for them. In this case, children believed they could benefit from external support suggesting something for them to do or talk about with others. In addition, engaging with others in a collaborative activity could help them defeat their shyness.

Not being social and having challenging behaviour such as lying, shouting, and not sharing can make friendship development difficult. Children believed that working together, having a safe space and seeking external support suggesting something to do or talk about can all help with these challenging behaviours.

Although children were encouraged to suggest their own solutions to the challenges they identified, most of the solutions suggested were selected from the three example solutions provided which are: (1) suggesting something to do or talk about, (2) working together and, (3) having a safe space. Only three solutions came from the children themselves which are "being

respectful", "talk to an adult" and "being humble". The first two were suggested as solutions to being scared while the third was a solution for being arrogant. Table 8.2 is a combined summary of all challenges identified from the four workshops with their suggested solutions.

Table 8.2: Summary of identified challenges and solutions indicating which workshops they appeared in

<i>Challenge</i>	<i>Workshops</i>	<i>Solution</i>	<i>Workshops</i>
Being scared	1,3,4	Suggesting something to do or talk about	1,3,4
		Having a Safe Space	1,3,4
		Working together	1,3,4
		Talk to an adult	1
		Be respectful	3
Being shy	2,3,4	Suggesting something to do or talk about	2,3,4
		Working together	3,4
Arrogance	3	Working together	3
		Be humble	3
Difficult behaviour	2,4	Working together	2,4
		Having a Safe Space	1
Not knowing anyone	1	Working together	1

Game Design

While designing the game, children provided ideas on how these strategies suggested can be incorporated into a game to facilitate friendship development. One of the game aspects suggested was that the player needs to collect "Friends" to advance in the game. These friends were other Non-Player Characters (NPCs) in the game who the players need to help, collaborate with or learn something about in order to be their friends. Figure 8.5 shows a puzzle children created where they meet a Yeti up Mount Everset and make him a snowman.



Figure 8.5: a sample of children puzzles where the player needs to become friends with a Yeti to collect friendship points

Sailor: "Yeah maybe you need to dance with the dinosaur, so they don't eat you."

Researcher: "Well, that's a good friendship thing. If you dance with somebody, they can become your friend."

Sailor: "Maybe you can get like friendship points along the way so maybe if you dance with the dinosaur you can get a friendship point and then you can do that for lots of other characters as well. You might find a Yeti up Mount Everest and you might get a friendship point if you make a snowman with him or something. And you need to collect 10 friendship points or something to open the treasure chest".

Although this aspect of the game does not involve interacting with the other player who is the actual target for the relationship, it can help the player learn about developing friendships and practice these strategies in a safe and comfortable space due to the predictability of the interaction and knowing that the other character is not a real person. This also allowed the

children to incorporate potentially challenging elements to friendships such as conflict resolution which the player can practice without creating an actual conflict between the players which can be disturbing.

To incentivise collaboration and provide a safe space, the children suggested a range of mini games and puzzles within the game, where some were collaborative while others could be solved individually. Social tasks such as asking the other player about their favourite colour and drawing a picture of the other player as they describe themselves were also added as tasks the players need to complete to advance in the game. These tasks were an implementation of the "Working together" strategy, while puzzles that can be solved individually were added to implement the strategy "Having a Safe Space".

Blackbeard: "When you are in the artist's cabin, he asks you what is your favourite colour and when the players accidentally ruin the artist's painting the world changes into only your favourite colour that you typed in when you made your account. The only way to get it back is to do this mini-game where you pair up and one person describes how they look and what their personality is like and the other person has to draw them."

Children suggested that these tasks can mimic the role of the adult who would initiate the interaction between two children by suggesting to them what to do. Learning more about the other player and self-disclosing information about oneself can give more intimacy in the interaction.

Reflection was an important step not only at the end of each activity but during the brainstorming process. The researcher listened closely to the participants' ideas and explicitly linked them to the Affinity Diagram and design purpose by stating the connections aloud.

Alex: "The story of the game can be that their plane falls in a mysterious island where a treasure is hidden. The treasure is actually the key for their way out. To find the

treasure they have to solve many puzzles. My character name is Sarah and she is super smart and can find solutions quickly"

Zed: " Oh! My character is actually a non-human. He can be a creature that lives in the mysterious island! I think all the humans from the plane will work together to find the treasure and they will fight my character and think he is their enemy because they don't know him and they are afraid of him. But he did not do anything to them at all!"

Researcher: "Well, that reminds me of one of the challenges of friendship we came up with in the previous activity. Sometime people are scared of others or are afraid of their reaction which discourages them from becoming their friends"

Zed: "yeah! Maybe after solving some puzzles with my character they will learn not to be afraid of him and become friends!"

NaMeimo: "My character is also not human. She came from another planet looking for the treasure. She is more than one million years old! Humans will learn to be her friends as well".

In another instance the researcher pointed out how the puzzle the participant is describing can be an implementation of the strategy "Working together".

P.P. Mudd: "They have to collect squirrels. They have to find all the squirrels. There will be hints on where you would find them for example the last squirrel will be in a bush. But you can find two squirrels in a row you would not be able to pick it up. if you happen to find two squirrels in a row you will have to tell your teammate of where to find it for them to pick it up"

Researcher: "If you remember what we put on the sheet here [Affinity Diagram] we said that they need to work together to make friends so telling the other team member where to find it is teamwork isn't it?"

P.P. Mudd: "yeah!"

These moments of reflection throughout the design process kept participants focused on the design purpose.

There were instances where children were truly thinking about the target audience for their game and considering their abilities and needs.

Ninja: "How old would the players be?"

Researcher: "They would be your age. It should be suitable for children from 7 years old to 13 years old".

Ninja: "I was thinking of adding math problems as a puzzle. This would be difficult for 7 years old".

Researcher: "maybe the math problem can be different depending on the player's age".

Ninja: "Yeah! It can be fractions for kids my age and addition and subtraction for younger children".

They have also considered how appropriate their ideas would be for different age groups.

Hunter: maybe we can have a lab in and you need to be 12+ to enter. And inside there will be deformed test subjects and stuff. And if you make your way through there will be rewards and friends to save. The reason it is 12+ is because chances a 3-year-old would want to enter a lab with deformed subjects are very slim".

Although Hunter was only 10 years old and would probably not enter the lab since it is only for children 12 and older, he was able to design for others considering what an older child might like. During the evaluation of their design, all participants kept their characters outside of the lab and only allowed Blackbeard to enter the lab since he was the only participant over 12 and was allowed to test this part of the game according to the rules they designed.

8.4 Asynchronous Remote Community (ARC) workshops

8.4.1 Methods

8.4.1.1 Recruitment

A study advert was sent out to parents of children who previously participated in similar workshops. It was also shared with schools where the researcher had previously arranged to conduct the workshop physically before COVID19 lockdown in March 2020. Parents of participants were asked to complete an online form. In the form parents were asked whether their child has an autism diagnosis or not and whether it was confirmed through assessment.

8.4.1.2 Participants

13 children expressed interest in participating and filled out the registration form. 2 autistic children registered for the first run of the workshop. 1 autistic child and 4 neurotypical children registered for the second run of the workshop and 6 neurotypical children registered for the third run of the workshop. 11 children completed the warmup activity and 2 withdrew from participation before the beginning of the workshops. 4 participants completed all workshop activities. Other participants either explicitly withdrew or did not complete any of the activities. Table 8.3 shows the list of participants registered along with their demographic and number of activities they completed. Participants who have chosen a pseudonym will be referred to by their pseudonym. Disclosing P1's chosen pseudonym would violate their confidentiality agreement so their participant number will be used instead.

Table 8.3: ARC Workshop Participants' Demographic Information

#	Autism Diagnosis	Age	Sex	Run	Activities Completed	Chosen Pseudonym
P1	Yes	12	Male	1	9	(censored)
P2	Yes	13	Male	2	3	KV
P3	Yes	9	Male	1	2	-
P4	No	8	Male	2	0	-
P5	No	12	Male	2	10	CW
P6	No	9	Female	2	10	IZ
P7	No	13	Female	2	0	-
P8	No	12	Male	3	0	-
P9	No	9	Male	3	10	Nerf Pro
P10	No	11	Male	3	0	-
P11	No	9	Female	3	0	-
P12	No	7	Female	3	0	-
P13	No	12	Female	3	2	-

8.4.1.3 Procedure

After completing the registration form, parents were contacted to arrange a suitable time for the warmup interview and to share the ethical information booklet for both parent and child. Three runs of the workshops were conducted, each taking 3 weeks. The workshop overlapped. Figure 8.6 represent how the three workshops were arranged.

Week 1	Week 2	Week 3	Week 4	Week 5
Run 1				
	Run 2			
		Run 3		

Figure 8.6: Design Workshops' Schedule

Each run of the workshop was intended for a specific combination of autistic and non-autistic children. Run 1 was for autistic children only while Run 3 was for neurotypical children only. Run 2 had a mix of autistic and non-autistic participants. The purpose of these different combinations is to observe any similarities or differences in interactions between the different groups.

Before the start of the workshop, each participant was invited to an individual warmup live interview on Microsoft Teams. The goals of these warm-up interviews was to collect and audio record participants' consent, answer any of their questions and to support them if they had any technical difficulties. To ensure they had the required tools and were set and ready to complete all workshop activities, a quick 4-part activity was conducted which mimics what the actual workshop activities would require. The warmup interview took from 20 to 60 minutes and was audio recorded with the participant's permission.

Before the beginning of the warmup interview, participants were added to a team on Microsoft Teams similar to the planned workshop setup. In the first part of the warmup activity, the child was asked to draw a plate with their favourite meal using paper and coloured pencils or their preferred software. They were then asked to post their drawing as a reply to a post in

the team they were part of. For the second part, participants were introduced to Miro (“Miro,” 2022), which is an online platform which mimics a whiteboard where participants can collaboratively draw and do different illustrations. Using Miro, participants were asked to add to the board some of their favourite foods in postit notes. The researcher joined in adding some of her favourite foods as well to emphasize the collaborative nature of the actual workshop. Next, participants were asked to group the foods based on their similarity and differences and give each group a name. Finally, participants were then asked to label each group with "Healthy" and "Unhealthy" labels which were available in the Miro board beforehand. Figure 8.7 shows samples from children work during the warm-up session.

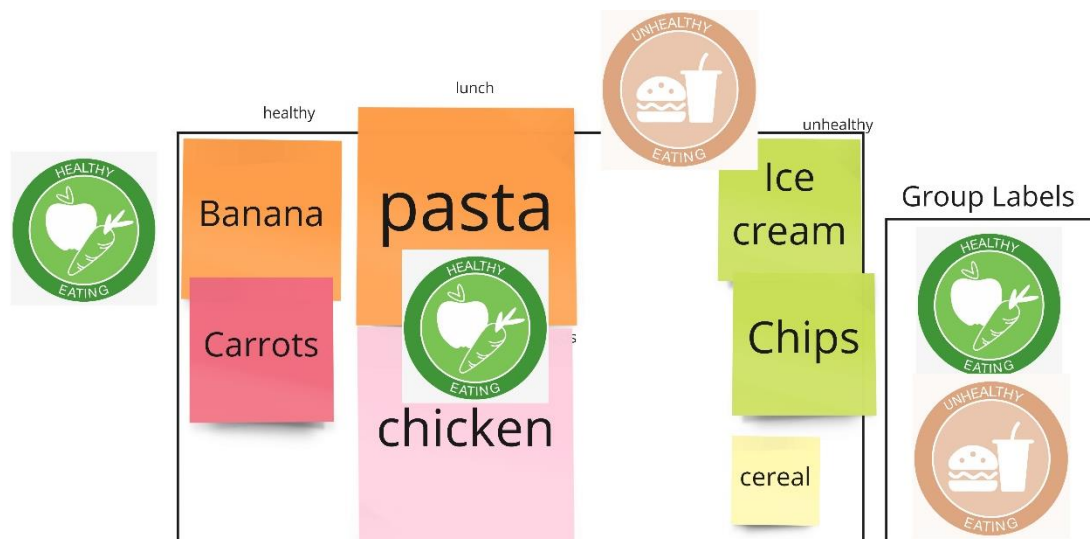


Figure 8.7: Sample of a child's work during warm-up session

Upon completion of the warm-up interview, participants were added to their corresponding team on Teams. Participants' parents were alerted by email every time a new activity was posted to remind their children to complete the activity.

