

The Use of Socially Assistive Robots with Autistic Children

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Author's declaration

I, Athanasia Kouroupa, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Researcher's contribution

I completed the work for the thesis as a part-time PhD student. The thesis presents findings from original studies undertaken as a part-time PhD student. The data presented in chapter 6 is from a study funded by the National Institute for Health Research (NIHR; award ID: PB-PG-0215-36122) in which I was employed as a research assistant in 2017 – 2019. Though the analysis in chapter 6 draws on an existing study, this element was designed by me for secondary data analysis and is not part of the original grant planned analyses. I conducted all the data analyses for all studies included in the thesis.

Table of Contents

| | |
|---|----|
| Acknowledgements | 2 |
| Author's declaration | 3 |
| Researcher's contribution | 4 |
| Table of Contents | 5 |
| List of tables..... | 10 |
| List of figures | 11 |
| PhD published output..... | 12 |
| Conferences..... | 12 |
| Terminology used in the thesis | 13 |
| Abstract | 14 |
| Chapter 1: Introduction | 16 |
| 1.1 The emergence of autism as a diagnostic entity..... | 16 |
| 1.1.1 Prevalence of autism | 20 |
| 1.1.2 Aetiology of autism..... | 22 |
| 1.1.3 Early recognition of autism..... | 23 |
| 1.1.4 Specific autistic experiences and characteristics in daily life | 24 |
| 1.2 Conceptualising autism | 30 |
| 1.3 Psychosocial support in autism | 35 |
| 1.4 Summary..... | 44 |
| Chapter 2: Introduction | 45 |
| 2.1 Socially Assistive Robots (SARs)..... | 45 |
| 2.1.1 Humanoid robots..... | 47 |
| 2.2.2 Animal-like robots | 49 |
| 2.2.3 Mechanical or other robots..... | 50 |
| 2.2 The introduction of technology in autism research | 51 |
| 2.2.1 Stakeholder's views of technology use in autism..... | 53 |
| 2.2.2 The role of technology in autism..... | 55 |
| 2.2.3. From other technology devices to SARs..... | 56 |
| Chapter 3: Research programme | 59 |
| 3.3.1 How have SARs been used with autistic children?..... | 62 |
| 3.3.2 What are parents'/carers' preferences about technology-based support including SARs with autistic children? | 63 |

| | |
|--|----|
| 3.3.3 What are parents' views on the way a humanoid robot might support autistic children in a session?..... | 64 |
| 3.3.4 What is the effect of Kaspar, a humanoid SAR, in the joint attention skills of autistic children compared to a human therapist in a session? | 64 |
| Chapter 4: The use of SARs in autistic children: a systematic literature review and meta-analysis | 66 |
| 4.1 Introduction..... | 66 |
| 4.1.2 Study objectives..... | 68 |
| 4.2 Methods | 68 |
| 4.2.1 Search strategy | 68 |
| 4.2.2 Inclusion and exclusion criteria | 69 |
| 4.2.3 Study selection | 70 |
| 4.2.4 Data extraction | 71 |
| 4.2.5 Quality assessment..... | 71 |
| 4.2.6 Data synthesis..... | 72 |
| 4.3 Results | 74 |
| 4.3.1 Overview of included studies | 74 |
| 4.3.2 Study characteristics..... | 74 |
| 4.3.3 Quality assessment and risk of bias in included studies | 76 |
| 4.3.4 Robot types..... | 68 |
| 4.3.5 Settings | 69 |
| 4.3.6 Robot's role and training session characteristics | 71 |
| 4.3.7 Targeted skills and outcomes..... | 72 |
| 4.3.8 Meta-analysis | 73 |
| 4.4 Discussion | 76 |
| 4.4.1 Strengths and limitations | 80 |
| 4.4.2 Future recommendations..... | 82 |
| 4.5 Conclusions..... | 83 |
| Chapter 5: Parents'/carers' knowledge and preferences about technology-based support for autistic children: An international online survey | 84 |
| 5.1 Introduction..... | 84 |
| 5.1.1 Study objectives..... | 87 |
| 5.2 Methods | 88 |
| 5.2.1 Participants and recruitment | 88 |
| 5.2.2 Questionnaire | 88 |

| | |
|---|-----|
| 5.2.3 Procedures..... | 90 |
| 5.2.4 Data analysis..... | 91 |
| 5.3 Results | 94 |
| 5.3.1 Participants..... | 94 |
| 5.3.2 Access to autism specific support | 98 |
| 5.3.3 Knowledge about technology-based support | 102 |
| 5.3.4 Most preferred technology-based support..... | 105 |
| 5.3.5 Parent's/carer's attitudes about most preferred technology-based support..... | 107 |
| 5.3.6 Least preferred technology-based support..... | 112 |
| 5.3.7 Parent's/carer's attitudes about least preferred technology-based support | 114 |
| 5.3.8 Decision-making factors | 119 |
| 5.3.9 Parent/carer, child characteristics and mostly preferred technology-based support | 121 |
| 5.3.10 Correlation analyses | 125 |
| 5.3.11 Logistic Regression model | 127 |
| 5.3.12 Concerns about technology use in general | 129 |
| 5.3.13 Attitudes about technology use during the pandemic..... | 130 |
| 5.4 Discussion | 134 |
| 5.4.1 Strengths and limitations | 138 |
| 5.4.2 Implication and suggestions for future research | 139 |
| 5.5 Conclusion | 141 |
| Chapter 6: Exploring parents' perspectives on the use of humanoid robots with autistic children: A qualitative study..... | 142 |
| 6.1 Introduction..... | 142 |
| 6.1.1 Study objectives..... | 144 |
| 6.2 Methods | 145 |
| 6.2.1 Design | 145 |
| 6.2.2 Participants..... | 145 |
| 6.2.3 Recruitment procedure | 147 |
| 6.2.4 Interview procedure..... | 147 |
| 6.2.5 Ethical considerations..... | 148 |
| 6.2.6 Topic guide | 150 |
| 6.2.7 Data Analysis | 151 |
| 6.3 Results | 153 |

| | |
|---|-----|
| 6.3.1 Findings..... | 153 |
| 6.4 Discussion | 164 |
| 6.4.1 Strengths and limitations | 168 |
| 6.5 Conclusions..... | 170 |
| Chapter 7: Joint attention skills in autistic children interacting with a human therapist alone or a humanoid robot along with a human therapist..... | 171 |
| 7.1 Introduction..... | 171 |
| 7.1.1 Joint attention in autism | 172 |
| 7.1.2 Robots and joint attention in autism..... | 173 |
| 7.1.3 Study objectives..... | 174 |
| 7.2 Methods | 174 |
| 7.2.1 Participants..... | 175 |
| 7.2.2 Robot | 177 |
| 7.2.3 Procedure | 178 |
| 7.2.4 Secondary data collection and coding..... | 181 |
| 7.2.5 Secondary data analysis | 183 |
| 7.3 Results | 184 |
| 7.3.1 Are there greater improvements in joint attention skills of autistic children receiving a session from a human therapist along with Kaspar compared to those receiving the same session with a human therapist alone? | 184 |
| 7.3.2 Is there an improvement within the Kaspar or the human therapist group in the joint attention skills of autistic children from the first to the last session? | 184 |
| 7.4 Discussion | 184 |
| 7.4.1 Strengths and limitations | 186 |
| 7.5 Conclusions..... | 188 |
| Chapter 8: Discussion | 189 |
| 8.1 Summary of findings..... | 189 |
| 8.2 Implementation framework | 193 |
| 8.3 Thesis implications | 196 |
| 8.3.1 Bridge the gap from research to practice..... | 196 |
| 8.3.2 Collaborative research culture | 199 |
| 8.3.3 Affinity for robots | 201 |
| 8.4 Future directions | 201 |
| 8.4.1 Transparent reporting of procedures in autism specific support studies | 201 |
| 8.4.2 From small to larger sample sizes | 203 |

| | |
|--|-----|
| 8.4.3 Better link of research findings with clinical practice | 203 |
| 8.4.4 Parents’ preferences and the autistic community | 204 |
| 8.4.5 Autistic children and (young and older) adults in research | 205 |
| 8.4.6 Exploring motivation and/or interest in robots | 206 |
| 8.5 Personal reflections..... | 206 |
| 8.6 Conclusions..... | 209 |
| References..... | 210 |
| Appendices | 280 |
| Appendix A: Checklist for Reporting Results of Internet E-Surveys (CHERRIES) | 280 |
| Appendix B: Copy of the Parents, Autism, TechNology (PATH) participant information sheet , consent form and survey | 285 |
| Appendix C: University of Hertfordshire ethical approval for conducting a survey..... | 308 |
| Appendix D: COnsolidated criteria for REporting Qualitative research (COREQ) Checklist | 310 |
| Appendix E: University of Hertfordshire ethical approval for conducting interviews with parents of autistic children..... | 313 |
| Appendix F: Qualitative study with parents – interview topic guide | 315 |
| Appendix G: University of Hertfordshire ethical approval to analyse the video recordings from the Kaspar feasibility trial | 317 |

List of tables

| | |
|--|-----|
| Table 4. 1 <i>Search strategy for systematic literature review</i> | 69 |
| Table 4. 2 <i>Quality assessment breakdown of included studies (maximum number of studies = 44; RCT = 18 and non-RCT = 26)</i> | 73 |
| Table 4. 3 <i>Individual study quality assessment overview by study design and mostly used robot</i> | 77 |
| Table 4. 4 <i>Summary of study characteristics by study design and mostly used robot</i> .. | 57 |
| Table 4. 5 <i>Vote count mapping RCTs and non-RCTs by setting and session gain</i> | 69 |
| Table 4. 6 <i>Summary of evidence from robot-mediated support in autistic children</i> | 70 |
| | |
| Table 5. 1 <i>Parent/carer demographic characteristics</i> | 95 |
| Table 5. 2 <i>Demographic characteristics of children by age group</i> | 97 |
| Table 5. 3 <i>Access autism specific support and location of delivery</i> | 99 |
| Table 5. 4 <i>Types of specific support tried by parents/carers by age group</i> | 100 |
| Table 5. 5 <i>Number of professionals parents/carers consulted about autism specific support</i> | 102 |
| Table 5. 6 <i>Parents'/carers' knowledge about technology-based support</i> | 103 |
| Table 5. 7 <i>Number of parents/carers whose children engaged with technology-based support</i> | 104 |
| Table 5. 8 <i>Number of parents/carers interested in technology-based support</i> | 105 |
| Table 5. 9 <i>Number of parents/carers selected most preferred technology</i> | 106 |
| Table 5. 10 <i>Reasons for most preferred technology-based support</i> | 107 |
| Table 5. 11 <i>Number of parents/carers selected least preferred technology</i> | 113 |
| Table 5. 12 <i>Reasons for least preferred technology-based support</i> | 114 |
| Table 5. 13 <i>Decision-making factors to access technology-based support by age group</i> | 120 |
| Table 5. 14 <i>Number of children with access to technology devices</i> | 120 |
| Table 5. 15 <i>Presentation of most preferred technology-based approach by demographic characteristics</i> | 123 |
| Table 5. 16 <i>Spearman's correlations among parent/carer and child characteristics with most preferred technology</i> | 126 |
| Table 5. 17 <i>Covariates between parent/carer, child socio-demographic characteristics and tablet as a mostly preferred technology</i> | 128 |
| | |
| Table 6. 1 <i>Demographic characteristics of parents</i> | 146 |
| Table 6. 2 <i>Demographic characteristics of children</i> | 146 |
| | |
| Table 7. 1 <i>Demographic characteristics of autistic children per allocation group</i> | 176 |
| Table 7. 2 <i>SCERTS coding scheme and definitions for each behaviour</i> | 182 |
| Table 7. 3 <i>Description and relationship of joint attention skills in autistic children per session group</i> | 185 |

List of figures

| | |
|--|-----|
| Figure 2. 1 <i>Humanoid robots</i> | 48 |
| Figure 4. 2 <i>PRISMA flow diagram of the study selection process</i> | 72 |
| Figure 4. 3 <i>Forest plot showing efficacy of robot-mediated support on emotional, motor and social outcome variables</i> | 74 |
| Figure 4. 4 <i>Funnel plot exploring publication bias</i> | 74 |
| Figure 4. 5 <i>The impact of age on effect size for robot-mediated support</i> | 75 |
| | |
| Figure 5. 1 <i>The proportion of respondents reporting an awareness of different technology-based support by age group</i> | 103 |
| Figure 5. 2 <i>Percentage of parents/carers selected most preferred technology</i> | 106 |
| Figure 5. 3 <i>Percentage of parents selected least preferred technology</i> | 113 |
| Figure 5. 4 <i>Access to technology devices</i> | 121 |
| | |
| Figure 6. 1 <i>A visual representation of data analysis</i> | 152 |
| Figure 6. 2 <i>Summary of themes and subthemes</i> | 154 |
| | |
| Figure 7. 1 <i>Picture of Kaspar</i> | 178 |
| Figure 7. 2 <i>Session room layout</i> | 180 |
| | |
| Figure 8. 1 <i>Implementation framework in robot-mediated sessions</i> | 194 |

PhD published output

Kouroupa, A., Laws, K. R., Irvine, K., Mengoni, S. E., Baird, A., & Sharma, S. (2022). The use of social robots with children and young people on the autism spectrum: A systematic review and meta-analysis. *PLoS one*, 17(6), e0269800.

Conferences

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Terminology used in the thesis

There are variations in the way that terms to describe autism are used in the literature and in everyday practice. Different individuals and groups (e.g., parents, professionals) have variable preferences for particular terms such as identity-first language (e.g., autistic) or person-first language (e.g., with autism) (Bury et al., 2020; Kenny et al., 2016). There are also other alternative terms in the literature including children on the autism spectrum or with autistic spectrum condition (Bury et al., 2020; Kenny et al., 2016). Within this thesis, the term autism is used to refer to autism spectrum disorders (ASD) (including autism, Asperger's syndrome or Pervasive Developmental Disorder-Not Otherwise Specified) which is consistent with the National Institute for Health and Care Excellence guidelines (NICE, 2013, 2017). The term "autistic" is used to describe children and/or their community throughout the document which has been endorsed as most preferred term by adults and parents in the literature (Kenny et al., 2016). In addition, the use of functioning labels (e.g., high or low functioning) is not used in the thesis as it refers to external environmental factors (Silberman, 2015). Instead, the term "autistic children with an intellectual disability" or "autistic children with additional needs" is used throughout this thesis. The choice of words used to describe individuals is important in terms of positioning views related to society, clinical practice, research, and public policy. Finally, the term "robot(s)" or "socially assistive robot(s) (SARs)" are used interchangeably in the thesis. According to the literature, there is no clear terminology to distinguish these terms (Feil-Seifer & Matarić, 2005).

Abstract

The use of socially assistive robots (SARs) appears to facilitate learning, social and communication, and collaborative play in autistic children, though rigorous research to drive translation into everyday practice is limited. This thesis, comprised of four studies, was aimed at providing a comprehensive overview of how SARs have been used with young autistic people, to identify the factors that might encourage their future use, and to consider the scope of SAR benefit for autistic youth via secondary data analysis from a specific SAR support programme. The first chapters provide an overview of autism, theories, and models, and the available psychosocial support for autistic children and their families as per current practice. Within this, the different SARs types used in autism research are described followed by an outline of the rationale for each study design methodology to address the aims of this thesis. Chapter 4 presents an up-to-date evidence summary of the nature of SARs research in autism reporting that robot-mediated support has predominantly been administered in autism clinics/centers with benefits in the social and communication skills of autistic children. Chapter 5 explores parents'/carers' knowledge and preferences about the use of smartphones, iPods, tablets, virtual reality, robots or other technologies to support the specific needs/interests of autistic children offering guidance on how to extend the benefits of the systematic review findings. The online survey reported that 59% of parents/carers mostly preferred a tablet, followed by virtual reality and then robots that were the least preferred technologies due to being immersive, unrealistic or an unknown technology. To delve deeper into parent views about SARs, chapter 6 provides data from 12 individual interviews and one focus group with parents of autistic children. Parents were receptive to the use of a robot-mediated support acknowledging that the predictability, consistency and scaffolding of robots might facilitate learning in autism. Independent living skills and social and communication skills were the two domains of focus in future robot-mediated support with autistic children. Such a finding indicates that there may be scope to extend robots in the autism community. The final data analysed in chapter 7 draws on ten video recordings of autistic children exploring the effect of triadic robot-mediated support with a human therapist alongside a humanoid robot, called Kaspar, compared

to a dyadic interaction with a human therapist alone on the development of children's joint attention skills. Retrospective data analysis here showed no statistically significant difference in the joint attention skills of autistic children in the human therapist compared to the robot-mediated group nor in their skills from the first to the last session in either group. A statistically significant difference was observed on the requests for social games which improved from the first to the last session in the human therapist group. This study highlights the challenges SARs research facing to evidence demonstrable impact on everyday life skills as a driver of parent and child buy-in to this type of support. Taken together, the studies in this thesis suggest that SARs have a role in autism support, mainly in social and communication domains. Parents/carers have valid reasons for preferring other types of technology support though when asked to think about SARs, they do acknowledge ways in which robots may be advantageous. Existing data and secondary analysis reported that rigour in reporting the way that SARs may benefit skills development is needed and that life skills impact may be difficult to assess over a short-term period. To take SARs research forward, it is imperative to deepen partnerships with autism stakeholders to ensure fit for purpose skills selection, measurement of impact, and take up of support to expand benefit.

Chapter 1: Introduction

The overarching aim of this thesis is to explore the use socially assistive robots (SARs) with autistic children. Concerns about the development and impact of using SARs with autistic children are common among researchers and the public with particular questions about the way SARs may influence the development of social, emotional, cognitive, gestural and other skills in autistic children (Baraka et al., 2021; Fosch-Villaronga & Albo-Canals, 2019). Using a mixed-methods programme of work, this thesis aims to make a novel contribution to understanding the use of SARs among autistic children while developing a framework that can help understand ways in which future research can support better translation of robot-mediated sessions with autistic children into practice. As a foundation, this introductory chapter provides an overview of autism, its theoretical models and the available psychosocial support for autistic children as per current practice.

1.1 The emergence of autism as a diagnostic entity

The Diagnostic and Statistical Manual of Mental Disorders version 5 (DSM-5; American Psychiatric Association, 2013) and the new International Classification of Diseases (ICD-11; World Health Organization, 2018) describe autism as a lifelong neurodevelopmental condition. An autism diagnosis is attributed to children who present with support needs in two core domains including social interaction and communication, and restricted interests and repetitive behaviours (also called specialised, focused, or intense interests) (American Psychiatric Association, 2013; World Health Organization, 2018). Social and communication support needs comprise of delays in the use and understanding of spoken language and the need for additional support with non-verbal social skills such as eye-contact, gestures, body language, facial expression, difficulty in responding to, initiating, or understanding social interactions with peers and others, understanding of other people's feelings and emotions, and lack of imaginative and/or reciprocal social play (NICE, 2013, 2017). In addition, specialised, focused, or intense interests describe stereotyped motor movements, repetitive play patterns, resistance to change and/or new situations, environment, adherence to routines, and overreaction or underreaction to sensory stimuli (e.g., textures, sounds, smells, taste) (NICE, 2013, 2017).

Autism was first observed in the early 1940s. In 1943, Leo Kanner, a child psychiatrist, introduced the term “infantile autism” to describe children with a tendency to focus on objects with a “need for sameness” (Kanner, 1943). A year later, in 1944, Hans Asperger, a paediatrician, referred to autistic psychopathy describing four case studies of male children with similar autistic experiences and characteristics and focused on children’s strengths as well as their specific support needs (Asperger & Frith, 1991). A decade later, in 1952, the second version of the DSM recognised autism as a psychiatric condition of childhood schizophrenia (American Psychiatric Association, 1952). It was in the 1960s and 1970s that a growing body of research distinguished autism from schizophrenia reporting that there are neurodevelopmental underpinnings in autism (Rutter, 1978).

Autism was first listed in the ninth version of the International Classification of Diseases (ICD-9; World Health Organisation, 1977). It took 10 years to recognise autism as a distinct diagnostic category described as “pervasive developmental disorder” within the DSM-3 (American Psychiatric Association, 1980). In 1980, autism was defined by limitations in children up to 30 months with the following three essential characteristics: 1. Limited or lack of interest in humans; 2. Severe communication difficulties; and 3. Unusual response to the environment (American Psychiatric Association, 1980). In 1987, the DSM-3 further expanded the criteria for a pervasive developmental disorder diagnosis omitting the age requirement for the onset of specific autistic experiences and characteristics and clinicians were referring to pervasive developmental disorder-not otherwise specified (PDD-NOS) (American Psychiatric Association, 1987).

Five years later, the tenth revision of the International Classification of Diseases manual (ICD-10; World Health Organisation, 1992) referred to “pervasive developmental disorder” (PDD) to categorise in one group a diagnosis relating to the autism spectrum. The terms pervasive developmental disorder and autism spectrum disorder (excluding Rett’s syndrome) were regarded as conveying the same meaning. In ICD-10, the autism diagnosis has been based on support needs in three core domains: 1. Social; 2. Communication; and 3. Stereotyped and repetitive behaviours (also called specialised, focused, or intense interests). The “triad of impairments (or

support needs)” was first suggested by Wing and Gould (1979). Wing and Gould conducted an epidemiological study screening children who were registered in social services in Camberwell for having a physical or mental ill health or behaviour disturbances and met the following criteria: 1. Absence or limited social interaction with peers; 2. Absence or limited verbal or nonverbal language skills; and 3. specialised, focused, or intense interests. They reported that 21 per 10,000 children under the age of 15 years old were autistic. This study was also the pillar of the proposed relationship between limited or lack of imagination with specialised, focused, or intense interests which was later supported by established autism researchers (Frith, 1989b; Happé, 1994).

Autism was first described as a spectrum disorder in DSM-4 (American Psychiatric Association, 1994; 2000). Autism Spectrum Disorders (known as ASD) were characterised by difficulties in communication, social relationships, as well as inflexibility of thought and action – and these were known as the “triad of impairments” at the heart of the autism diagnostic criteria (American Psychiatric Association, 2000). The manual included five conditions with distinct characteristics. These were the following: 1. Autism; 2. PDD-NOS; 3. Asperger’s disorder; 4. Childhood disintegrative disorder (CDD); 5. Rett Syndrome. The concept of autism as a spectrum condition emphasised the variability of the autistic experiences and characteristics. For example, Asperger’s disorder referred to individuals with a specialised interest in particular topics, which led to the popular misconception that all individuals with Asperger were savants (American Psychiatric Association, 2000). CDD was defined as severe regressions in a range of skills including language, social skills, play skills, motor skills, cognition and bladder or bowel control (American Psychiatric Association, 2000). Finally, Rett syndrome was a genetic condition that was more common in girls with language and coordination support needs and specialised, focused, or intense interests. Children with Rett syndrome often presented with slower growth, difficulty in walking, and a smaller head size (American Psychiatric Association, 2000).