8.4.1.4 Study Design

The activities designed for this study are an adaptation of the physical design activities discussed in Section 8.3.1.4. However, certain modifications were needed to be able to conduct

the design workshop using this new format. For example, instead of providing a large sheet of paper for participants to do the affinity diagram, Miro was used instead, and participants were introduced to this tool and trained on using it during the warm up interview which was conducted beforehand. After participants were added to their corresponding Teams team, they were first presented with the brief of the workshop. 11 activities were posted throughout the 3 weeks of the workshop run. Each activity took 3 to 5 minutes to complete. The time to complete an activity before the next one was posted ranged from 1 to 3 days based on the activity's complexity. The more brainstorming required to complete the activity the more time that activity was given to allow participants the opportunity to complete it before the next was posted. Table 8.4 shows the list of workshop activities and how they were adapted to the ARC workshop format.

Table 8.4: ARC Workshop Activities

#	W	Name	D	Tool	M	Activity
A1	1	Introduction	1	Paper/Preferred Software	Draw	Participants draw a portrait of themselves, choose a pseudonym and talk about their strengths as designers.
A2	1	Team Building	1	Teams	Text	Group members agree on the group rules and the admin updates them based on what participants have posted.
A3	1	Friendship Challenges	1	Miro	Text	Participants are asked to identify 3 difficulties to making friends and add them to the Miro board.
A4	1	Friendship Affinity Diagram	3	Miro	Text	Participants group similar challenges into clusters and choose possible solutions on Miro.
A5	2	Develop Narrative	2	Teams Group	Text	Participants develop the game narrative and build on each other's ideas in the form of discussions.
A6	2	Create Characters	2	Paper/Preferred Software/Teams	Draw/Text	Participants draw a character and talk about their back stories and how they fit into the narrative of the game developed.

#	W	Name	D	Tool	M	Activity
A7	2	Environment Design	2	Paper/Preferred Software/ Miro	Draw/ Text	Participants choose to draw part of the world and describe the place. The researcher adds all participants ideas to the Miro board.
A8	3	Puzzle Brainstorming	2	Paper/Preferred Software/Teams	Draw/ Text	Each participant comes up with 3 challenges/puzzles one of each category: 1) social 2) collaborative 3) cognitive and fits them to the narrative and environment.
A9	3	Reflection	1	Teams	Text	Participants describe how the game so far can address the challenges to friendship they identified originally.
A10	3	Review	1	Teams	Text	Participants edit the game to make it more enjoyable or to fit it to its purpose better.
A11	3	Survey	1	Microsoft Forms	Text	Participants fill out a survey about their experience in the study

W=Week to introduce in the study. D=Duration of activity in days. M=Media type

8.4.1.5 Ethics

Ethical approval was obtained from both the School of Informatics and the School of Health in Social Sciences ethics panels. Interested parents and children were sent a registration link which includes the study information for both parents and children along with consent forms for both (see Appendix L). All images of children's creations were stored in an encrypted folder on a university-secure server, separately from any identifying information and accessible to the research team only. Participants were removed from the team after the end of each workshop.

8.4.2 Results

Team Building and Engagement

Participants were mostly not engaged with the workshop activities. Very few completed all the tasks of the workshop. Most stopped engaging with the activities after a few tasks. Participants did not engage in any discussion with each other and did not build on each other's ideas at all. Each child created their own narrative and added puzzles, characters and game elements

without involving ideas introduced by other team members. Despite the researcher's efforts to combine team members ideas and encourage them to discuss them, there was minimal response. An example of such interaction can be observed in Figure 8.8.

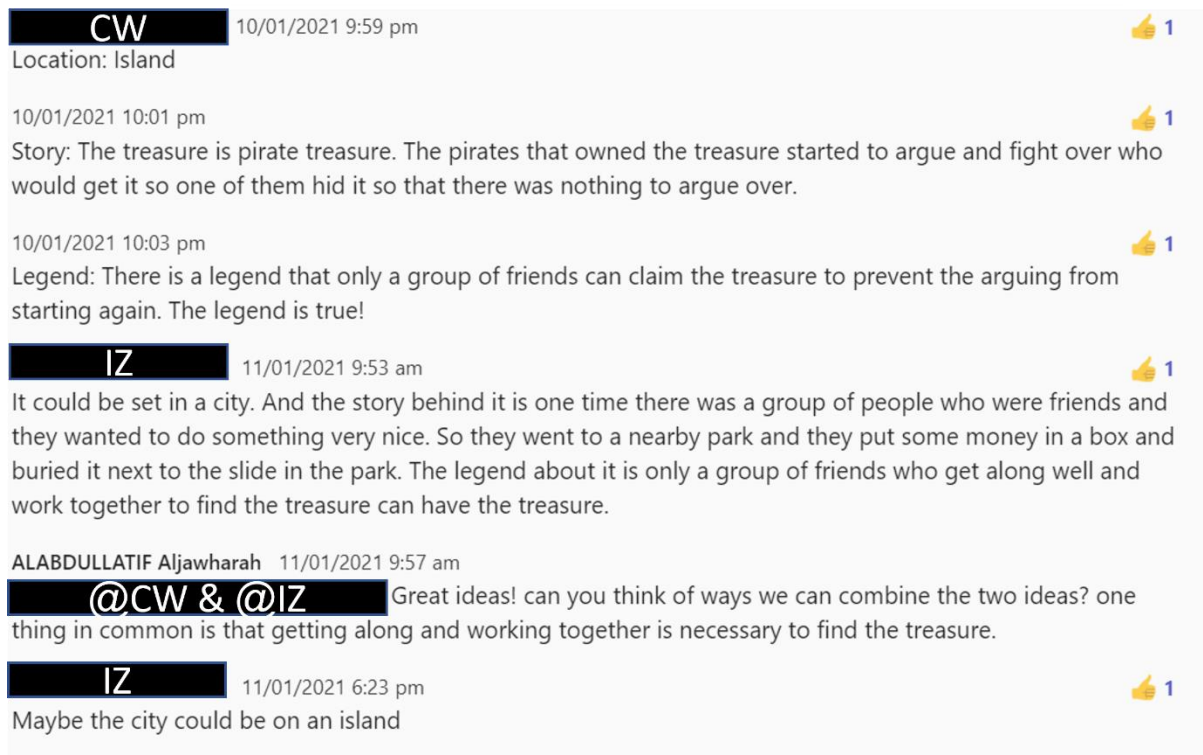


Figure 8.8: Example interaction between team members during ARC workshop

It is important to note that run 2 of the workshop was the only run where more than one child completed most activities. Only one child completed most activities in run 1 and 3 hence no interaction was expected during these runs.

In addition, the asynchronous nature of the communication made it difficult to get answers on follow up questions about their creation as children often lost interest in the ideas after a while and often did not reply to follow up questions and clarifications from the researcher or they would give very short answers.

When participants did not fully understand the task or completed it incorrectly, and were then corrected by the researcher, they usually did not go back to redo the activity. This led to many tasks not being completed.

Friendship Affinity Diagram

Following from the previous section in terms of children's engagement and understanding of the activities, the affinity diagram activity was not completed as was expected. Children identified some challenges and solutions, but they did not always link them together. Figure 8.9 shows the affinity diagrams which resulted from each run.

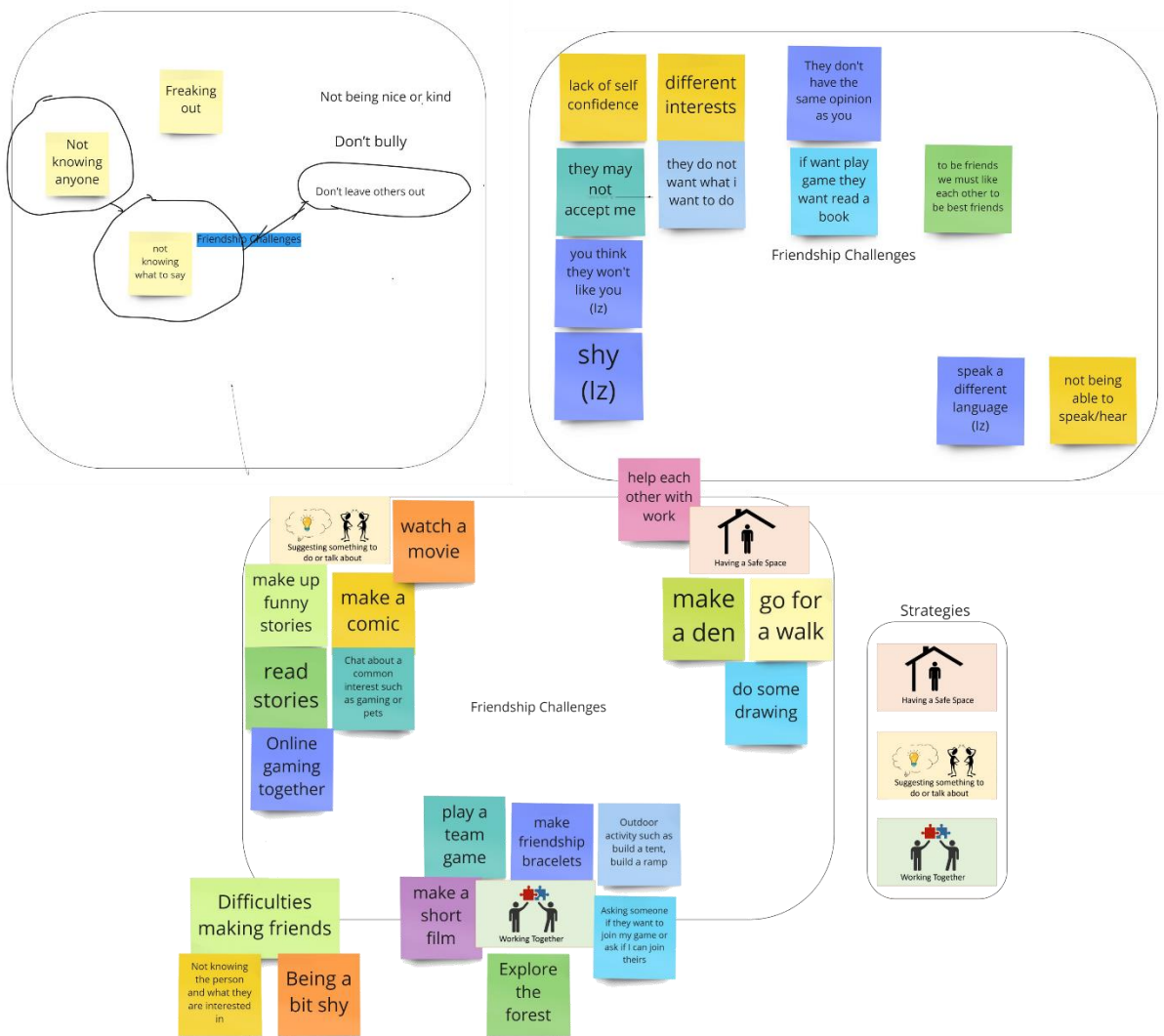


Figure 8.9: Affinity diagrams from workshop runs 1, 2 and 3, ordered clockwise

Participants identified a number of challenges such as "not knowing anyone" and "not knowing what to say" and believed that a good solution would be to "not leave others out". "Not being nice or kind" was another solution children identified and chose "Don't bully" as a solution to this issue. Many challenges were identified by children without linking them to a specific

solution such as being shy, "freaking out", fear of not being accepted, different interests and speaking a different language.