In 2013, DSM-5 introduced the concept of an autism spectrum after numerous research attempts to pinpoint the genes responsible for the onset of autism (American Psychiatric Association, 2013). The identification of hundreds of genes led to a

diagnostic entity that is more inclusive of the broad autism phenotype which describes individuals who exhibit variable needs ranging from mild, moderate, or more complex ones (American Psychiatric Association, 2013). Therefore, the autism spectrum diagnosis criteria were recently redefined by two broad categories: “persistent impairment (also called support needs) in reciprocal social communication and social interaction” and “restricted, repetitive patterns of behaviour (also called specialised, focused, or intense interests)” that were both present in early childhood (American Psychiatric Association, 2013). The conceptualisation of being autistic as a spectrum resulted in autism, Asperger’s disorder, PDD-NOS, CDD and Rett Syndrome (previously presented in DSM-4) to become redundant as discrete diagnostic entities which came under the umbrella term autism spectrum disorder.

The autism criteria change in DSM-5 in May 2013 stimulated a debate in academia, clinical practice, other practitioner groups and the autistic community. Clinicians raised their concerns related to a high threshold of diagnosis under DSM-5 for those who would have received an autism diagnosis under the DSM-4 criteria. These individuals were likely to lose access to specific support and/or services (Maenner et al., 2014). The first systematic review following the publication of DSM-5 in 2013 was published two years later (Smith, Reichow, & Volkmar, 2015). The review included 25 articles that evaluated whether individuals would be diagnosed as autistic according to the DSM-4 and DSM-5 criteria concluding that those children previously diagnosed with PDD-NOS or Asperger, or autistic disorder were likely not to receive an autism diagnosis based on the new DSM-5 classification system verifying the concerns raised by the autistic community, researchers, and practitioners. Although, it was clarified that previously diagnosed individuals will maintain their diagnosis and access to specific support and/or services will remain as usual, the future of newly diagnosed individuals based on the new system was uncertain. The long waiting lists in assessment clinics, the heterogeneous autistic experiences and characteristics that might delay a referral to an autism diagnostic clinic and challenges to access other services even with an autism diagnosis remained major concerns. According to the new DSM-5 criteria, autistic individuals with good educational attainments and no behaviour that challenges were also more likely not to be diagnosed at an early age

and have early access to support and/or services which is well reported having optimal outcomes in the future (Rogers & Vismara, 2008; Camarata, 2014; Charman, 2014). A systematic literature review and meta-analysis with 33 articles reported that one in five autistic children who would have been diagnosed under the DSM-4 criteria did not meet the DSM-5 criteria (Kulage et al., 2020). However, that population existed and was still in need of support to flourish and live independently but without a diagnosis they fell under the radar. Similarly to DSM-5, the proposed ICD-11 criteria (World Health Organisation, 2018) suggested an autism diagnosis to be organized by support in two core dimensions including “social-communication” to reflect the fact that social and communication support needs in ICD-10 were intertwined and “restricted and repetitive behaviour (also called specialised, focused, or intense interests)” which describes the need for additional support with changes and accommodation of specialised, focused, or intense interests, as well as sensory support needs. The ICD-11 came into effect in January 2022 and is commonly used by healthcare professionals throughout the rest of the world compared to the DSM that is predominantly used in the United States (US).

1.1.1 Prevalence of autism

For years, autism was considered to be a condition that was either present or absent. Prevalence was reported to be around 1 in 10,000 children (Rutter, 1978). Wing and Gould (1979) conducted an epidemiological study reporting that autism appeared to be more common than this affecting 21 in 10,000 children. In 1988, Wing’s contribution to autism was of utmost importance suggesting the term “autistic spectrum disorder” to reflect the fact that autism was a dimensional condition that presented in various degrees of severity (Wing, 1988).

Over the years, the research interest about the epidemiology of autism has been evolving. A comprehensive worldwide review of epidemiological studies starting from 1966 to 2011 gathered data from Northern Europe (e.g., United Kingdom, Sweden, Iceland, Denmark), Western Pacific/Southeast Asia (e.g., Japan, China, and Indonesia), America (e.g., United States and Canada), Southeast Asia (e.g., Sri Lanka) and Eastern Mediterranean (e.g., United Arab Emirates, Oman, Iran) reported that the median prevalence estimates of autism were 62 in 10,000 (Elsabbagh et al., 2012). A recently

published review on autism prevalence since 2014 showed that the median prevalence estimates were 1 in 1,000 (ranging from 0.19 in 1,000 in Germany to 7.26 in 1,000 in Sweden) and 6.16 in 1,000 for PDD-NOS (ranging from 3 in 1,000 in Denmark to 11.6 in 1,000 in United Kingdom) (Chiarotti & Venerosi, 2020). A US study reported the average autism prevalence in children under 8 years old to be 16.8 per 1,000 children with a range from 13.1 to 29.3 children in 1,000 (Baio et al., 2018). Another US study reported that the average autism prevalence in children aged 8 years in 2018 (born in 2010) was 23.0 per 1,000 children with a range from 16.5 to 38.9 children (Maenner et al., 2021). The variable findings in epidemiological studies highlight the variability of autism estimates worldwide. According to the Centre for Disease Control and Prevention (CDC; 2018), the autism prevalence was estimated to be 1 in 44 children compared to 1 in 54 children in 2016. A constellation of factors such as increased awareness among healthcare professionals, parents, and teachers as well as better diagnostic criteria appear to have contributed to the upward trend of autism worldwide over the years (Happé et al., 2016; Murphy et al., 2016).

A striking and consistent feature of autism is the fact that males are four times more likely to get diagnosed as autistic compared to females (American Psychiatric Association, 2013; Cooper, Smith, & Russell, 2018; Hull et al., 2019; Lawson et al., 2018; Maenner et al., 2021; Wood-Downie et al., 2021). The epidemiology of the 4:1 male to female ratio has been researched for years (Fombonne, 2009; Loomes, Hull, & Mandy, 2017). In addition, the ratio of sex bias increased to 7:1 for autistic children with limited to no additional needs decreased to 2:1 for those with moderate to profound intellectual disability (Fombonne, 2009). A recent systematic review and meta-analysis of 54 articles endorsed the current 4:1 male to female ratio report in DSM-5, although this reduced to 3.5:1 when considering methodologically high-quality studies only (Loomes, Hull, & Mandy, 2017). It is also well-documented in the literature that the currently used diagnostic and classification criteria have largely been shaped by researching autistic males (Kirkovski et al., 2013; Kopp & Gillberg, 2011; Mattila et al., 2011).

1.1.2 Aetiology of autism

The gradual rise in the prevalence of autism had led healthcare professionals and researchers to work together using technology (e.g., smartphones, tablets, machine learning) and conducting large population studies to better understand autism and the possible role of environmental factors in autism aetiology (Alcañiz et al., 2022; Georgescu et al., 2019; Simeoli et al., 2021). Concordance rates for autism appear to be higher for monozygotic than dizygotic twins (Bailey et al., 1995; Folstein & Rutter, 1977), indicating a strong genetic component. Multiple genes (Buxbaum, 2009) and genetic mutations (Leblond et al., 2014) have been identified to be a risk factor to autism. Previous twin studies reported 80% – 90% heritability of autism with minimal environmental contribution to its aetiology (Bailey et al., 1995; Constantino & Todd, 2005; Ronald & Hoekstra, 2011). However, recent studies emphasised that up to 50% of variance in autism diagnosis is determined by environmental risk factors (Deng et al., 2015; Edelson, Ronald, & Saudino, 2009; Gaugler et al., 2014; Hallmayer et al., 2011; Hoekstra et al., 2007; Stilp et al., 2010). Newer twin studies highlighted that concordance rates are more than 50% in monozygotic twins (Kim & Leventhal, 2015; Lichtenstein et al., 2010; Rosenberg et al., 2009). Therefore, the extent to which environmental risk factors are also involved is still questionable. There is evidence that the increase in autism prevalence is associated with known environmental risk factors, including parental age at the time of conception, prenatal exposure to air pollution or certain pesticides, premature birth, or low birth weight as well as any birth difficulty leading to periods of oxygen deprivation to the baby's brain (Modabbernia, Velthorst, & Reichenberg, 2017). Finally, the association of nutrition (e.g., folic acid, omega 3) and the increased likelihood of being autistic has been inconclusive, but it was noted that autistic people tend to have deficiency in vitamin D (Modabbernia, Velthorst, & Reichenberg, 2017). Overall, the interplay among environmental risk factors appears to increase the likelihood of being autistic in children when combined with genetic risk factors, but these factors alone are unlikely to cause autism.

1.1.3 Early recognition of autism

Over the years there has been progress in the National Health Service (NHS) child and adolescent mental health services to establish multi-disciplinary teams that aim to improve the recognition of specific autistic experiences and characteristics in children from an early age, enhance the referral process, accelerate the diagnostic process, and recognise the need for specific support and/or services (NICE, 2017). In the past, research reported that autism could be diagnosed in 24-month-old infants (Johnson et al., 2007). Recent work reported that it is feasible to diagnose autism in toddlers aged 18-months (Dawson et al., 2010). However, a recent meta-analysis conducted with 66,966 autistic individuals from 35 countries (covering a study period from 2012 to 2019) reported that the mean age of diagnosis was five years old (range: 2.5 – 19.5 years old) (van't Hof et al., 2021).

Waiting times from referral to an autism assessment had been reported being 6 – 7 months and referral until receipt of an autism diagnosis for children and adolescents in the United Kingdom (UK) was 9 – 11 months (McKenzie et al., 2015). The National Institute for Health and Care Excellence guidelines (NICE, 2017) had emphasised that the autism diagnostic assessment should start within three months since the receipt of a referral. However, there was no clear recommendation about the duration of an autism assessment that leads to diagnosis (NICE, 2017). A recent study highlighted an improvement in the waiting times between a referral and an autism assessment which has reduced to 10.4 weeks [compared to 6 – 7 months (equivalent of 21 – 25 weeks) in 2015 (McKenzie et al., 2015)], as per NICE guidelines recommendation (Rutherford et al., 2018) and the waiting time from a referral till an autism diagnosis was reported to be four months (Rutherford et al., 2018).

The most recent NICE guidelines also recommended that children as young as three years old should be referred to specialists if autism is suspected due to lack of support needs in social and communication skills as well as motor support needs (NICE, 2017). The latter is based in part on findings such as a recent longitudinal study reported that delayed development of fine motor skills might be a predictor of delayed expressive language development in autistic children that might persist until adulthood (Bal et al., 2020). Previous studies have repeatedly emphasised the close association of poor

motor skills in autistic infants as young as six months old and expressive language at 2 – 3 years old (Canu et al., 2021; Choi et al., 2018; Le Barton & Landa, 2019; Leonard et al., 2015). Therefore, such research findings highlight the importance of monitoring the development of infants including high-risk ones to be referred to an autism specialist team in a timely manner.