Participants in runs 1 and 2 of the workshops did not use the strategies provided as solutions at all and instead used their own solutions or did not provide any solutions to the challenges they identified. In run 3 however, the participant used all three strategies provided, giving examples of how these can be implemented, but they did not link these solutions to a specific challenge they had identified. Table 8.5 is a combined summary of all challenges identified from the three runs with their suggested solutions.

Table 8.5: Summary of identified challenges and solutions indicating which run of the workshop they appeared in

<i>Challenge</i>	<i>Run</i>	<i>Solution</i>	<i>Run</i>
Not knowing anyone	1	Don't leave others out	1
Being shy	2,3	-	-
Not knowing what to say	1,3	Don't leave others out	1
Freaking out	1	-	-
Not being nice	1	Don't bully	1
Fear of rejection	2	-	-
Different Interests	2	-	-
Speaking different language or not being able to speak	2	-	-
-	-	Working Together	3
-	-	Suggesting something to do or say	3
-	-	Having a Safe Space	3

Game Design

Children often focused on friendship as the centre of the game narrative itself as well as being the purpose of playing the game for the players they are designing for. When designing the game characters, children incorporated challenges or useful skills they previously identified in the affinity diagram activity as traits of their character. For example, CW's character is shy and has no friends and comes from a homeless family. He seeks the treasure to better his family's

life. IZ's character has a superpower which is kindness. These choices indicate that participants were considering the design challenge and designing the characters with the design goal in mind. Figure 8.10 shows an illustration and description of the characters mentioned.

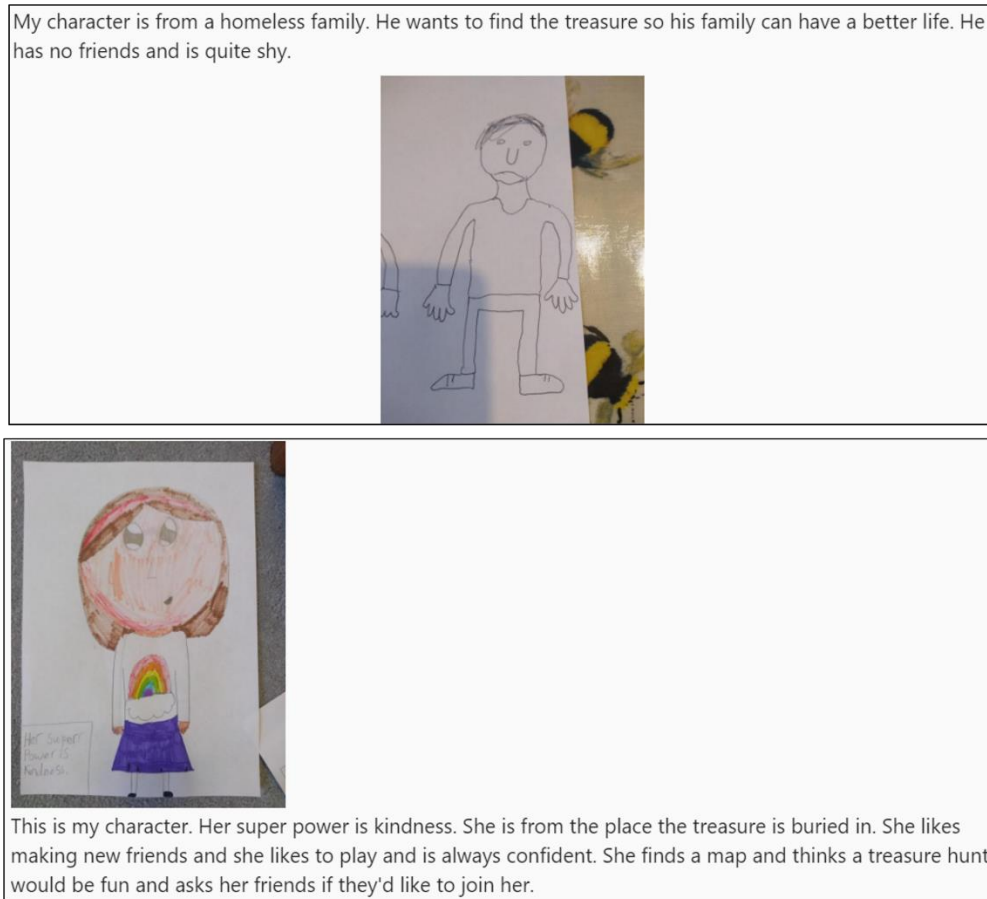


Figure 8.10: Characters illustrations and description from run 2

In run 1, P1 also suggested a game narrative that focuses on friendship making the purpose of the treasure hunt for players to work together and develop friendships.

P1: " The location is in a mansion Spider-Man hid the treasure as he wants everyone to find it together as he wants to make everyone make friends"

P1's design expected the characters within the game to become friends as well as the players controlling these characters.

Children developed a number of puzzles and game elements to address the challenges they identified. Nerf Pro designed a puzzle where players need to collaboratively fix a broken

object by linking coloured wires. Nerf Pro explained how this activity is an implementation of the "working together" strategy and how it might help with shyness.

Nerf Pro: "The game of linking wires links to working together and suggesting something to do. It helps with being shy as you are both working on something as you might start talking about the problem and it is easier when you have a subject to talk about."

CW developed a puzzle in the game which would help children overcome their differences and learning more about others.

CW: "Helps with getting to know everybody and realizing people can be the same and different. Social puzzle: Then that one says to go to Big Ben. There is a timer (you have 5 minutes for each question). You answer 5 questions. Answer question 1 in the time it takes Big Ben to go to the next number. The first question could be What is everyone's favourite colours and then mix those together for the team answer. The answer would probably be brown."

IZ developed a puzzle which allowed players to have a safe space and work on their own to overcome feeling shy.

IZ: "Helps with shyness as it is a chance to do your own thing: A baking challenge where everyone has to bake a cake of their choice without a clear recipe."

Another puzzle suggested by Nerf Pro was a social puzzle to help players learn more about each other

Nerf Pro: "Series of questions about interests, favourite colour, favourite movie. You have to chat together to find out the information. Each person has their answers pre-programmed. When you key in a correct answer a door opens. Or find out five facts about each other in a certain time limit. If 10 facts are input you get to the next section."

When asked to reflect on how this puzzle help with the challenges identified Nerf Pro explained that the game guiding you on what to ask others would help with being shy and allow you to know the other players.

Nerf Pro: "The game where you unlock doors by asking and answering questions about each other helps with being shy as the game guides you to ask things. And it helps you get to know the other person well and it might lead to more chats. This comes under the strategy of doing something together"

After coming up with different puzzles in the game, and when asked to reflect on how these puzzles contribute to the problem of friendship by looking at the challenges and solutions they had identified in the affinity diagram, some children were able to identify how each puzzle positively contributes to helping children develop friendship. However, not all the challenges and solutions they identified after creating the puzzles reflected the challenges and solutions that they identified when they were developing the affinity diagram. This suggests that the process of developing the puzzles themselves allowed participants to think more about the challenges and possible solutions.

8.5 Discussion

Three different designs of workshops were conducted and presented in this chapter. Variation in the results based on the activities introduced and mode of delivering these activities indicates critical differences that may result from these different designs. In the physical synchronous less structured pilot workshops it was difficult to ground children's designs in the purpose of the design workshop. Although they started engaging in a discussion about friendship, identified some challenges and introduced possible solutions, their proposed designs were distant from the design goal as they were too engaged in the design process itself. This resulted in creative designs which do not necessarily serve their purpose. As a result of this, subsequent workshops had a reflection activity where children purposefully took time out from the design

process to reflect on how their design served the purpose of supporting friendship and using the affinity diagram they created as a visual aid. This emphasis on reflection throughout the design process did seem to lead children to voluntarily think reflectively on their designs while engaging in different activities, even when it was not prompted by the researcher during the reflection activity. The reflection activity also helped children not get distracted by the design materials that were provided and helped to keep the design purpose front and centre.

There was a clear difference in the engagement of participants between the physical workshops and the ARC online workshops. Children in the physical workshops completed all activities and were enthusiastic about working together and building on each other's ideas. Although the ARC workshop had the same activities as the physical workshop, children in the ARC workshops did not discuss each others' ideas or comment on them unless prompted by the researcher. In addition, many children did not complete the design activities and only a few completed most of the design activities. This resulted in two of the workshop's runs having only one child completing the activities. Hence, it was not possible to observe interaction with other children. There are many possible explanations for why many children did not continue to complete the design activities in the ARC workshop while children in the physical workshops were very engaged completing the same activities. First, it is important to consider the timing of the ARC workshop: the workshop was conducted remotely during the COVID-19 lockdown. During this time, school and most other activities were moving online as well. Children may have felt overwhelmed by the amount of time and activities they needed to complete online. Being exhausted from the constant use of different technologies and the fact that many aspects of children's lives has moved online during COVID-19 lockdown was also confirmed by both parents and children interviewed in Chapter 5 and 6 respectively. Hence, children may have prioritised schoolwork and other activities over completing the workshop activities. In addition, the asynchronous nature of ARC may have had a negative impact on

participants' engagement as irregularity of activities can impact attention span (Batejat, Lagarde, Navelet, & Binder, 1999). Furthermore, working with tangible materials during physical workshops may have increased children's engagement and interest in the activity (Penfold, 2019).

The richness of data collected during the physical workshops was evident compared to what was obtained from the ARC workshops. Children in the physical workshops explained their ideas verbally and used illustrations. They occasionally wrote down their ideas after explaining them to the group. In many cases, as the child repeated their idea either verbally, in illustration or writing it down on paper, they enhanced the idea, built on it or provided justifications for their design. This repetition allowed participants to think more about their ideas and gave the researcher more insights into their designs. This was not present during the ARC workshop as children wrote their ideas on the group board and did not need to rethink them. In addition, as the researcher in both the physical and ARC workshops often asked follow-up questions about the designs requesting further explanation or justification, children in the ARC ignored these questions or provided very short answers. In contrast, children in the physical workshops provided more details and were encouraged to give examples and drew some illustrations when prompted. This difference may be due to the asynchronous nature of the ARC workshop: the questions from the researcher were not asked right after the participants were thinking about their idea, so they may have lost interest by the time they saw the question and were able to reply. Furthermore, the format of the ARC workshop was text heavy and required children to type in their ideas or upload illustrations only. Offering a voice alternative can be beneficial in enhancing the richness of the data in this type of format. Nevertheless, other DPD workshops have found that children did not use this option when it was offered (Walsh & Foss, 2015).

Results from these workshops showed that children are able to design for others who are different from them or have different circumstances. The children were able to consider their target audience's abilities and needs and were interested in catering the design to their intended users. They were able to understand their role as designers and how they are different from the target audience, which is a concept often taught in the HCI field. However, children sometimes struggled to understand the difference between what happened to *playable characters within the game* they created and what happen to *players of the game*. They often assumed that making the *playable characters* of the game friends consequently makes the *players of these characters* friends as well. Distinguishing between the two is important for understanding of the impact of the design and how well it serves its purpose. Introducing personas can be a possible way to overcome this issue as it may help participants develop a more accurate mental model of the difference between the player and their character in the game.

The design workshops with children helped capture the children's perspective on friendship development and support. In their designs, children utilised the strategies identified from the teachers' interviews and provided ideas on how to design them into a game to support friendship development. Conducting the teachers' interviews discussed in Chapter 4 prior to designing these workshops was essential as it helped structure the affinity diagram activity and to provide strategies for children to use as solutions to the challenges they identified. It is reasonable to not expect children to have solutions to the challenges they identify, and hence providing these strategies while encouraging them to introduce their own allowed children to complete the affinity diagram and design the game. In addition, the children's choice of using the teachers' strategies as solution to the challenges they identify is a way to validate the results obtained from teachers as proxies. Children may believe that these strategies can be appropriate in supporting friendship, but they might not be necessarily able to produce them themselves.

The low number of participants who completed the ARC workshops activities is a limitation of this study, which makes it difficult to evaluate the appropriateness of the ARC approach. However, considering the circumstances in which this study was conducted, it can be used as a first step into exploring the use of DPD methods especially with autistic children. Furthermore, the physical workshops did not include any autistic children which makes direct comparison of the two formats based on the autistic children experience impossible.

9 DISCUSSION AND CONCLUSION

9.1 Introduction

This chapter discusses the main research question identified in Chapter 1 in relation to the studies conducted within this thesis and summarises the main results and thesis contributions. It starts with a summary of results, discussing the results presented within each chapter in relation to the research question they address and the research contribution they impact. It then takes a step back to criticise the presented work, laying out its limitations. Several potential paths are suggested to take this work further and to expand its contribution. The chapter concludes by providing a short summary of the research contributions and key findings.

9.2 Summary of Results

As identified in Chapter 1, the three main contributions of this thesis are:

1. Providing an in-depth exploration of the supporting role proxies can take in the design process for autistic children.
2. Evaluating the use of different modes of design workshops with autistic and non-autistic children.
3. Exploring the potential of using a technical solution for supporting friendship between autistic and neurotypical children.

Next, we discuss each of these three contributions in relation to the relevant research questions examining the results from each of the studies and how they contribute to the body of knowledge.

9.2.1 The Role of Proxies in the Co-Creation Process

Here we discuss results in relation to the following research question:

RQ1: What role can proxies play in the co-creation process of technologies to support friendship?

RQ1.1: How can teachers inform the design process in the context of supporting friendship?

RQ1.2: How can parents inform the design process in the context of supporting friendship?

RQ1.3: How can autistic adults inform the design process in the context of supporting friendship?

RQ1.4: How can autistic and neurotypical children inform the design process in the context of supporting friendship?

Chapter 2 discussed PD with autistic children and challenges to involving autistic children were presented. Some PD frameworks were designed to overcome these challenges however these were still limited in terms of the type of autistic children they target and their applicability. Thus, we reintroduced proxies as a means of improving autistic children's involvement rather than limiting it. Previously, proxies' involvement was utilised as a way to replace the involvement of autistic children. However, using that approach, benefits from involving the children themselves were missed. Hence, in this thesis, we explored how proxies can enrich the design process while still involving the children themselves.

Friendship between autistic and neurotypical children was used as the context in which the use of proxies was explored. Friendship was an interesting choice for exploring proxies as

each of the four proxies explored can inform it from a different perspective. Unlike sensory difficulties or repetitive behaviour, friendship is a social experience for all children and is not specific to autistic children alone. This makes non-autistic and specifically neurotypical children a possible proxy in the design process for friendship. Furthermore, friendship is a continuing experience and is not limited to a specific age (e.g. starting primary school). Hence, autistic adults can be involved in this context as they are still experiencing friendship in addition to reflecting on their childhood experiences, and sharing any challenges that they encountered and how they overcame them or if they still persisted. Teachers' and parents' input as proxies both come from them observing autistic children or directly interacting with them. However, there is an important distinction between the two. Teachers observe and work with many children with varying personalities and needs but they mostly observe them within one context which is in the school. On the contrary, parents only observe their own child with their specific personality and needs, however they observe them within multiple contexts. This difference makes teachers' input in regard to friendship more generalised in terms of the child's specific needs while it is particular to the school context. On the other hand, parents' input is more specific to the experience of their own child, but it is generalised to different contexts.

Chapter 4 explored the role of teachers as proxies for autistic children. Ten teachers and support staff from a special school were interviewed. Input from teachers helped shape the design of the activities of the design workshop described in Chapter 8. The strategies they suggested were added to the affinity diagramming which was the core activity the rest of the activities were built on. As evident from the pilot design workshop discussed in Chapter 8, structure in the design activity may help the creative process rather than limit it for children. In the physical design workshops, children often chose to use one of the strategies suggested by the teachers rather than generating their own. This highlights the potential benefit of involving proxies in the earlier stages of the design, when designers are still exploring the

problem space to learn more about the context, and helps them to design better activities when working with the target group directly. In addition, teachers indicated that supporting friendship was not their primary goal and that they are more concerned with their pupils' academic progress and providing a safe and comfortable environment for their pupils to learn. Hence, their input in this regard would help designers eliminate teachers as potential intervention agents for friendship support. Generally, teachers as proxies can be involved in the early stages of the design when the problem space is still being explored. It is specifically beneficial when the design problem is relatively new to the HCI field. In the case of this study and as discussed in Chapter 3, friendship itself has never been an explicit target for intervention whether it was traditionally or technology based. Hence, it was beneficial in this case to involve teachers to get insight into how to target friendship directly and explicitly.

In Chapter 5 the role of parents as proxies was explored by interviewing 17 parents. Evident from the results from these interviews, results from Chapter 4 and 6, and previous research (Howard et al., 2006), parents are highly involved in the friendships of their children especially those with autism. They often have an active role in coordinating their child's friendships by arranging meeting and supporting their child in meeting others with similar interests. Their experience with acting in this role can inform the design for supporting friendship as they are the embodiment of such support. In addition, in order for children to have access to any technology to be designed at home it needs to get the parents' approval. Hence, designers are not only designing for their target group they also need to create a design that would appeal to their parents. In the case of friendship and creating a technology that would allow a child to meet others online, parents were concerned about safety online and protecting their children from predators. Hence, parents resisted the idea of their younger children meeting new friends online using currently available technologies and often had rules on who their children could talk to and what information they were allowed to disclose online. As a result,

designs need to take into consideration that any technology designed adheres to parents' rules and standards to ensure the safety of the children and ensure the acceptance of parents given their involvement in the design.

Following the interviews with parents, Chapter 6 discusses interviews with fourteen neurotypical children and two autistic children to explore their experience with friendship online and in-person and the nature of friendships between neurotypical and autistic children. Children confirmed many of the results found from teachers' and parents' interviews such as how consideration for safety online can hinder the possibility of creating new friendships. This indicates that it was not only a concern for parents but it was also a risk understood and avoided by children. In addition, children discussed how parents of autistic children are often more involved in the friendship compared to parents of neurotypical children which is consistent with what teachers and parents reported. Interviews with children themselves were essential to compare results from their interviews with results obtained from interviews with their proxies. Although children confirmed what their parents and teachers expressed, they were able to provide deeper understanding of these findings by sharing their first-hand experiences.

The perspective of autistic adults was explored in Chapter 7 where 20 adults were interviewed and asked about their experience with friendship. In the interviews, participants confirmed that as they grew into adulthood and with the different experiences they have encountered, they have now overcome some of the challenges to friendship they used to experience as children. This makes their input in this context very valuable as they have experienced these challenges first-hand and were able to suggest solutions to resolve them. In addition, given their age and the support and experiences they potentially had throughout their life, they may be more comfortable interacting with adult researchers compared to an autistic child. However, it is important to note the limitation of involving autistic adult only, rather than taking the perspective of autistic children themselves. Firstly, they only provide a retrospective

view and their experience or challenges may no longer be present or other challenges may have evolved. In addition, due to technology constantly evolving, what children are dealing with now may not have been present when those autistic adults were children. In this case, autistic adults can only predict what challenges children nowadays are facing and suggest what potential solutions and support can be provided. The involvement of autistic adults as proxies can be beneficial at any point of the design process however their involvement would be more valuable when the context to be studied is something persistent and not specific to childhood experience, although they can provide input by reflecting on their past experience as well.

Neurotypical children within the same age range of the target group would share some similarities in their experiences and preferences, especially when it comes to informing elements related to engagement and aesthetic. Involving neurotypical children in pilot design workshops can be beneficial as their feedback allows designers to improve the design activities to make sure they are understandable to the participants and that they serve their purpose. As presented in Chapter 8, the involvement of neurotypical children in the pilot design workshop changed the format of the workshop drastically, as more structure was added to the design activities and a reflection element was added to all stages of the design to ensure children focused their designs on the purpose of the workshop.

Revisiting the discussion in Chapter 2 of the difference between a proxy and a stakeholder, it can be observed how some participants served as both proxies and stakeholders while others were only involved as proxies. Parents and Teachers are examples of participants who fill both roles. When parents shared their concern about children safety online, they were impacting the design both as a stakeholder and a proxy since this specific requirement was to address their own requirements and concerns not only their children's. Similarly, when teachers shared how they prioritise academic and behavioural goals over friendship support they were acting as stakeholders rather than proxies. However, describing the need for autistic children

to have a "Safe Space" is an example of teachers acting as proxies since it concerns the target users rather than the teachers themselves. On the other hand, when considering the involvement of autistic adults, they acted as a proxy as they are no longer can impact or be impacted by the design. Their input is a retrospective view of the needs of the target children based on their childhood experience. Neurotypical children have a unique role within this problem space as they are both proxies and potential users. Being a potential user imply that they are also a stakeholder. However, in other contexts where they are not a potential user, they cannot be considered a stakeholder since their involvement with the design is limited to the design process and it does not extend beyond the design deployment. While the technology is used by the target users, it cannot impact or be impacted by neurotypical children. Nevertheless, in this specific context they are considered a stakeholder as the impact they may cause or experience will be due to them being potential target users.

As discussed in Chapter 1, the involvement of autistic children in the design process can be challenging and the time they spend working with designers can be taking from their time in school. Hence, it is important to ensure that this time is utilised in the best way possible striking a balance between involving the children themselves and involving their proxies when needed. Table 9.1 summarize the roles of proxies highlighting the main advantages, limitations, and their recommended involvement.