There has been a global and national emphasis to recognise autism as early in a child's life as possible so they can access support and/or services early in their lives too (WHO, 2014; NICE, 2017). Early recognition of autism and early access to support and/or services has been identified to have positive outcomes in children's language and cognitive skills (Clark et al., 2018; Dawson & Burner, 2011). An autism diagnosis requires a multidisciplinary group of professionals including a paediatrician, speech and language therapist and a clinical and/or educational psychologist to work collaboratively with a neurologist, occupational therapist and/or psychiatrist to review referrals, discuss the needs of the individual following diagnosis and/or signpost autistic children and their parents/carers to relevant services for additional support (NICE, 2017). Enabling access to autism specific support and/or services in early life aims to enhance the autistic child's quality of life short-term which, if sustained, it could potentially impact the life of the autistic young person or adult long-term (NICE, 2017). Indeed, many countries promote early access to support and/or services for autistic children, and often recommend that each autistic child should receive a minimum of 20 – 25 hours of intervention per week (Ministries of Health and Education, 2016; NICE, 2013, 2017; National Research Council, 2001).

1.1.4 Specific autistic experiences and characteristics in daily life

Autism is a spectrum condition associated with several co-occurring conditions (Tye et al., 2019). A recent study from the Autism and Developmental Disabilities Monitoring Network reported over 95% of autistic children present with at least one co-occurring condition (Soke et al., 2018). Epidemiological studies have also reported that there are 51% – 70% of autistic children with intellectual disability (intelligent quotient [IQ] below 70) (Charman et al., 2011; Isaksen et al., 2013; Loomes, Hull, & Mandy, 2017; Mandell et al., 2012; Matson & Kozlowski, 2011). Autistic children often present with additional support needs including attention deficit hyperactivity

disorder (ADHD – 78%), oppositional defiant disorder (58%) and anxiety (56%) (Brookman-Frazee et al., 2018; Rydzewska et al., 2018). In adult life, common co-occurring conditions include mental ill health in 33% of the autistic adult population followed by intellectual disabilities (29%), sensory support needs (12% visual and 14% hearing support needs) and physical disability (24%) (Rydzewska et al., 2018).

Autistic children often present with behaviour that challenges. Parents of autistic children aged 3 – 18 years described behaviour that challenges containing verbal and physical aggressive behaviour to others, antisocial behaviour (e.g., damage property), meltdowns, sensory (e.g., skin-picking, nail-biting, chewing clothes) and/or physical arousal (e.g., increased levels of activity, nervous behaviour, tearful), social and emotional withdrawal, somatic behaviours (e.g., sleep), specialised, focused, or intense interests (Bearss et al., 2016; Ozsivadjian et al., 2012). Disruptive behaviour impacts the well-being of autistic children and their primary carers (often being family members) responsible for their safety (Lovell & Wetherell, 2015; O’Nions et al., 2018).

After many years of research, autism is perceived as a social identity (Cooper et al., 2023; Cooper, Smith & Russel, 2017). Parenting an autistic child can be a rewarding experience if autistic experiences and characteristics are embraced and perceived as part of the child’s identity. There is evidence that autism acceptance from the self, the family and the wider context is associated with better mental health in autistic people and their family carers (Cage, Di Monaco & Newell, 2028; Corden, Brewer & Cage, 2021; Cooper, Smith & Russel, 2017; Da Paz et al., 2018). There is also evidence that autistic people experience positive feelings when connected with other autistic people (Crompton et al., 2020; Milton & Sims, 2016). These positive processes are the outcome of a collective, stepwise approach to enhance our understanding and break the stigma of being autistic.

During COVID-19, the introduction of remote access to support (e.g., clinical, educational, social care) appeared to act as a protective factor for autistic children’s and their carers’ quality of life (Logrieco et al., 2022). During lockdowns, some carers increased the level of engagement with their autistic children that might explain the improved perception of carers about their child’s skills, the better engagement in joint

activities, the increased opportunities for play and more time for physical exercise in a safe and stable context (e.g., at home, outside, with family or other carers) (Logrieco et al., 2022). These are indicators of the importance of an adaptive and responsive social care context to support families, autistic children, and the wider context (e.g., professionals working or having access to equipment remotely) on an ongoing basis.

Inevitably, parenting an autistic child may also be a demanding task because it requires ongoing adaptations to the child's needs and preferences for rigid routines such as eating the same dinner every night or following rituals before bedtime (Adams et al., 2019; O'Nions et al., 2018) (see Figure 1.1). In addition, forward planning to eliminate the occurrence of unexpected events (e.g., unexpected visitors at home) or sensory stimulation (e.g., shopping over the weekend is busy and crowded) is often a mentally exhausting activity for parents who modify their lives to accommodate their child's needs (Adams et al., 2019; O'Nions et al., 2018). For example, daily tasks including dressing up, shopping, preparing for activities, or visiting a restaurant require parents of autistic children to be more vigilant (Adams et al., 2019; O'Nions et al., 2018). That is because their children might have daily living support needs and might present impulsive behaviour which often mandates timely parental support to avoid escalation such as behaviour that challenges (Adams et al., 2019; O'Nions et al., 2018). Therefore, parents are more likely to request access to respite care and adjust and/or end their employment to look after their autistic children compared to parents of non-autistic children (Shorey et al., 2020). Nonetheless, in the literature, it has been documented that working mothers of autistic children value the importance of employment which they described as improving their mental well-being, giving them a sense of purpose, and making them feel "normal" again (McCabe, 2010; Shorey et al., 2020).

There are also concerns that autistic children are more likely to be absent from school more often compared to neurotypical peers (Adams, 2021; Ingul, Havik, & Heyne, 2019; Pas et al., 2016). Previous research described that on average autistic children miss 22% of school days (five days out of 23) (Totsika et al., 2020). More importantly, persistent absence which is defined as missing 10% or more of available school sessions (Department for Education, 2019) occurred for over 40% of autistic

children (Totsika et al., 2020). Refusal of going to school has been reported being the most prevalent reason autistic children miss school (Totsika et al., 2020) which is often correlated with anxiety or depression (Munkuhaugen et al., 2019). Previous research described that the sensory demands (e.g., noise, uniform), performance demands (e.g., tests), social anxiety and unexpected events are common triggers of anxiety in autistic children (Adams et al., 2019; Magiati et al., 2016; Neil, Olsson, & Pellicano, 2016; Simpson et al., 2020). Therefore, the overall school experience appears to be a challenging routine for some autistic children with unpredictable implications in future life.



Figure 1.1 *Spheres of impact on parenting experience*

Autistic children with additional needs (e.g., intellectual disability, ADHD, anxiety) are more likely to be in contact with health and social care services. It is imperative to examine and understand the way autistic experiences and characteristics vary across the spectrum and provide practical recommendations for those who work with autistic children (Dingfelder & Mandell, 2011; Long et al., 2017). Early recognition of autism has also a public health benefit. As described in this chapter, autism is a lifelong

condition that impacts multiple life aspects of the autistic individual and the family environment. Apart from the costs of healthcare services, there are hidden costs related to formal and informal care and support, education, and employment which impact the functioning of the wider society. The cost of hospital and community healthcare services in preschool autistic children was estimated to be equivalent of £430 per child per month (Barrett et al., 2012). The cost of raising (e.g., toys, diet, training courses, house/room repairs and adaptations, personalised material, not working/time off work because of the child's condition) a young autistic child aged 2 – 5 years in England was estimated to be equivalent of £500 per month (Barrett et al., 2012).

Mental ill health, intellectual disability, sensory support needs, and physical disability as co-occurring conditions may exacerbate communication and interaction support needs in autistic children and young people, and this is likely to have a substantial impact on family and peer relationships, academic performance, and future employment (Simpson et al., 2020). Social relationships and well-being, employment and active participation in the society have been reported to be positive predictors of a good quality of life in autistic people (Mason et al., 2018). The World Health Organization (WHO) defined quality of life as a subjective appraisal of the person's relationship to the world related to its physical, psychological, social and environmental well-being (WHO, 1998). There is evidence in the literature that autistic adults typically report lower levels of satisfaction with life compared to neurotypical adults (Ayres et al., 2018; Van Heijst & Geurts, 2015).

Autism is described as multifaceted and heterogenous because each autistic individual has different experiences and characteristics that affect multiple aspects of life. A Swedish longitudinal study which followed 50 male autistic adults for 20 years (from 10 years old till 30 years old) reported that 62% of male autistic adults were living independently or in shared accommodation with a friend and/or partner, 24% were living in supported accommodation and 14% were still living with their parents (Helles et al., 2017). More recently, the Office for National Statistics reported that 75% of autistic adults aged 16 – 64 years were living with parents compared to 19% of non-disabled people (Coates, 2021). Approximately 50% of male autistic adults had 1 – 2

friends compared to 23% of male autistic adults who reported having no friends (Helles et al., 2017). In addition, almost 50% of male autistic adults had no experience of a romantic relationship (e.g., being in a relationship or married) compared to 22% who were single but with prior experience of romantic relationships (Helles et al., 2017). Therefore, autistic adults appear to be more likely to need additional support throughout different aspects of their life. These data also indicate that a residential care home facility in autistic adults might be imperative due to the need for intensive support that the family environment might not be able to provide which in turn is financially costly for the family and the society, as presented earlier (Chasson, Harris, & Neely, 2007; Cimera & Cowan, 2009).

Research studies also report the social inequalities of autistic people nowadays. It is important to emphasise that only 13% of autistic male adults were university students and/or had graduated with a university degree compared to 28% who had dropped out from higher education (Helles et al., 2017). In addition, 69% of male autistic adults were students and/or in paid employment (Helles et al., 2017). The Office for National Statistics summarised that 21.7% autistic people aged 16 – 64 years were in paid employment compared to 83% of non-disabled people in the UK (Coates, 2021). However, research indicates that autistic people tended to be employed on less qualified jobs than their skills and on part-time contracts compared to their peers without autism (Harvery et al., 2021).

Autistic children often have increased number of medical appointments with paediatricians, neurologists, psychologists, and psychiatrists compared to neurotypical children to prescribe and/or monitor medication related to co-occurring conditions (Rogge & Janssen, 2019). Medical appointments and care costs also increase as autistic children transition into adulthood (Rogge & Janssen, 2019). The latest data from the Assuring Transformation NHS dataset reported that approximately 14% of inpatient mental health admissions included autistic children and young people under 18 years of age (NHS Digital, 2022). A recent German study reported that the annual cost per admission for an autistic individual (age range: 4 – 67 years old) was €3,287 of which 12% included costs related to inpatient admission, 11% for polypharmacy and 12% for occupational therapy (Höfer et al., 2022). This

finding is also an indicator of the autistic person's life expectancy as a result of polypharmacy and the likelihood of adverse events (NICE, 2018). Research has also shown that the average age of death of autistic individuals in a 20-year study period was 58 years old whereas for those with an intellectual disability and autism was 39 years old (range: 18 – 65 years old) in the US (Smith DaWalt et al., 2019). A Swedish study which examined the national patient register from 1987 till 2009 study reported that autistic adults died on average at 54 years old whereas non-autistic adults died at a mean age of 70 years old (Hirvikoski et al., 2016). Similarly, an Australian study of almost 36,000 autistic people aged 5 – 64 years who died between 2001 to 2015 reported that the median mortality age of autistic people and/or those with an intellectual disability was 35 years old (age range: 20 – 53 years old) compared to 52 years old (45 – 58 years old) in neurotypical adults with a reported reason of death (Hwang et al., 2019). In England, the LeDeR report (Learning from lives and deaths – People with a learning disability and autistic people) published national mortality data on 3,304 autistic adults and adults with intellectual disability reporting the median age at death being 61 years old in 2021 (White et al., 2022). The global life expectancy is estimated to be 73 years old (United Nations, 2019). The most common reasons of mortality in autistic individuals were the following: 1. Chronic illness (e.g., seizures, cancer); 2. Accidents (e.g., poisoning, choking on food); and 3. Adverse reaction to medication (Hwang et al., 2019; Smith DaWalt et al., 2019).