Table 9.1: A summary of proxies' roles

Proxy Type	Advantage	Limitation	Recommended Involvement
Teachers	Experience with children with varying needs	Observations within a specific context	In the early stages of the design process and when the context of the study is in a new research area
Parents	Experience with a child in multiple contexts	Observations specific to their own child	Anytime during the design process
Autistic Adults	First-hand experience of being an autistic child	Retrospective view, experiences may change over time	Anytime during the design process in contexts persistent through one's life
Neurotypical children	Similarity in preferences and experiences due to age	Do not share experiences relevant to autism	Anytime during the design process in contexts not specific to an autism diagnosis, mainly informing aspects of engagement and aesthetic

9.2.2 Involving Autistic and Non-Autistic Children in the Design Process using Remote and Physical Workshops

Here we discuss results in relation to the following research question:

RQ2: How can autistic and non-autistic children be involved in designing technologies for supporting friendship ?

RQ2.1: How might design workshops be used, with neurotypical children, to inform designing for supporting friendship?

RQ2.2: How can remote methods be used to best provide accessibility for autistic and neurotypical children?

As discussed in Chapter 2, there is little known about involving children in remote design workshops within the HCI body of knowledge. One study focused on developing a tool to allow children to participate in design workshops online while physically apart (Walsh & Foss, 2015). This involved neurotypical children using a synchronous approach. To the author's knowledge, there have been no studies to date on how to involve autistic children or whether children in general would benefit from asynchronous settings. In Chapter 8, three

different design workshops were conducted each with different settings. Although the purpose of all workshops was to design a game to support friendship, the results from the three different settings were diverse. This indicates the impact of workshop design on the results of the workshop, highlighting the importance of carefully planning the design workshop to achieve the design goal.

From the pilot design workshops, two issues were identified. Firstly children were distracted by the workshop materials (in this case Lego) and were not focusing on the design goal. As a solution, a prompting strategy was suggested. Secondly, children's designs did not directly serve the purpose of the design workshop as children found it difficult to focus their designs due to the lack of structure. Different ways of providing structure were suggested to help the children's creative process. These two recommendations were applied in the subsequent workshops by adding a reflection activity where children were periodically asked to reflect on their design and how it served the design purpose. This was combined with the affinity diagram that children created which served as a visual aid reminding them of the design purpose. This addition helped with both issues identified as it served as a prompt for children to reflect on their design and provided structure as well. In addition, the theme of the game was predetermined to allow the creation of more structured design activities. Furthermore, strategies identified by teachers in Chapter 3 were added as possible solutions to challenges the children identified and children had the opportunity to choose from these solutions or generate their own. All these features contributed to structuring the design workshops and the difference in the designs produced was apparent. In these design workshops, all designs were focusing on friendship and children spontaneously linked their designs to challenges and solutions they identified in the affinity diagramming activity.

During the design workshops, children often asked about the target users while generating their ideas to ensure their designs were suitable for their intended users. This is an

interesting observation as it highlights children's ability to take the role of a designer separating themselves from the users and making sure that what they design appeals to the intended users and their needs. This is a skill that is often taught in the HCI field and it is what motivates the call to adopt a participatory design approach in general. For children to understand the need for their designs to appeal to children other than themselves enhances the generalizability of the designs they create. Nevertheless, children often did not distinguish between the playable characters in the game and the player who controls them which made it difficult for them to understand the impact of their designs.

As previously discussed in Chapter 1, recruiting autistic children in design workshops can be challenging as there is high demand on their participation in different research projects. Moreover, participating in this specific study was more demanding as it expected children to spend more hours in design workshops than in studies that only required short interviews or completion of a questionnaire. In addition, recruiting both autistic and neurotypical children to work together in the same workshop made conducting these workshops in a special school not possible since there are no neurotypical children attending these schools. On the other hand, conducting these workshops in a mainstream school with fewer autistic children required making sure that these children were willing to participate before arrangements to conduct the workshops at the school were made. Thus, the workshops might be better taking place outside of school and in an environment comfortable and familiar to autistic children, where other neurotypical children were available and willing to participate.

With the COVID-19 lockdown, an opportunity presented itself as it moved the design workshops online creating potential for recruiting children who are geographically distant. This option was not considered prior to COVID-19 circumstances as limited research was available on DPD with children especially those with autism. Theoretically, asynchronous DPD would appeal to autistic children specifically as they will be within their own environment engaging

with the activities at their own pace when they feel comfortable to do so, reducing anxiety that may arise from the social interaction and new environments that might be expected within a physical design workshop. Nevertheless, only a few children completed the design workshop in this format which makes judging its effectiveness difficult due to the many circumstances which may have impacted their participation.

There was a clear difference in the engagement and enthusiasm from participants in the physical workshop compared to the ARC workshops. Children in the ARC workshops did not engage with other participants unless prompted by the researcher, contrary to the physical workshops where they were constantly building on each other's ideas. The timing of the workshop being within the COVID-19 lockdown when most aspects of participants' lives have moved to online may have caused online fatigue. However, the asynchronous nature of the activities itself may explain the difference in engagement because of its impact on their attention span. Furthermore, using tangible materials in the physical workshop may have enhanced children's engagement and interest in the workshop activities.

The different format also impacted the quality and richness of the data collected. During the physical workshop, children constantly revisited their ideas as they explained them to others or as they wrote them down which allowed them to improve their ideas and provide justifications for their designs. This was not the case for the ARC workshops although the researcher prompted them to provide further explanation and justification. This difference might be due to the asynchronous nature of the workshop as children would lose interest in the idea over time. In addition, communication within the ARC workshop was text-heavy and required children to type regularly, which may be more challenging for younger children who are new to writing in general especially on a keyboard. In the physical workshop, children were freely speaking their ideas as they thought of them providing as much details as they need.

Voice recording option is an obvious alternative to overcome this issue however, a previous study showed that children did not use this option when it was available (Walsh & Foss, 2015). Although ARC in our study produced very limited results in terms of how many completed the activity and the richness of the data produced, it is still a potential approach to adopt when working with autistic children specifically. Prior to offering this option, many efforts to recruit autistic children in physical design workshops were carried out however none of them were successful. Offering a remote asynchronous option allowed some autistic children to take part. This study is only the first step into learning more about how to utilise remote methods to increase the access to autistic children and inclusivity of participatory design.

9.2.3 Potential for technology as a medium for supporting friendship

Section 9.2.1 justified the use of friendship as a context to study the role of proxies in this thesis. This section discuss why technology could potentially support friendship and why it is worth exploring within HCI, while also summarising preliminary results obtained as a consequence of conducting the studies within this thesis.

Chapter 3 discussed friendship for autistic children and the efforts to develop interventions to support friendship both traditionally and technically. A common factor in all interventions is that friendship was never the explicit goal. Interventions often targeted other skills and expected friendship to develop as a by-product of mastering these skills. Hence, these interventions only tested whether the child obtained the target skill: whether they were successful in developing friendship as a result was never measured. Therefore, targeting friendship itself was the goal when designing the current studies, rather than focusing on a specific social skill.

Two theories inspired the potential of technology as a suitable medium to target friendship which are the stages of pair relatedness theory and the double empathy theory discussed in Chapter 3. The double empathy theory proposes that difficulty of communication

presented by autistic individuals is due to a lack of reciprocal understanding between autistic and non-autistic individuals and having different communication styles. Thus, there is a need to mediate the interaction between them rather than ‘resolve a deficit’ the autistic individual supposedly has. According to the stages of pair relatedness theory there are 4 stages in a relationship starting with zero relatedness when both parties are unaware of each other, moving to unilateral awareness when one notices the other person, and then moving to the surface contact stage where knowledge about the other person is limited and the interaction follows social norms. Finally, the relationship moves to the mutuality stage when both parties have a good deal of personal knowledge about each other through self-disclosure, and the interaction no longer follows socially prescribed rules as the pair has now developed their own preferred communication style. In light of the double empathy theory, it is reasonable to conclude that the surface contact level would be problematic when it comes to developing friendship between autistic and neurotypical children as, at this point, they are expected to follow social norms. Neurotypical individuals may find their autistic peer's communication style odd as it is different to their own which may discourage continuing the relationship to reach the mutuality stage. Technology can be utilised as a medium to mediate communication through the surface-level stage and allow the pair to move beyond this stage to a mutuality level where they can develop the interaction style comfortable for both. Online social norms are different to those expected offline. Moreover, these norms are different from one platform to another and can be controlled based on the design itself. In addition, communication online avoids aspects of social interaction that may make communication difficult for autistic individuals such as making eye contact or interpreting social cues.

In Chapter 7 autistic adult participants affirmed this assumption as they explained how online socialisation has "levelled the playing field" between them and non-autistic individuals. They have also indicated that they felt more comfortable interacting with others online.

Furthermore, they have specifically expressed how knowing someone online first and then meeting them in-person makes the interaction offline easier. Participants also preferred autistic spaces and communicating with other autistic individuals. This encourages more research on how to make all spaces inclusive for autistic individuals. According to Ochs & Solomon (2010) the socio-cultural context in which the social interaction is taking place impacts the ability of the autistic individual to manage the social interaction not only their own social ability. Hence, it is important to consider which factors support and encourage positive social interactions. In Chapter 4, teachers provided three strategies which can be designed into an environment to support friendship for autistic children, while children in Chapter 8 worked on adapting these strategies into a game for supporting friendship between autistic and neurotypical children. Parents and children have shared their experiences with online socialisation in Chapters 5 and 6 respectively. They expressed how safety online was an important element that, although necessary, may hinder the development of friendship using currently available platforms. Hence, it is important to consider how to design an online environment where safety can be guaranteed as the process of developing friendships requires a lot of self-disclosure of personal information that may put children at risk when using an unsafe platform.

This has been an exploration study on the potential of technology as a medium for supporting friendship. Present results confirm that technology can provide a medium for autistic and neurotypical children to develop friendships which they can later maintain both online and in-person encouraging future work to continue designing such technology.

9.2.4 Design Requirements to Support Friendship for Autistic Children and Their Neurotypical Peers

The previous sections established the potential for technology to support friendship between autistic children and their neurotypical peers. Based on the results from Chapter 7, autistic participants confirmed that socialising online has the potential benefit of supporting

friendship between autistic and neurotypical children, as it levels the playing field and allows the manipulation of social norms based on the design itself. This section reiterated the main requirements obtained as a result of conducting the various studies within this thesis. A list of requirements for design is provided below:

1. *The technology should enable parents to provide support for their children if needed:* evident from the results of studies discussed in Chapters 4, 5, 6 and 7 autistic children often need external support to manage their friendships whether this support is provided by parents, teachers or is automated. Although teachers may be considered as a user for potential technology to support friendship, if overlooking and managing the environment, the results discussed in Chapter 4 conclude that friendship development is a secondary goal for teachers and their main concern is their pupils' academic skills. Hence, it is more appropriate for parents to play this role.
2. *The technology should ensure the privacy and safety of its users:* based on the results obtained from Chapters 5 and 6, safety online was a barrier to friendship development online. Any technology developed for this purpose should consider the safety of users as one of its essential requirements.
3. *The technology should incentivise collaboration to encourage relationship development:* as one of the main strategies shared by teachers in Chapter 4 and utilised by children during the design sessions in Chapter 8, this requirement can be implemented in various ways as suggested in the Chapter 4 and inspiration for possible ways of implementation can be drawn from the children's designs in Chapter 8.
4. *The technology should implement "Safe Spaces" to provide comfort to its autistic users:* This was another strategy suggested by teachers in Chapter 4. Examples of possible implementations were discussed in Chapters 4 and 8.