1.2 Conceptualising autism

The most well-known and researched, yet controversial, theory for conceptualising autism is the theory of mind (Baron-Cohen, 1995, 2000a). The theory of mind (or mindblindness theory) proposes that autistic people find it hard to show empathy and understand other people's emotions, beliefs, intentions, and mental state (Baron-Cohen, 2000a). This theory has led to ongoing misinterpretations that autistic people are uncaring. However, research suggests that theory of mind changes over time in autistic people (Pellicano et al., 2010) and older autistic people respond differently in theory of mind tests as a result of ageing and (possible) deterioration of executive functioning skills (Cho & Cohen, 2019; Scheeren et al., 2013). The theory of mind concept may, however, to some extent justify the social and communication support

needs (e.g., cognitive empathy) in autistic people. Two key limitations of this model are nonetheless the lack of consideration of emotional empathy (Holm, 1999) and that the theory of mind is not autism specific because lack of empathy is seen in other conditions [schizophrenia (Sprong et al., 2007), borderline personality disorder (Nemeth et al., 2018) or conduct disorder (Happé & Frith, 1996)]. It is risky to state that due to scoring less well in a theory of mind test autistic people cannot understand others have a different view, belief, information, emotions. The human brain is so complex, the world is perceived by autistic people as busy and chaotic and other individual (e.g., sensory processing, auditory processing) factors may also be responsible for autistic children's response to a test. It is also important to emphasise that these tests are likely to have been developed by neurotypical researchers and/or clinicians or at least there is no reference that an autistic researcher and/or clinician has been involved in the development of these tests.

To address the limitations of the theory of mind theory, the empathising – systemising theory was developed. This addressed the distinction between cognitive and emotional empathy (Baron–Cohen, 2002). This theory proposes fundamental differences in the brain of autistic males and females (Baron-Cohen, 2002). Baron-Cohen (2002) suggested that, in general, females tend to “empathise” and succeed in social intelligence tests whereas males tend to “systemise”, abide by the rules, and excel in pattern recognition. The empathising – systemising theory is more analytic in the sense that it addresses the specific autistic experiences and characteristics in social and communication support (below average empathy) and specialised, focused, or intense interests (average or above average systemising; keeping things consistent and predictable; attention to detail skills). As the theory proposes, autistic people systemise very well but transferring knowledge from one context/situation to another may require additional effort and/or support because there might be minimal differences and consequently less predictability in new environments. The theory received criticism because it may not have portrayed all autistic people. First, it puts males (systemising) and females (emphathising) into categories instead of embracing autistic people as humans who experience the world differently. This narrative creates further confusion and intensifies stigma taking for granted that autistic people have

inherently poor social and communications skills and enjoy technology, gadgets, maths that may provide a sense of security, control, and predictability. In addition, some autistic people may “systemise”, not to abide by the rules, but instead to calm and pleasure themselves from the knowledge that a certain behaviour/movement will lead to a certain positive and/or familiar experience. That may explain stimming behaviour and/or routines which offer comfort at challenging and/or uncomfortable times for all people, including autistic people (Kapp et al., 2019).

The extreme male brain theory extends the empathising – systemising theory challenging the fundamental brain and sex differences in autism (Baron-Cohen, 2002). It proposes that autistic people, regardless of their sex, tend to fall on the systemising end and score less well on empathy (Baron-Cohen, 2002; Greenberg et al., 2018). Scoring less well on empathy simply indicates that autistic people need support with the cognitive elements of empathy (i.e., theory of mind). That explains the reason autistic people might be confused and/or upset with different social rules per context (Greenberg et al., 2018). There is, however, evidence that autistic people score well on tests related to emotional empathy (Dzioben et al., 2008; Rueda, Fernández-Berrocal, & Baron-Cohen, 2015). Some of the criticism the extreme male brain theory has received is presented below. First, the questionnaires tested the theory focused a lot on gender stereotypes without taking into consideration the effect of social, cultural, and contextual factors as well as that most research studies are male oriented. Therefore, females were (unintentionally) excluded from previous studies to explore this theory. In addition, it is likely that there are minimal, not measurable differences, in the social and communication support needs of males and females. Taking into consideration the male bias in research and the different autism presentation in females, it is hard to pinpoint from this theory if nature or nurture may be the reason for the social and communication support needs. There is evidence that the social context and gender stereotypes influence the choices of young children aged 3 – 5 years when it comes to selection of activities/toys, colours, occupations, and subsequent skill acquisition (King et al., 2021). The social context influences autistic children as well. The theory also fails to address that autistic people, regardless of their gender, may be able to both empathise and systemise. Finally, it has been

observed there is lack of theory replication from independent researchers because most of the bibliography derives from Prof Simon Baron-Cohen's students and/or colleagues. It is, therefore, likely that there are shared interests and a common way of thinking and perceiving autism that may not be always attuned to the real autistic experience.

The Weak Central Cohesion theory proposes that autistic people find it hard to incorporate information from a mass of details to understand the environment due to their strong attention to detail skills (Frith, 1989a, 2003). This theory shifts attention from the support needs of autistic people as it is introducing us to the strengths of being autistic. This theory may explain the reason autistic people may need support to conceptualise the gist of a long story and/or a film, but it may be easier to develop their mathematical or scientific skills. The Weak Central Cohesion theory is somehow linked with the theory of mind. To understand the views, thoughts and feelings of other people, a person needs to process, analyse, and integrate a mass of information such as the context, the culture, the timing, the state of the person and other factors to make sense of it. On a similar note, the Weak Central Cohesion theory may also be related to the emphasising – systemising theory because attention to detail is a core skill indicating that autistic people can successfully handle mass of information to systemise. Most of the evidence on this theory is conducted with autistic people (Joliffe & Baron-Cohen, 1999; Caron et al., 2006; Pellicano et al., 2006; Ropar & Mitchell, 2001; Shah & Frith, 1983, 1993) reporting mixed findings whereas studies that compared autistic people with non-autistic people reported no differences in visual processing (Joliffe & Baron-Cohen, 2001; Ozonoff, Pennington, & Rogers, 1991). The failure of the theory to generate consistent evidence questions its credibility to be a universal theory that captures all autistic individuals.

The ongoing attempt to better understand sex differences in autism has led to the female protective effect theory (Jacquemont et al., 2014). The theory proposes that females are “protected”, without specifying by which biological protective factor(s), presenting with fewer autistic experiences and characteristics compared to males because females need to inherit more gene mutations and be exposed to more environmental risk factors (Jacquemont et al., 2014). This theory is argued to support

the evidence around the 4:1 male to female ratio (Fombonne, 2009; Loomes, Hull, & Mandy, 2017). There is, however, epidemiological data from national registries in Sweden looking at data over a period of 10 years reporting that this theory cannot explain the sex imbalance in autism diagnoses (Bai et al., 2020). The key limitation of this theory is the fact that the existing evidence derives from autistic females who meet the diagnostic criteria based on the current diagnostic tools. As described earlier, autistic females are less likely to get diagnosed compared to autistic males due to the male bias in diagnostic tools. As a result, it is likely that undiagnosed autistic females may demonstrate differences in their genetic profile and/or behavioural presentation to those diagnosed autistic females. Therefore, the organization of the theory is questionable until there is substantial evidence that it applies to all (or a representative sample) of autistic females.

The female autism phenotype theory suggests that there is a different presentation of autistic experiences and characteristics in females compared to males which might provide an explanation for the delayed diagnosis in females (Begeer et al., 2013; Hull, Mandy & Petrides, 2017; Kirkovski et al., 2013; Kopp & Gillberg, 1992; Russell, Steer & Golding, 2011; Rutherford et al., 2016). There is evidence that autistic females may camouflage some of their support needs learning to establish eye-contact, interact in a “socially accepted” manner, empathise with others, be more facially expressive (Auyeung et al., 2009; Dworzynski et al., 2012; Lai et al., 2011, 2015). There is also evidence that autistic females seek and receive a diagnosis in adult life reinforcing the argument about autism camouflaging in females (Happé et al., 2016). Therefore, it looks like diagnostic procedures are established on pre-conceived ideas about autistic experiences and characteristics. This indicates it might be more challenging to identify autistic females especially those without intellectual disability not taking into consideration that autistic experiences and characteristics might be slightly different in females (Hull, Mandy & Petrides, 2017; Russell, Steer & Golding, 2011; Van Wijngaarden-Cremers et al., 2014).

Although the theories discussed above aim to help understand autism, some of these have contributed to the medicalisation of autism meaning that autism has been viewed as a constellation of social, cognitive, emotional, motor “deficits and/or a

disorder". This has contributed to stigmatisation as a sense that autistic individuals should adapt to the norms of society rather than society genuinely being inclusive. As a response to the medical model, the neurodiversity paradigm has been critical in shifting the way autism is positioned in society. Neurodiversity is situated in the social model of disability (see chapter 8.5) recognises that diversity in minds is a good thing. Over the past decade, there has been a critical shift to reflect on language use, definitions, research priorities and clinical practices stemming from this shift and location in the social model of disability (Roche, Adams, & Clark, 2021). That is to reduce stigma of viewing autistic individuals from the lens of impairment, deficit, intervention but instead to understand that we are all diverse in our own way, and the guiding approach should be the one of inclusion and acceptance. The emphasis is not on normalising individuals and/or their behaviour, but on celebrating and valuing diversity. Still, many of the approaches to supporting autistic individuals in fulfilling their potential has been based on earlier conceptualisations of normalising behaviour, reducing deficits and alike. The majority of support mechanisms have, as advocated for in current guidelines, been psychosocial.

1.3 Psychosocial support in autism

Despite the lifelong character of autism, support is limited worldwide (Howard, Gibson, & Katsos, 2021; Mandy, 2022). In the UK, the National Institute for Health and Care Excellence suggests psychosocial support as best practice to support autistic children whereas medical support is primarily directed to target co-occurring conditions (i.e., irritability, lack of concentration, anxiety) (NICE, 2013). Psychosocial support aims to support autistic children to live independently either working through parents, carers, teachers, and the wider environment or directly with the autistic child (Reichow et al., 2012; Reichow & Wolery, 2009; Seida et al., 2009).

Psychosocial support is not routinely delivered within the NHS in the UK. There might be occasions that the autistic child might receive occupational therapy, speech, and language therapy and/or mental health support, if a GP or the assessment team refer the child to a specialist (NHS, 2022). Publicly funded support and/or services are usually covered from education budgets and provided within a school setting for a restricted number of sessions (6 – 12 sessions) (NICE, 2021). Alternatively, support for

autistic children and their carers is sought via charities, local support groups, and/or online forums/groups (NHS, 2022). There is evidence that autistic children need at least 20 – 25 hours per week of autism specific support to obtain any long-term gains (Ministries of Health and Education, 2016; NICE, 2013; Johnson & Myers, 2007; National Research Council, 2001).

Psychosocial support aims to enhance the social and communication support needs and minimise behaviour that challenges in autism. Generally, there is weak evidence for the relative effectiveness of psychosocial support due to lack of robust research designs (Howard, Gibson, & Katsos, 2021; Mandy, 2022). Most studies, however, highlight the positive outcomes of psychosocial support suggesting that some form of support is favourable over no support at all (Makrygianni & Reed, 2010; Rao et al., 2008; Warren et al., 2011). The heterogeneity, however, of autistic experiences and characteristics highlights the need for multiple and flexible support and/or services adaptable to the needs of autistic children (Crowe & Salt, 2015).

Research suggests that early recognition of being autistic and access to early support and/or services acknowledging the support needs of autistic children and young people might significantly enhance their subsequent quality of life (Lovaas, 1987; National Research Council, 2001; Rogers & Vismara, 2008). Substantial evidence reports that autistic children need support with multisensory processing (Redcay & Courchesne, 2008; Stevenson et al., 2014), face recognition (Gunji et al., 2013; Klin et al., 2002; Luyster et al., 2014; Pelphrey et al., 2002), eye-contact (Klin et al., 2002; Pelphrey et al., 2002; Elsabbagh et al., 2012; Jones & Klin, 2013; Von dem Hagen et al., 2013), joint attention (Charman, 2003; Charman et al., 2000; Morgan, Maybery, & Durkin, 2003; Mundy & Jarrold, 2010; Redcay et al., 2013), and empathy (i.e., ability to differentiate the difference between their own knowledge and that of the others) (Baron-Cohen et al., 1985; Happé, 1995; Charman et al., 2000).

Dr Stephen Shore, an autistic professor of special education in the US, has used the following quote to describe autism *“If you’ve met one individual with autism, you’ve met one individual with autism”* (Flannery & Wisner-Carlson, 2020). This quote encompasses the diversity of autism as a spectrum condition. Autism differs because

its main characteristics blend together in a different way in each person in certain domains of life that change as people age.

The need for ongoing support to autistic people (e.g., access to specific support and/or services) should then remain a priority to the research and clinical community as well as policy makers. The recognition of specific autistic experiences and characteristics over the course of life is not a justification for reducing the level of support and/or services to autistic adolescents and adults who may still require additional support from others on a daily basis (Monz et al., 2019). On the contrary, longitudinal studies give greater incentive to extend specific support and/or services for autistic adolescents and adults across the life course. It is imperative to recognise that as autism is a lifelong condition so autism specific support and/or services should be available into adulthood.

What follows is an overview of available support for autistic children as per current practice. There is substantial evidence reporting that Applied Behaviour Analysis (ABA) is the gold standard support for autism (Fein et al., 2013). ABA is defined by systematic strategies such as prompting and reinforcing at an early stage of the autistic child's life usually before the age of three years that is guided by an ABA-certified professional in a one-to-one and/or group setting (Lindgren & Doobay, 2011). Although ABA has attracted criticism from the neurodivergent community because of the negative outlook of the approach (McGill & Robinson, 2020), several services incorporate these practices to support the social and communication needs of autistic children (Spreckley & Boyd, 2009). There are no longitudinal studies supporting the long-term impact of ABA. Conversely, there have been testimonials from autism advocates, many of whom were recipients of ABA in childhood, that ABA is inhumane and harmful (Leaf et al., 2022). Despite this, ABA-influenced support is incorporated in a number of autism specific support including, but not limited to:

1. Pivotal Response Training

Pivotal Response Training (PRT) is a naturalistic play-based interactive approach that targets pivotal areas of a child's development such as motivation, self-management, and social initiations (Koegel et al., 1999). PRT aims to create learning opportunities

by following the child's specialised, focused, or intense interests, attracting the child's attention, and providing immediate reinforcement in response to the child's initiations and/or attempts to make initiations with the aim to acquire and establish a new skill (Koegel & Koegel, 2006, 2016). Over the years, systematic reviews have emphasised the positive impact of PRT in autistic children in expressive language, social interaction, and specialised, focused, or intense interests (Ona et al., 2020; Verschuur et al., 2014).

2. Discrete Trial Training

Discrete Trial Training (DTT) is an intensive behavioural approach focused on the analysis of skills into small elements and units consisting of a series of direct, systematic instructions, used repeatedly until the child acquires the skill (Lovaas, 1987; Smith, 2001). A number of studies reported better non-verbal and verbal communication, social interaction, and academic attainment (Downs et al., 2008; Holding, Bray, & Kehle, 2011; Tsiouri, Schoen Simmons, & Paul, 2012; Turner, 2011).

3. Early Start Denver Model

The Early Start Denver Model (ESDM; Rogers & Dawson, 2009) is a manualised early support that promotes the active involvement of parents to empower them to capture the child's attention before an instruction, embed teaching in play (Rogers et al., 2012). A recent meta-analysis reported that autistic children who received ESDM showed better cognitive and language skills, but no significant changes in social and communication skills (Fuller et al., 2020).

4. Early Intensive Behaviour Intervention

The Early Intensive Behavioural Intervention (EIBI) includes breaking down complex instructions in smaller components while rewarding the autistic child during learning (Lovaas, 1981, 1987, 2003). Research suggests that supporting autistic children younger than four years old while involving parents/carers up to 40 hours per week in one-to-one sessions brings positive outcomes in domains of independent living and social and communication (Eldevik et al., 2009, 2010). Systematic reviews and meta-

analyses have emphasised the effectiveness of EIBI over the years (Reichow & Wolery, 2009; Reichow, Steiner, & Volkmar 2012).

5. Picture Exchange Communication System

The Picture Exchange Communication System (PECS; Frost & Bondy, 2002) is a well-known manualised behavioural approach that is focused heavily on symbols to support spontaneous communication and facilitate social interaction in children who speak few or no words (Rutherford et al., 2020). It aims to support the autistic child to understand social situations, interact with others and develop coping strategies in challenging social situations (Flippin, Reszka, & Watson, 2010). It is widely used across different settings (e.g., schools, clinics, home) (Howlin et al., 2007). The success of the PECS depends on the competency of those using it to facilitate interaction via symbols (Ameis et al., 2018). Systematic reviews and meta-analyses have reported the gains of the PECS in the social and communication support needs of autistic children (Flippin, Reszka, & Watson, 2010; Mahoney et al., 2018).

6. Functional Communication Training

Functional Communication Training (FCT) supports autistic children to identify a communicative response to replace behaviour that challenges that serves the same function (Carr & Durand, 1985; Hanley et al., 2001; Reichle & Waker, 2017; Tiger et al., 2008). FCT involves interviewing parents, teachers and carers followed by observation of the child in naturalistic settings to identify the function of a behaviour that challenges to complete a functional analysis of a behavior (Mancil, 2006). Research reports the positive effect of FCT on minimising behaviour that challenges (Falcomata et al., 2018; Fisher et al., 2018; Lindgren et al., 2016; O'Brien et al., 2021).

7. Social Skills Training

Social Skills Training (SST) provides a safe and structured environment for children to interact and communicate with peers (Laugeson et al., 2009; Soares et al., 2021). Systematic reviews and meta-analyses have emphasised the effect of SST in autistic children to enhance their social skills, problem-solve and form friendships (Gates et al., 2017; Reichow, Steiner, & Volkmar 2012).

8. The Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH)

The Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH; Mesibov et al., 2004) is a multidisciplinary programme suggested by the National Institute for Health and Care Excellence guidelines for autistic children (NICE, 2021). The TEACCH provides a structured and consistent environment to practice everyday activities aiming to initiate communication and regulate emotional response in autistic children (Zeng et al., 2021). It is often implemented in educational settings but later transferred across different environments including the home and the community. The TEACCH programme puts emphasis on the use of pictorial prompts and cues to support the autistic child change activities (Sanz-Cervera et al., 2018). There is evidence that the TEACCH supports the social and communication skills and emotional regulation in autistic children (Rutherford et al., 2019; Yu & Zhu, 2018; Virues-Ortega, Julio, & Pastor-Barriuso, 2013).

9. The Social-Communication, Emotional Regulation, and Transactional Support model (SCERTS)

The Social-Communication, Emotional Regulation, and Transactional Support model (SCERTS) (Prizant et al., 2006) is a multidisciplinary programme suggested by the National Institute for Health and Care Excellence guidelines for autistic children (NICE, 2021). The SCERTS provides a structured and consistent environment to practice everyday activities aiming to initiate communication and regulate emotional response in autistic children (Zeng et al., 2021). It is often implemented in educational settings but later transferred across different environments including the home and the community. The SCERTS model is an innovative educational model that is focused on prioritising goals in social communication and emotional regulation through implementation of transactional support throughout the autistic child's daily activities with support from an adult who facilitates the child to be a more competent social partner (Rutherford et al., 2019; Yu & Zhu, 2018). There is evidence that the SCERTS programme supports the social and communication skills and emotional regulation in

autistic children (Rutherford et al., 2019; Yu & Zhu, 2018; Virues-Ortega, Julio, & Pastor-Barriuso, 2013).

With the increasing recognition of autistic children and the heterogeneity of their specific experiences and characteristics, there is a growing number of autism specific support indicating favourable but inconclusive outcomes. As a result, more high-quality research is needed to establish their effectiveness. These are listed below:

The Differential, Individual differences, Relationship-based (DIR) approach is based on understanding the child's behaviour with the aim to individualise and tailor the session (Boshoff et al., 2020). DIR may be referred to by other names such as Floortime (Mercer, 2017). DIR/Floortime seeks to support the development of social and communication skills in autistic children through intensive child-directed play and positive interactions (Boshoff et al., 2020). It is recommended that DIR/Floortime is integrated with other autism specific support (e.g., speech therapy and occupational therapy) (Boshoff et al., 2020). DIR/Floortime is intended for young autistic children but can be used in some form with all ages (Mercer, 2017). DIR/Floortime requires a certified trained professional to organise and deliver a session targeting the development of emotional and social skills during play (Thayer & Bloomfield, 2021). Research has shown improvements in social, emotional, and functional skills of autistic children (Casenhiser, Shanker, & Stieben, 2011; Dionne & Martini, 2011; Liao et al., 2014; Pajareya & Nopmaneejumrulers, 2011, 2012; Reiss, Pereira, & Almeida, 2018; Solomon et al., 2007, 2014). Overall, the criticism of DIR/Floortime is the low number of randomised controlled trials that present with a diverse methodological quality, an inconsistent framework of the session frequency and duration and lack of generalisability of the study findings to diverse socio-economic populations (Boshoff et al., 2020).

Play therapy is a structured autism specific support approach for autistic children delivered by trained play therapists to support domains of social and emotional development (Gallo-Lopez & Rubin, 2012; Ray, Sullivan, & Carlson, 2012). Unlike previously described autism specific support that focus on behaviour and stimuli, child-centred play therapy focuses on the importance of the relationship between the

child and the therapist to modify target behaviours (Ray, Sullivan, & Carlson, 2012). A recent systematic review with autistic children with additional needs (e.g., ADHD, Post-Traumatic Stress Disorder, anxiety, disruptive or aggressive behaviour but without intellectual disability) (Drisko et al., 2020) and a literature review with autistic children (Hillman, 2018) concluded promising findings in the social and emotional behaviour support needs of autistic children. However, more research is needed to determine its effect as current studies classify play therapy as a low to moderate approach in autism (Drisko et al., 2020).