5. *The technology should utilise initiation and fading to support the interaction between its users:* similar to the previous requirement, this strategy was suggested by the teachers in Chapter 4 and examples of ways to implement it are discussed in Chapters 4 and 8.
6. *The technology should make the interaction purposeful to encourage initiation from its autistic users:* this is based on strategies suggested by autistic adults in Chapter 7. Autistic individuals tend to initiate when the interaction is necessary and purposeful rather than for the sole purpose of engaging in a social interaction.
7. *The technology should provide a set of ready-to-use scripts which can be used in a social interaction:* this was another strategy suggested by autistic adults in Chapter 7.

9.3 Limitations

Although the main purpose of this thesis is to explore the role of proxies, it would benefit from more representation from autistic children themselves. Despite various efforts to recruit autistic children, only a few chose to participate in this research. Although it limits what can be concluded from our results, it motivates the need for more research on how to increase access to and participation of autistic children in participatory design. It is important to note that although a reasonable number of autistic adults were willing to participate in such a study, only a few autistic children did. This observation may indicate that whether children are willing to participate or not is not necessarily due to them personally not wanting to participate, but is also the decision of their parents who may think that their children would not be able to participate in such a study or may believe their children would not enjoy it. When recruiting children for participatory design research it is not only the child who is invited to participate in the study but it is also the parent. Hence, it is vital to consider how invitations would not only appeal to children but to parents as well.

In Chapter 8, physical and asynchronous online workshops were conducted in order to study how to use design workshops to inform friendship support, evaluating ARC as a method to enhance access to autistic children. However, the number of children who completed the ARC workshop activities was very limited, which made evaluating aspects such as interaction between autistic and neurotypical children during the ARC workshop difficult. In addition, the physical design workshop did not include any autistic children which makes comparing their experience with the physical workshop as opposed to the ARC workshop not possible. These aspects would be beneficial to inform the HCI community looking to adopt such a format in order to select the best approach for their purpose. Nevertheless, the choice to not include autistic children was not intentional as plans to conduct physical workshops with them were made, and permissions obtained from schools. However, due to COVID-19 lockdown and social distancing measures it was no longer possible to conduct these workshops physically. Furthermore, the circumstances of COVID-19 and the increased time spent online by children may have impacted their willingness to continue working on the design activities, and which may have led many of them to withdraw.

9.4 Future Directions

In this thesis, four proxies were considered which are teachers, parents, autistic adults and neurotypical children. However, these are not the only proxies that can inform designs for autistic children. Practitioners such as Educational Psychologists or Speech and Language Therapists can also be included as a proxy for autistic children. Their input on best practices, how they deliver interventions and how children usually interact with them can be beneficial depending on the context studied. Another proxy may be researchers within the autism research community, whether they are specifically within HCI or from other disciplines. Their knowledge can not only inform the technology design but also the design of the methodology. Siblings of autistic children can also be another proxy to consider as they can be more

knowledgeable on autism compared to the average neurotypical child. Exploring the role of each one of these proxies and at which stage and in what contexts can they be involved in the design process would be beneficial to the research community ultimately, allowing the inclusion of more autistic voices within the design.

The study of the role of these four proxies was specific to the friendship context and possible contexts these proxies may inform were suggested based on results obtained from this thesis. However, exploring different contexts may allow the research community to further understand the possible contributions of proxies in participatory design.

To further explore the role of proxies, it would be beneficial to evaluate the effectiveness of designs produced with proxies with other designs produced only with the target population, considering not only the impact of the design on the participating children but the general impact it has on other potential autistic child users. Evaluating the usability, effectiveness, acceptance, engagement and appeal of each of the produced designs and then comparing the two results would help improve participatory design methods.

Although theoretically ARC might have resolved many of the issues around autistic children's access and participation, the circumstances in which it was conducted made it difficult to produce generalizable results. Hence, further exploration of this method with autistic children is needed. In addition, exploring other remote methods such as synchronous online workshops or a combination of remote and physical workshops would be beneficial.

This thesis explored friendship support as the context in which proxies are studied. However, preliminary results indicate the potential benefits a technical solution may have on supporting friendship. It begins by identifying three possible strategies to support friendship and developed a design workshop protocol in which these strategies can be utilised. The protocol can be used to conduct further design workshops with neurotypical and autistic children, in order to develop a technical solution for friendship support.

9.5 Summary of Contributions

This thesis produces three main contributions to the body of knowledge.

Firstly, this research attempts to respond to the challenges around including autistic children in participatory design by exploring the roles of their proxies and how the involvement of proxies within the design process can ease and support the involvement of autistic children themselves. It provides an in-depth exploration of the supporting roles of teachers, parents, autistic adults and neurotypical children in the design process.

Secondly, this research further explores ways to involve autistic and non-autistic children by evaluating the use of physical and asynchronous remote workshops. It adopts an ARC approach which has previously been little used with children especially those with autism.

Thirdly, it provides a theoretical discussion on friendship development and technology as a possible aid to scaffolding interaction and exploring the potential of designing such technology using a participatory design approach, creating the first step towards further research in this area.

9.6 Conclusions

The benefits of adopting a participatory design approach are widely accepted. However, when working with autistic children, using a PD approach might present a number of challenges. Using proxies such as teachers, parents and autistic adults is proposed as a method to improve the inclusion of autistic children in the design process. However, each proxy is unique in terms of what advantages and limitation they have, which impact how they can inform the design in a PD approach. Hence, an in-depth exploration of four different proxies which are teachers, parents, autistic adults and neurotypical children is provided and recommendations on when and in what contexts to involve them are laid out. Results from this research indicate that input from proxies not only informs the design directly but also indirectly by helping develop better methods for involving autistic children in the design process.

Another approach to address the limitation of conducting PD with autistic children was the use of online asynchronous design workshops which increases the access to autistic children by not limiting participants to those physically co-located with the researchers but rather geographically spread. The asynchronous nature of the workshop allows the participants to complete activities at their own pace reducing potential anxiety resulting from overstimulation. This research provides evaluation of using such an approach laying out issues and possible solutions.

Finally, the context of supporting friendship was the theme used to explore ways to improve participation of autistic children in participatory design. The results obtained from the different studies establish the potential benefit of developing a technical solution for supporting friendship. The design workshop protocol developed for the purpose of addressing the thesis research question can be used in future studies in a participatory design approach to develop a technical solution to support friendship for and with autistic children.

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A TEACHERS' INTERVIEW QUESTIONS

Semi-Structured Interviews for Teachers

Goals:

- Understand what strategies are used to support friendship and their limitation
- Understand the role of the environment to support friendship
- Understand what activities encourage social interaction between children

1. Friendship Dynamics and Support Strategies

Q1: Can you think of a pairs or group of friends in your classroom?

Q1.1: Where do they mostly interact?

Q1.2: What activities do they engage in together?

Q1.3: How do you support their relationship?

Q2: What are the challenges of developing friendships between children?

Q2.1: Can you think of someone in your classroom who find it difficult to develop friendships?

Q2.1.1: How can you support such student in making friends?

2. Environment

Q2.1: How do you arrange the classroom to encourage social interaction?

Q2.2: Where do most interactions happen?

Q2.2.1: can you recall the last time you observed children interacting there?

Q2.2.2: When was it?

Q2.2.3: What happened?

Q2.2.4: Did the interaction between these children extend beyond <that place>?

Q2.3: Is there anyway you could modify the environment so it would encourage more interaction?

3. Activity

Q3: What activities encourage social interaction between the children?

Q3.1: How do you encourage the children to engage in <these activities>?

Q3.2: can you remember the last time children engaged in <this activity>?

Q3.2.1: When was it?

Q3.2.2: What happened?

Q3.3: What are the features of an activity that encourages social interaction between the children?

4. Technology use

Q4: How often do you use computers or tablets as a learning tool?

Q4.1: is there any challenges to their use?

Q4.2: how does the student interact with them?

4. Contact

Q4: can we contact you later to get your feedback on a game design for children?

B PARENTS' INTERVIEW QUESTIONS

Semi- Structured Interview Questions for Parents

Your child's friendships:

1. Do you think your child has close friendships?
2. Do you have any concerns about your child making friends? If so, what are they?

Friendships between similar and mixed groups:

1. Does your child have friends who are autistic/non-autistic?
2. Do you think their relationships are different with other autistic/non-autistic children? If so, how are they different?

Friendships online/offline:

There is friends who we meet in-person and become friends with them but now there is also friends who we meat online through social media or online games.

1. Does your child have online friends?
2. Do you think it is easier for your child to make friends online or in-person? Why?
3. What do you think the differences are between online and in-person for your child?
4. Do you think your child finds it easier to maintain friendships online or in-person? Why?

Friendships during lockdown:

We have been in and out of lockdown for almost a year now. I would like to discuss with you your children's experience with friendship during lockdown.

1. Has your child managed to maintain their previous friendships during lockdown?
2. Has your child made any new friends? If so, how did they do this?
3. Has lockdown affected your child's friendships with others in any other way?

Is there anything else you would like to add, in terms of your child's online and in-person friendships before and during the pandemic?

C PARENTS' AND CHILDREN'S INFORMATION SHEET AND CONSENT FORMS FOR FRIENDSHIP INTERVIEWS

Supporting Friendship for Children with Autism Spectrum Condition and Their Neurotypical
Peers



Hello! We are Aljawharah, Alicia and Taylor and we are exploring ways to help children make friends. Both you and your child are invited to take part. The project has obtained ethics approval from the School of Health in Social Science (HiSS) Ethics Committee at the University of Edinburgh.

Inside this booklet you will find both a parent information sheet and a consent form. Please read them carefully.

Parent Information Sheet

WHAT WILL HAPPEN?

In this project, because your child is typically developing (or autistic) and aged between 8-13 years you and your child will be invited to do interviews with one of the research team. We will conduct the interviews over Microsoft Teams. The interview with you and your child can be conducted back to back or at different times based on your availability. During the interviews we will talk about friendships and their experience with making and maintaining peer relationships during COVID-19 lockdown. Interviews will be audio recorded only. Although we will not be video recording, turning on your camera during the interview is encouraged so we can make sure your child is not getting upset or distracted. You can choose if you want to stay with your child during the interview or leave the room.

HOW LONG WILL IT TAKE?

Each interview should take 20 to 30 minutes.

WHAT IF I DON'T WANT MY CHILD TO TAKE PART?

You may decide to stop your child's participation at any time. You have the right to ask that any data supplied to that point be withdrawn/destroyed.

We will ask your child's permission before we begin the interview, and they can choose to stop if they wish.

Feel free to ask questions at any point. If you have any questions as a result of reading this information sheet, you should ask the researcher before the interview.

ARE THERE ANY RISKS OR BENEFITS TO TAKING PART?

This study poses no known risks to your child. There are no direct benefits for children who take part, however the information provided will contribute to understanding of how to design technologies to support friendship development between children with ASC and their neurotypical peers.

WILL THIS STUDY BE CONFIDENTIAL?

The data we collect will only be seen by the researchers and will not be linked to any identifying information (e.g., name, address, email) that you supply. Pseudonyms will be used to protect confidentiality. The data collected may be presented at conferences, academic publications or lectures.

HOW WILL MY INFORMATION BE STORED?

The data collected will be stored separately from consent forms to preserve anonymity. The audio data will be kept on an encrypted folder on the University of Edinburgh secure server. None of the data will be publicly accessible.