Joint attention, symbolic play, engagement, and regulation (JASPER) is a semi-structured, naturalistic developmental behavioural specific support approach that can be delivered by parents/carers at home, trained professionals in clinics and/or educators in school (Kasari, Freeman, & Paparella, 2006, Kasari et al., 2010, 2014). JASPER involves preparing the environment, being alert to follow the child's lead, developing and/or maintaining an activity while modelling and training a skill (Kasari et al., 2010, 2014). A systematic review reported that JASPER supports the development of joint attention, engagement, social communication, and play skills via play in autistic children (Waddington et al., 2021). However, the quality of these studies is questionable due to lack of fidelity checks, inconsistent use of appropriate outcome measures, and a small sample size (Waddington et al., 2021).

There is a number of autism specific support well-known to parents/carers of autistic children that has not been thoroughly evaluated yet such as sensory integration, facilitated communication, music, art, animal therapy and hydrotherapy (Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006; Monz et al., 2019; Salomone et al., 2016).

Sensory integration for autistic children has been both popular and controversial. Many autistic children are believed to have a form of sensory neural dysfunction where the nervous system inefficiently receives and processes incoming information leading to hypersensitivity or hyposensitivity to sensory input, high or low activity levels, coordination issues, additional support with speech, motor skills, and/or behaviour (Schoen et al., 2019). Sensory integration is delivered by an occupational

therapist supporting via play the child's sensory and motor skills in an individual session (Schoen et al., 2019). A recent randomised controlled trial funded by the National Institute for Health Research reported no clinical effect of sensory integration therapy in autistic children aged 4 – 11 years compared to usual care (Randell et al., 2022).

Facilitated communication was designed to be an augmentative communication approach that involves the use of a "facilitator" who gently provides hand-over-hand physical assistance to individuals with disabilities as they type (or point to pictures) to communicate (Crossley, 1992; Ganz, 2014). Facilitated communication is a highly controversial technique due to concerns that the facilitator may actually guide the individual's responses (Mostert, 2014; Schlosser & Wendt, 2008; Singer et al., 2014). Anecdotal evidence only exists to support the effect of facilitated communication in autism (Biklen & Schubert, 1991; Biklen et al., 1992; Crossley, 1992), while blinded objective analyses have consistently failed to find empirical support for this approach (Ganz, Katsiyannis, & Morin, 2018).

Finally, music, art, animal therapy and hydrotherapy have strong advocates who emphasise their effect in autistic children. Systematic reviews on music, art, animal therapy and hydrotherapy indicate mixed results with positive outcomes in social and communication skills and behavioural regulation, but most studies are single case studies or include small sample sizes (D'Amico & Lalonde, 2017; Durrani, 2019; Hardy & Weston, 2020; Hill et al., 2019; LaGasse, 2017; Marino & Lilienfeld, 2021; Marquez-Garcia et al., 2021; Mills et al., 2020; Naumann et al., 2021; O'Haire, 2017; Schweizer et al., 2020). There is a need for additional scientific evidence to support these approaches.

1.4 Summary

This chapter highlighted that autism varies from one autistic child to another and differs across the lifespan. It also emphasised the need for early recognition and access to support and/or services. These will impact on the quality of life and mental well-being of autistic children (e.g., friends, school attendance, academic progress, independent living, work) and the surrounding environment. The theories conceptualising autism over the years and the direction towards ABA support has been criticised by the literature and autism advocates. After years of research, it is evident that there still appears to be inadequate support not only for autistic children but for parents/carers whom as primary caregivers are in charge of multiple responsibilities including identifying the appropriate support and/or services for their child's needs. Finally, the shift towards neurodiversity in society still needs to deepen amongst the public and professionals. This is an important step driving further change in the social position and support for autistic people and their families.

Chapter 2: Introduction

The previous chapter presented an overview of the key features and theories of autism and the psychosocial support available for autistic children. This chapter provides an overview of the use of technology with a particular emphasis on Socially Assistive Robots (SARs) with autistic children.

2.1 Socially Assistive Robots (SARs)

According to Encyclopaedia Britannica, a robot is a broad term used to describe an autonomous machine that replaces human effort or function in a human like manner (Moravec, 1999). The diversity of robots in size, design and capabilities makes it challenging to create one definition only (Guizzo, 2018). Robots can be as small as a coin and as big as a human body or a car (Guizzo, 2018). They can take the form of industrial machines that are often used in factories and/or look like a standing human body in airports (Guizzo, 2018). Also, robots can support physicians to deliver a surgery while others can land on other planets (Guizzo, 2018). Nonetheless, the common ground of robots includes three key components: 1. They sense the environment; 2. They carry out computations to make decisions; and 3. They perform actions in real world (Guizzo, 2018). There is great variability in the way a robot senses, computes, and acts but they operate similarly (Guizzo, 2018). A child can “interact” and/or “engage” with a robot by a control pad, by touching the robot on the face or elsewhere and/or by talking to it directly (Guizzo, 2018). Sensors feed to a computer, the computer processes these signals, and the robot repeats the so called, “feedback loop” which is the process of sensing, computing, and acting (Guizzo, 2018).

In this thesis, use of SARs is explored. The field of SARs is still growing, and definitions are not yet definitive, but they are the intersection between social robots and assistive robots (Feil-Seifer & Matarić, 2005). The term “socially interactive robots” or “social robots” describe robots that aim to engage in social interaction with people via speech or body language (Breazeal, 2004; Fong, Nourbakhsh, & Dautenhahn, 2003). Feil-Seifer & Matarić (2005) distinguished assistive robots, socially interactive robots, and SARs. Those machines that provide support to people are called assistive robots (Kwakkel, Kollen, & Krieb, 2008) and research with assistive robots include

rehabilitation robots (Burgar et al., 2002; Dubowsky et al., 2000; Harwin, 1988; Kahan et al., 2001), wheelchair robots (Glover et al., 2003; Yanko, 2002), companion robots (Plaisant et al., 2000; Wada et al., 2002), education robots (Kanda et al., 2003). Fong, Nourbakhsh, and Dautenhahn (2003) described socially interactive robots as machines whose role is to interact with humans via gestures and speech.

SARs are a combination of assistive robots and socially interactive robots. SARs are personalised social machines that are used to aid the delivery of a training session with a child and/or adult (Kidd & Breazeal, 2008; Provoost, Lau, & Riper, 2017). SARs can be designed to create audio sounds and/or maintain a small social conversation with humans which in turn builds a friendly and effective interaction pattern between two or more parties (Mollahosseini et al., 2018). SARs have the potential to mediate the way people socially interact with others. Social interaction is a broad term which generally refers to an array of verbal and non-verbal behaviours (e.g., words, gestures) that are intended to be received and processed by the conversation partner (Diehl et al., 2012). SARs allow people to engage in social interactions either by acting as a mediator in a triadic relationship or by generalising the benefits of dyadic relationship with a robot to a human – human interaction (Diehl et al., 2012). Therefore, SARs are multimodal machines that include the integration of multiple senses such as sight, sound and touch reflecting a human – human interaction. Humans are known to perceive the environment via their body using their senses including vision, audition, and touch (Noda et al., 2014). The integration of multiple sensory modalities facilitates the understanding of the surrounding environment. SARs attempt to replicate this interaction with autistic children so they can practise their skills in a safe and secure context before generalising the benefits of this approach in another environment with peers, family members and others.

This thesis will explore all types of SARs that might influence autistic children's overall development including social interaction and communication, cognition, behaviour, and any other aspects of life. The appearance of SARs can vary significantly. SARs tend to have bright colours, rotating mechanical parts, and sensors (Cabibihan et al., 2012). The most widely used SARs in autism research include humanoid and animal-like (or animaloid) robots. A small number of studies have used mechanical or other robots as

well. There is a great variability of SARs in autism research because each research team creates their own robot. Furthermore, there are very few commercially available SARs suitable for autism research (e.g., NAO, Milo).

2.1.1 Humanoid robots

Humanoid robots resemble the appearance of a human body and behave like people (Kanda et al., 2009; Newton & Newton, 2019). The most widely used SARs in autism include: 1. NAO (Anzalone et al., 2014; Bekele et al., 2013; Peca et al., 2014; Shamsuddin et al., 2012, 2013; Zheng et al., 2013); 2. Kaspar (Costa et al., 2015; Mengoni et al., 2017; Peca et al., 2014; Wainer et al., 2014); 3. Milo (Goodman, 2017; Margolin, 2016); 4. Tito (Duquette, Michaud, & Mercier, 2008; Michaud et al., 2007), *Robota* (Robins et al., 2005); 5. PALRO (Lee & Obinata, 2013); 6. Pepper (Jan, 2016), CommU (Kumazaki et al., 2017, 2018b; Shimaya et al., 2016) and 7. Actroid-F (Kumazaki et al., 2018a, Yoskikawa et al., 2011, 2019) (see Figure 2. 1).

NAO is a child-sized commercially available SAR developed by Aldebaran Robotics which is a robotics company based in Paris, France. Its height is 58cm and weights 4.3kg. It is made of plastic and its body includes a head, two arms, hands, and legs. NAO has sensors and microphones to capture information about the environment and can speak 19 different languages including English, French, Arabic and German. It can speak and engage in non-verbal communication via its wide and luminescent eyes. NAO is an autonomous robot that can walk, stand, sit, dance, grasp simple objects, talk, listen, and recognise faces.

Kaspar is a child sized SAR developed by researchers in the School of Computer Science within the Adaptive Systems Research Group at the University of Hertfordshire. It is approximately 60cm in height and weights 15kg. Its face is made of silicone, and it has a neck, arms, hands, and legs. The core characteristic of Kaspar is its minimally expressive facial features. Its face can show a range of expressions but in a less complex way than a human face. There are also sensors on its hands, feet and tummy that can respond to the touch of children. Kaspar can play games (e.g., brush teeth, comb hair, eat), say its name, say hello to people and sing songs. Its arms, head and eyes can move if controlled either via a laptop or a wireless remote-control pad.

Milo is a 60cm tall SAR that can tell or listen to a story. It can interact with people using vocal and facial expressions and help autistic children learn about, practise, and build critical social skills. Milo has been designed by RoboKind that is an education technology company dedicated to autism based in the United States.

Tito is a SAR made in soft material. It is 60cm tall and uses wheels to move. It has two arms that move up and down. Its head can turn right, left, and up. It has two eyes and a mouth by which it can smile. Tito can engage in a conversation via pre-recorded vocal messages. It also has a microphone camera and can also be controlled by a wireless remote-control pad.

Robota was developed at the University of Hertfordshire, is 45cm tall, weighs 500g and looks like a baby doll. The body of Robota consists of LEGO parts and plastic components. Robota can copy movements of the user's arms via a motion tracking system. It reacts to touch, says its name, and describes its behaviour.

PALRO was developed by Fujisoft in Japan. It is 40cm tall and weighs 1.6kg. PALRO can greet people, dance, play games, and recognise human voice. It has been used in health care facilities including nursing homes and day care centres for people with dementia (Ozeki et al., 2020; Rouaix et al., 2017).