WHAT HAPPENED TO MY INFORMATION AFTER THE STUDY?

The research supervisors will retain copies of the anonymous data on an encrypted folder on the university of Edinburgh server until they are no longer needed. The data may be used in subsequent research projects. When data is no longer needed, Physical and electronic data will be destroyed.

MY CHILD AND I WANT TO TAKE PART IN THIS STUDY, WHAT DO I DO?

Please complete the form in the link below and we will contact you to a convenient time for you and your child to do the interview.

https://forms.office.com/Pages/ResponsePage.aspx?id=sAafLmkWiUWHiRCGaTTcYRthPjVN_a5MpVuqG5m4P1VURTBWRVE5TjI3QJJEWUQ0VklANFY4M0JMV4u

IF I HAVE A QUERY, WHO CAN I CONTACT?

For any further information, please contact the research team:

Researcher: Aljawharah Alabdullatif
Email:
Tel: +966 504121214.
Researcher: Alicia Smith
Email:
Researcher: Tavlör Bartow
Email:
Supervisor: Prof. Helen Pain
Email:
Tel: +44 (0) 7974 971 475
Supervisor Dr. Karri Gillespie-Smith
Email:
Tel: +44 (0) 7854428924

We will be glad to answer your questions about this study.

If you wish to speak to an object academic advisor who is external to the project please feel free to contact –

External Contact: Dr Clara Calia, Lecturer in Clinical Psychology

Email:

If you wish to make a complaint about the study, please contact the head of school at the School of Health in Social Science:

Prof Matthias Schwannauer

Email: headofschool.health@ed.ac.uk

In your communication, please provide the study title and detail the nature of your complaint.

For general information about how we use your data go to:

<https://www.ed.ac.uk/records-management/privacy-notice-research>

Child Information Sheet

We are exploring ways to help children make friends. To do this, we need to know more about how children make friends. we want to know especially how you kept in touch with your friends during COVID-19 lockdown. If you want to help, please read this information sheet carefully and talk about it with your family.

Do I have to take part?

It is up to you if you would like to take part. If so, there is a form to let us know that you will help us know more about children and friendships.

What do I have to do?

During the interview, we will ask you some questions about your friendships. How you make friends and how you keep in touch with them. There is no right or wrong answer to the questions we will ask. Anything you say will be very helpful to me.

What if I have a problem during the interview?

We will be there to help answer any of your questions.

Will anyone know what I've answered?

Nobody will know what you've answered, only the researchers of this study.

Who has reviewed this study?

It is important that every study is checked by a Research Ethics Committee. They make sure the research is fair and safe to do. This study has been checked by the School of Health in Social Science (HiSS) Ethics Committee at the University of Edinburgh.

I want to take part, what should I do?

If you would like to take part, please ask your parent to contact us so you can meet us online with you and your parent. You can then tell us yourself that you want to participate in this study.

What if I don't want to take part anymore?

You can stop your taking part in this study at any point, for any reason. The information you gave will be deleted. If you feel you don't want to take part anymore, let us know.

D VERBAL PROTOCOL FOR FRIENDSHIP INTERVIEWS

Verbal Protocol - Brief

In addition to the parental/guardian consent form, this verbal protocol must be read out to the children to ensure that they are aware of what they are taking part in. If they do not wish to take part, the researcher must thank them for their time and end the meeting.

My name is Aljawharah Alabdullatif/Alicia Smith/Taylor Bartow and I am a researcher from the University of Edinburgh. I am here to ask if you would like to help us with some research that we are doing. We will first tell you about the research and you can let us know if you are happy to help.

Our research is interested in understanding children friendships and exploring ways to help children make friends.

We are hoping to do a short interview with you and ask you about your experience with friendships and how you managed them during COVID-19 lockdown.

Thank you for joining us here. Are you happy to help us out with this research or would you like to end the meeting?

If the child say 'Yes' that they are happy to take part, then allow them to participate and ask the first questions. Remind the child that they can stop and end the meeting at any point during the session.

If the child say 'No' that they are not happy to take part, then end the meeting.

E PARENTS' AND CHILDREN'S DEBRIEF FOR FRIENDSHIP INTERVIEWS

Parent Verbal Protocol – De-Brief

In addition to the parental/guardian consent form, this verbal protocol must be emailed out to the parents to reiterate the purpose of the research, provide an opportunity to ask questions and to give follow-up care information (i.e., contact information about who the parent can contact if they or their children felt negatively affected by the research). Afterwards, the researchers must thank the parents for their participation and time.

We have now completed the interviews. Thank you very much for your participation and time.

We hope that you have enjoyed taking part in our study. If you have any concerns or if you or your child don't feel good after completing the interview, please do not hesitate to contact us about this.

You have our contact details, so if you have any further questions or require additional information please contact us to let us know.

Thank you again.

Child Verbal Protocol – De-Brief

In addition to the parental/guardian consent form, this verbal protocol must be read out to the children to reiterate the purpose of the research, provide an opportunity to ask questions and to give follow-up care information (i.e., contact information about who the child can talk to if they felt negatively affected by the research). Afterwards, the researchers must thank the children for their participation and time.

We have now completed the interview questions. Thank you very much for your participation and time.

We hope that you have enjoyed taking part in our study. If you have any concerns or if you don't feel too good after completing the interview, please know that you can talk to us or your parents/caregiver about this.

Now I will end the meeting. Your parents/caregiver have our contact details, so if you have any further questions or require additional information please let them know so that they can contact us.

Thank you again

F CHILDREN'S INTERVIEW QUESTIONS

Semi-Structured Interview Questions for Children

Warm-up:

1. Do you have friends?
- 1.A. Yes
 - 1.A.1. what is your closest friend name?
 - 1.A.2. How long have you been friends?
 - 1.A.3. How did you meet them?
 - 1.A.4. What do you do together?
 - 1.A.5. What makes your friend different from other children you know?
 - 1.A.6. Why did you become friends with them?
- 1.B. No
 - 1.B.1. Who is someone you are close to?
 - 1.B.2. How did you meet them?
 - 1.B.3. What do you do together?
 - 1.B.4. How long have you known each other?

Friendship Definition:

1. What makes a good friend?
2. Do you think it is important to have a good friend or more?
3. How do you make friends?
4. How is having friends different from not having any friends?
5. Do you enjoy having friends? Why?
6. Are you happy with how many friends you have?
7. Would you like more friends?

Friendship between similar and mixed groups:

8. Do you have friends who are autistic/ non-autistic?
- 8.A Yes
 - 8.A.1. How is your relationship with them different or similar to other autistic/non-autistic friends you have ?
 - 8.A.1.1. Do you do the same activity?
 - 8.A.1.2. Do you meet as often?
 - 8.A.1.3. How do you feel when you are with them?
- 8.B No
 - 8.B.1. Do you anyone who is autistic/non-autistic?
 - 8.B.1.A Yes
 - 8.B.1.A.1. Who are they? what is your relationship with them?
 - 8.B.1.A.2. How do you feel when you are with them?
 - 8.B.1.A.3. How is your relationship with them different or similar to other autistic/non-autistic people you know?

8.B.1.B No

Friendships online/in-person:

1. Do you have any friends who you meet in the park, school, playground, clubs? Friends that are in-person and meet them face-to-face and not online?
 - 1.1. What do you and your in-person friends do together?
2. Do you have any friends that you just meet online?
 - 2.1. What do you and your online friends do together?
3. Are online and in-person friendships different?
 - 3.1. Is it easier to make friends online or in-person?
 - 3.2. In normal times [not Covid] who do you like to spend time with, your online friends, in-person friends or both?
4. What would happen if you met one of your online friends in-person?
5. What would happen if you met one of your in-person friends online?

Friendships during lockdown:

1. How did the lockdown affect your friendships?
2. Have you made any new friends during Covid?
 - 2.1. How did you make new friends during Covid?
3. Did you keep in contact with your in-person friends? If yes, how?
4. Did you keep in contact with your online friends? If yes, how?
5. Which tools did you use?
 - 5.1. What did you like about this tool?
 - 5.2. What was missing from this tool?
 - 5.3. How would you change it?

Maintaining Friendships normally and during lockdown:

1. How do you keep your in-person friendships going normally?
2. How do you keep your online friendships going normally?
3. Has the pandemic changed the way you keep your friendships both online and offline? If yes, how?
4. Overall has the pandemic been good or bad for your friendships? Why?

Is there anything else you would like to tell us?

G AUTISTIC ADULTS' INTERVIEW QUESTIONS

Semi-Structured Interview Questions

Prior to starting the session, the interviewer will outline terminologies and clarify how the participant wishes to be identified (person first/identity first/preferred terminology for ASC). An opportunity to ask any questions regarding the research will also be offered and the plan for the session and research process will be briefly outlined. A short demographics form will be completed including age, gender, UK region, level of education and employment status.

Demographic questions:

1. Age
2. Gender
3. UK region of residence
4. Highest level of education (Less than a high school diploma (GCSE), high school degree or equivalent, Bachelor's degree, Master's degree, Doctorate, Other)
5. Employment status (student, unemployed, self-employed, employed full-time, employed part-time)

(Before the questions we should point out to the participant that the questions refer to their experiences prior the current situation with the pandemic and the lockdown.)

Topic 1 - View of friendship (Perception):

- What do you think about when you think of friendship? [How would you describe what a friend is? Tell me more about what makes a friend different to someone else you know/acquaintance?]
- What role does friendship play in your life? [What are your experiences? How do your friends affect your life?]

- In your view what makes friendship in the Autistic community similar to and different from “neurotypical” friendship? [Could you give an example of that.]
- Are there differences in your friendships with others with Autism as opposed to those without Autism/neurotypical? [can you tell me more about that.] [Do you do different things with your autistic friends as opposed to your neurotypical ones?]
- Do you think your friendships are different online and virtually compared to face to face (offline)? [What do you think makes them different? Could you give me some examples?]

Topic 2 - Making friends/Forming friends:

- What are your experiences of making friends?
- Where did you meet your friends (school, work. . .)?
- How much impact has technology (e.g., video games, computer games, social media, etc.) had on you making new friends?
- Do you think this is different between other autistic people and people who are not?
- Is this different in online/offline? [Does it make it easier or harder to form friendships online as opposed to offline? In what way is it different or easier to make friends online or in person?]

Topic 3 - Maintaining friendships:

- What do you often do with your friends? Is this the same for autistic friends as well as others? (What things do you do online and offline with your friends)?
- Please describe - Do you meet face to face (e.g. and chat), share activities (e.g. hobbies) or mainly online (chatrooms, online gaming)?

Have you met any of your online friends face to face? [If not, why do you think that is?]

Sub Topic - Frequency:

- How often do you see your friends or chat before the current situation with the lockdown?

(Prompt-Offline/online & Neurotypical/atypical)

- How do you keep in contact with your friends? (Prompt-Offline/online & Neurotypical/atypical)
- What do you find difficult about maintaining friendships? (Prompt-Offline/online & Neurotypical/atypical)

- How long have you been friends with your friends? (Prompt-Offline/online & Neurotypical/atypical)

Topic 4 – Coronavirus (COVID-19) pandemic and self-isolation:

- How has the current situation regarding the coronavirus outbreak affected your friendships?
- How have you kept in contact with your friends during this period?
- Have you struggled to keep in contact with some friends and not others, and why do you think that is the case?

H GAME DESIGN SHEET FOR PILOT WORKSHOP

Game Design



Goal



Rules



Reward



Notes

I PILOT WORKSHOP CERTIFICATE



Certificate of Participation★

This is to certify that

Name

Was a great Game Designer



Signed:

Professor Helen Pain

J PHYSICAL AND ARC WORKSHOPS CERTIFICATE



K PARENTS' AND CHILDREN'S INFORMATION SHEET AND CONSENT FORMS FOR PHYSICAL WORKSHOPS

Supporting Friendship for Children with Autism Spectrum Condition



Hello! My name is Aljawharah, and I am exploring ways to help children make friends. Both you and your child are invited to take part. The project has obtained ethics approval from the School of Health in Social Science (HiSS) Ethics Committee at the University of Edinburgh.

Inside this booklet you will find both a parent information sheet and a consent form. Please read them carefully.

Parent Information Sheet

WHAT WILL HAPPEN?

In this project, your child will be asked to design/test a game. Design activities will involve drawing and playing games with other children. Pictures may be taken and the whole design session will be video\audio recorded for the researcher reference and to allow more natural communication with the children during the session. In the testing sessions your child will be asked to play a game and then comment on his/her experience.

HOW LONG WILL IT TAKE?

The workshop will take about 4 hours including a break for snacks or lunch.

WHAT IF I DON'T WANT MY CHILD TO TAKE PART?

You may decide to stop your child's participation at any time. You have the right to ask that any data supplied to that point be withdrawn/destroyed.

We will ask your child's permission before we begin the workshops, and they can choose to stop if they wish.

Feel free to ask questions at any point. If you have any questions as a result of reading this information sheet, you should ask the researcher before the workshop begins.

ARE THERE ANY RISKS OR BENEFITS TO TAKING PART?

This study poses no known risks to your child. There are no direct benefits for children who take part, however the information provided will contribute to understanding of how to design technologies to support friendship development between children with ASC and their neurotypical peers.

WILL THIS STUDY BE CONFIDENTIAL?

The data we collect will only be seen by the researchers and will not be linked to any identifying information (e.g., name, address, email) that you supply. Pseudonyms will be used to protect confidentiality. The data collected may be presented at conferences, academic publications or lectures. You can indicate your preference of whether we use videos/images of your child for publications, presentations or teaching purposes on the consent form. If you do not agree on the use of videos/images of your child for publications, presentations or teaching purposes, the video will be seen only by the researchers during analysis. If you are not comfortable with your child being video recorded at all, then your child should not participate in this study.

HOW WILL MY INFORMATION BE STORED?

The data collected will be stored separately from consent forms to preserve anonymity. Documents will be kept in locked cabinets on University premises. The video and audio data will be kept on an encrypted folder on the University of Edinburgh secure server. None of the data will be publicly accessible.

WHAT HAPPENED TO MY INFORMATION AFTER THE STUDY?

All physical data will be destroyed after the dissemination of this research. The research supervisors will retain copies of the anonymous electronic data on an encrypted folder on the university of Edinburgh server for 10 years. The data may be used in subsequent research projects. After 10 years have passed, electronic data will be destroyed.

IF I HAVE A QUERY, WHO CAN I CONTACT?

For any further information, please contact the research team:

Researcher: Aljawharah Alabdullatif
Email:

Tel: +447955380355.

Supervisor: Prof. Helen Pain

Email:

Tel: +44 (0) 131 650 8485

Supervisor Dr. Karri Gillespie-Smith

Email:

Tel: +44 (0)131 651 3932

We will be glad to answer your questions about this study. If you wish to make a complaint about the study, please contact the research supervisors or the Ethics and Integrity Lead at the School of Health in Social Science:

Dr. Clara Calia
Lecturer in Clinical Psychology, Ethics & Integrity Lead
Email

In your communication, please provide the study title and detail the nature of your complaint.

For general information about how we use your data go to:

<https://www.ed.ac.uk/records-management/privacy-notice-research>

Consent Form

By signing below, you are agreeing that: (1) you have read and understood the Participant Information Sheet, (2) questions about your child's participation in this study have been answered satisfactorily, (3) Following data coding and analysis of your child will be stored anonymously and confidentially for up to 10 years. and (4) you are willing for your child to take part in this research study voluntarily.

Caregiver's Name (Printed)*

Child's name (Print)*

Caregiver's signature*

Child's Date of Birth

Today's Date

Name of person obtaining consent (Printed)

Signature of person obtaining consent

Please tick in the box if you **Agree** that short videos/images of your child can be used as examples in documents and presentations for research and/or teaching purposes.

☐

**Participants wishing to preserve some degree of anonymity may use their initials (from the British Psychological Society Guidelines for Minimal Standards of Ethical Approval in Psychological Research)*

Child Information Sheet

I am asking if you would like to take part in a study which will help me design a game that help children make friends. I will ask you to share your personal experience with making friends and design the game activities with other children. Before you decide if you want to join in, it's very important you read this information sheet carefully and talk it through with your family.

Do I have to take part?

Not at all. It is up to you if you would like to take part. If you do, we would like you to sign a form letting us know you are okay designing the game.

What do I have to do?

You will be asked to help design the game by drawing and playing with other children.

What if I have a problem during the design sessions?

I will be there to help answer any of your questions.

Will anyone know what I've answered?

Nobody will know what you've answered, only the researchers of this study.

Who has reviewed this study?

It is important that every study is checked by a Research Ethics Committee. They make sure the research is fair and safe to do. This study has been checked by the University of Edinburgh School of Health in Social Science (HiSS) Ethics Committee.

I want to take part, what should I do?

If you would like to take part, please fill in the consent form and your parents can give it back to us. If you do not want to take part however, you do not have to fill this in.

What if I don't want to take part anymore?

You can stop your taking part in this study at any point, for any reason. The information you gave will be deleted. If you feel you don't want to take part any more, let us know.

Consent Form

Please tick if you do/do not wish to take part in this study.

- ☐ I want to take part in the study
- ☐ I do not want to take part in the study

Please tick the following boxes if you agree with them:

- ☐ I have read about this study and I have had a chance to ask any questions that I have.
- ☐ I know that I can choose to take part in this study and I can stop taking part at any time, without giving a reason.
- ☐ I know that all the information I give will remain private.
- ☐ It is okay to use video recordings of me playing and show it to other people who make games for children.

Your Name: _____ Date: _____

Age : _____

Your Parent's Name: _____

L PARENTS AND CHILDREN INFORMATION SHEET FOR ARC WORKSHOPS

Supporting Friendship for Children with Autism Spectrum Condition and their Neurotypical Peers



Hello! My name is Aljawharah, and I am exploring ways to help children make friends. Both you and your child are invited to take part. The project has obtained ethics approval from the School of Health in Social Science (HiSS) Ethics Committee at the University of Edinburgh.

Inside this booklet you will find both a parent information sheet and a consent form. Please read them carefully.

Parent Information Sheet

WHAT WILL HAPPEN?

In this project, because your child is typically developing (or autistic) and aged between 8-13 years they will be asked to design a game. Design activities will involve drawing and discussions with other children. Your child will be added to a team in Microsoft Teams platform where the researchers will post different activities that your child will be asked to complete. Your child will also be invited to participate in an interview where we will talk about friendships and their experience with making and maintaining peer relationships during COVID-19 lockdown. Interviews will be audio recorded only. Although we will not be video recorded, turning on your camera during the interview is encouraged so we can make sure your child is not getting upset or distracted.

HOW LONG WILL IT TAKE?

We will do 11 different activities each taking a couple of minutes to complete. The activity will be posted to Teams and your child can complete it at their own time. Activities due date will vary between 1 to 3 days and all activities will be posted within 3 weeks. The Interview will be carried out in the fourth week and we will agree with you on a time that is convenient for you and your child to be interviewed. The interview should take 20 to 30 minutes.

WHAT IF I DON'T WANT MY CHILD TO TAKE PART?

You may decide to stop your child's participation at any time. You have the right to ask that any data supplied to that point be withdrawn/destroyed.

We will ask your child's permission before we begin the workshops, and they can choose to stop if they wish.

Feel free to ask questions at any point. If you have any questions as a result of reading this information sheet, you should ask the researcher before the workshop begins.

ARE THERE ANY RISKS OR BENEFITS TO TAKING PART?

This study poses no known risks to your child. There are no direct benefits for children who take part, however the information provided will contribute to understanding of how to design technologies to support friendship development between children with ASC and their neurotypical peers.

WILL THIS STUDY BE CONFIDENTIAL?

The data we collect will only be seen by the researchers and will not be linked to any identifying information (e.g., name, address, email) that you supply. Pseudonyms will be used to protect confidentiality. The data collected may be presented at conferences, academic publications or lectures. You can indicate your preference of whether we use videos/images of your child for publications, presentations or teaching purposes on the consent form. If you do not agree on the use of videos/images of your child for publications, presentations or teaching purposes, the video will be seen only by the researchers during analysis. If you are not comfortable with your child being video recorded at all, then your child should not participate in this study.

HOW WILL MY INFORMATION BE STORED?

The data collected will be stored separately from consent forms to preserve anonymity. Documents will be kept in locked cabinets on University premises. The video and audio data will be kept on an encrypted folder on the University of Edinburgh secure server. None of the data will be publicly accessible.

WHAT HAPPENED TO MY INFORMATION AFTER THE STUDY?

All physical data will be destroyed after the dissemination of this research. The research supervisors will retain copies of the anonymous electronic data on an encrypted folder on the university of Edinburgh server for 10 years. The data may be used in subsequent research projects. After 10 years have passed, electronic data will be destroyed.

MY CHILD WANT TO TAKE PART IN THIS STUDY, WHAT DO I DO?

Please complete the form in the link below and we will contact you to arrange an initial introductory meeting online with you and your child to meet the researcher, record your consent and explore the tools used in the workshops.

<https://forms.gle/Z46Th4SYyHBh1SPu7>

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Child Information Sheet

Would you like to help me design a game that helps children make friends? I will ask you about making friends. We will design the game with other children. You will be in a team online. Microsoft Teams will be used to help you work with the other children on your ideas and to take part in various online activities. If you want to join in, please read this information sheet carefully and talk about it with your family. We will also do a short interview with you, about your friends and how you kept in touch with them during COVID-19 lockdown.

Do I have to take part?

It is up to you if you would like to take part. If so, there is a form to let us know that you will help us design our game.

What do I have to do?

You will help design the game by drawing and doing other activities, and working with other children (on Microsoft Teams). Activities will be posted almost every day for you to complete.

We love to hear your ideas, so it is good if you can do the activities, but it is ok if you miss some of them. During the interview, I will ask you some questions about your friendships.

What if I have a problem during the design sessions?

I will be there to help answer any of your questions.

Will anyone know what I've answered?

Nobody will know what you've answered, only the researchers of this study.

Who has reviewed this study?

It is important that every study is checked by a Research Ethics Committee. They make sure the research is fair and safe to do. This study has been checked by the University of Edinburgh School of Health in Social Science (HiSS) Ethics Committee.

I want to take part, what should I do?

If you would like to take part, please ask your parent to contact us so you can meet us online with you and your parent. You can then tell us yourself that you want to participate in this study.

What if I don't want to take part anymore?

You can stop your taking part in this study at any point, for any reason. The information you gave will be deleted. If you feel you don't want to take part any more, let us know.