Figure 2. 1 *Humanoid robots*

Pepper is a standing robot with a height of 120cm manufactured by SoftBank Robotics, a Japanese company. It can recognise approximately 15 different human languages including English, French, Spanish, Italian, German, and Dutch. It can recognise human voice and interact either by speech or on-screen text via a touch screen on its chest. Via its sensors and cameras, Pepper is fully aware of the surrounding environment and can navigate autonomously.

CommU was developed at Osaka University in Japan, is 30cm tall and weighs 740g. It is a child-sized robot made of plastic with distinguishable eyes. It can move its waist, shoulders, neck, eyes and eyelids, and its mouth. CommU has a smooth round body shape. It can shift its gaze and blink. CommU allows a range of simplified expressions that are less complex than those of a real human face.

Actroid-F was developed at Osaka University in Japan, is 165cm tall and weighs 30kg. It is a female robot that has an appearance similar to that of a real person. Its skin is made of silicone. Actroid-F can blink, breath, gaze, and move its head. It can also adjust its facial expressions including smiling, nodding, and brow movements.

2.2.2 Animal-like robots

Animal-like (or animaloid) robots resemble the appearance of animal toys. The most widely used animal-like SARs in autism include: 1. Pleo (Kim et al., 2013; Peca et al., 2014); 2. POL (Puyon & Giannopulu, 2013); 3. Aibo (Francois, Powell, & Dautenhahn, 2009) and 4. Probo (Peca et al., 2014) (see Figure 2. 2).

Pleo was manufactured by Jetta Company Limited in 2006. Caleb Chung designed Pleo which is available in the market at a price of \$350. Pleo is a 17.8cm tall dinosaur robot. Due to a camera-based vision system, microphones, and sensors it can move its tail, neck, mouth, and eyelids and can make slow movements (e.g., walk). Pleo can express emotions by motions and sounds in response to children's touch or various interactions such as strokes or offering food.

POL is a mobile chicken robot which is controlled by a teleoperator. The robot can move forward, backward, and turn itself at low speed. It has been designed at Pierre & Marie Curie University in Paris, France for research purposes only.

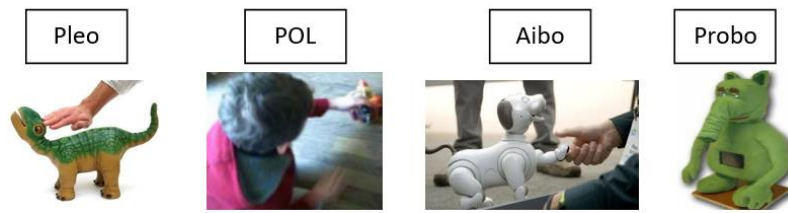


Figure 2. 2 *Animal-like robots*

Aibo is a robotic dog with touch sensors on its head, chin and on the back of its body to react to the environment and move autonomously. Aibo is programmed to recognise voice commands. Aibo was manufactured by Sony in Japan.

Probo is a soft and huggable robot that is 58cm tall. It has been developed by Vrije Universiteit Brussels. It is designed to provide a natural interaction with humans, can show facial expressions while its moving trunk is its distinct characteristic.

2.2.3 Mechanical or other robots

Very few non-humanoid or non-animaloid robots have been used with autistic children that mainly take the form of either everyday objects or industrial machines. These include the following: 1. Touch pad (Lee & Obinata, 2013; Lee et al., 2012a, 2012b); 2. Robot Based Basketball (Conn et al., 2008); 3. GIPY-1 (Giannopulu, 2013); 4. Romibo (Peca et al., 2014) and 5. LEGO Mindstorms NXT (Wainer et al., 2010) (see Figure 2. 3).

The touch pad is a touch ball with a force sensor which depending on pressure lights up in different colours. There is no available information about the designer of Touch pad.

Robot Based Basketball was designed at Vanderbilt University in the United States. It is a small size basketball hoop attached to a robotic arm that can move the hoop in different directions with different speeds.

GIPY-1 is a cylindrical robot that has a diameter of 20cm and is 30cm tall. It has two green circles for the eyes, a green triangle for the nose and a red oval for the mouth. GIPY-1 can move forward, backward, and turn on autonomously at low speed. Finally,

it is controlled by a wireless remote control. It has been designed at Pierre & Marie Curie University for research purposes only.

Romibo is a 28cm tall robot whose body is covered with Velcro suggesting easy change in the appearance of the robot. It is thought to be a social playmate that can roll around the room. Romibo was designed by Aubrey Shick, a human computer interactions researcher, at the University of Colorado.

LEGO Mindstorms NXT is a lightweight (2.1 kg) programmable robotics kit developed by LEGO that can receive input from a maximum of four sensors and controls three motors. Finally, it can reproduce sampled sounds.

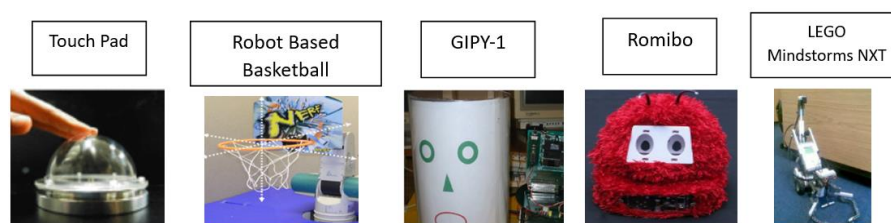


Figure 2. 3 *Mechanical or other robots*

2.2 The introduction of technology in autism research

Technology has the potential to mediate the way people socially interact with others. People engage with technology devices via pushing buttons, swiping across screens, or talking to a device to process and receive information back. People can play a video game and actively engage with more people via the computer or a tablet. The same applies to virtual reality where two or more people can interact in a virtual while still realistic, environment via a headset which stimulates real world situations and/or events by showing three-dimensional imagery. Therefore, technology might facilitate social interaction because two children and/or young people can share a tablet, take turns in video/virtual reality games and express feelings via written messages using words and/or emojis. Social interaction as a term encompasses verbal and non-verbal components of communication including spoken language, body language, written communication (e.g., text messages, emojis) that help to communicate a message and/or a feeling (Diehl et al., 2012). According to the Office for National Statistics (ONS, 2020), 96% of households in the United Kingdom had access to the internet. The

number of disabled adults who had access to the internet increased from 78% in 2019 to 81% in 2020 (ONS, 2020). Technology has revolutionised the way we work, live, relax and play. Smartphones, computers/laptops, and tablets have become an integral part of our lives because they are portable, easily accessible, socially accepted, and multifaceted devices. For example, these devices could be used for learning, communication, leisure, collaboration, reminders of tasks or appointments.

The use of technology in autism has been researched for approximately 50 years. Colby (1973) conducted a pioneering study with non-verbal autistic children who were facing challenges in symbol processing. Children played different computer games in classrooms while having full control of the keyboard. For example, the child pressed a letter (e.g., H) and then saw a horse moving across the screen and heard the sound of horses' hooves. The game increased in complexity and aimed to increase the level of understanding of English letters and sounds in autistic children. The study reported encouraging findings; 76% of autistic children speaking few or no words demonstrated improvement in involuntary speech. However, there was a lack of detail about the study design, demographic information of autistic children, method of autism diagnosis and the training sessions (e.g., number of sessions and length of sessions). The rationale of this study was based on the notion that computers could present visual information to autistic children in a more appealing and accessible format which might intrigue and attract the attention of autistic children.

In 1984, Panyan conducted a literature review on the use of computer technology with autistic children emphasising the potential of computers to circumvent learning deficits in autistic children. Panyan (1984) reported that the use of technology promotes responsiveness, attention, performance, verbal interactions, social skills, and interactions with peers. He found that technology can (a) benefit autistic students due to their differences in attention and motivation from neurotypical peers; (b) decrease stereotypic behaviours; (c) provide students with consistent feedback; and (d) increase language. Panyan (1984) also highlighted that computer use enabled the autistic child to be in control of the learning situation rather than a passive participant. This study contributed to a better understanding and knowledge of the impact of technology use in autism which is ongoing 40 years later.

2.2.1 Stakeholder's views of technology use in autism

Although technology advanced with more devices (e.g., smartphones, tablets, iPods, smartphones) being readily available over the years, high-quality research appears to be static. Preliminary evidence proposes that technology-based support including smartphones, iPods, computers/tablets, virtual reality, and robots is a potential avenue to support the development of skills in autistic children (Grynszpan et al., 2013; Kagohara et al., 2012; Syriopoulou-Deli & Gkiolnta, 2020). However, we are still very far from concluding that technology-based support can be considered as evidence-based practice to support the needs of autistic children (Knight et al., 2013).

Technology is often referenced by parents as an area of interest in autistic children (Grove et al., 2018) and autistic children reference technology as a preferred topic when asked about their skills (Clark & Adams, 2020). Parents have reported that autistic children use technology to listen to music and/or watch (cartoon) videos on YouTube and to play video games (Dong et al., 2021; Laurie et al., 2019). Autistic adolescents aged 13 – 17 years reported spending five hours per day on computers playing video games and/or browsing webpages (Kuo et al., 2013). Similarly, a comparative study of autistic children with their neurotypical siblings reported that autistic children spent 4.5 hours per day on screen-based technology including video games, television, and social media whereas their siblings dedicated 3.1 hours per day (Mazurek & Wenstrup, 2013). These findings reinforce the idea that autistic children show some affinity to technology (Clark & Adams, 2020).

Technology appears to offer a safe and logical space where autistic children are free to practise and repeat actions and/or responses while achieving the same outcome which might be to relate to people in a social context (Baron-Cohen, 2009; Baron-Cohen & Wheelwright, 1999). Additionally, technology is often easily available nowadays at different settings including home, school, or both and transportable on some occasions. Moreover, the fact that technology has been progressed to the extent there are also tangible devices with touch screens highlights that technology has been progressively more accessible to autistic children (Alper et al., 2016). The flexible and adaptable screen technology also allows autistic children to access visual information (e.g., images, words) anytime. Whereas iPods work as speech generating

devices or mediums to host applications to improve the spelling mistakes of autistic children or watch videos, listen to music, and look at pictures (Kagohara et al., 2012). Evidence suggests that autistic children prefer learning via visual information (Allen et al., 2016; Cumming et al., 2014). These are attractive features of technology to autistic children which rely on their strength of visual processing (Colby, 1973).

Research with parents has reported mixed attitudes towards technology use in autism. Parents have shared their concerns about the length of time autistic children spend on technology (Dong et al., 2021). A recent online survey reported that parents whose autistic children spent more time on technology were more concerned and sceptical about using technology with them (Laurie et al., 2019). However, this study reported a non-significant effect of the child's age, gender, and language level with children's technology use (Laurie et al., 2019). Parents have also reported being concerned about whether online content is age appropriate to autistic children as well as the limited opportunities for non-digital activities (e.g., invite people at home, walks in the park) (Just & Berg, 2017). Finally, parents whose children present behaviour that challenges (e.g., physical aggression to others) were more likely to apply restrictions on the use of technology to their autistic child (Engelhardt & Mazurek, 2014).

Professionals, including school staff, also appeared to be sceptical about technology use in autism learning (Alcorn et al., 2019). They mainly questioned whether technology might distract the child's attention (Alcorn et al., 2019). Therefore, technology, instead of being a facilitator of learning, was seen as a barrier, where learning opportunities decrease, and any observed educational gains cannot be transferrable in other educational settings where non-technology is lacking (Sabayleh & Alramamneh, 2020). Professionals argued that technology use might also distort face-to-face social interactions in naturalistic environments such as home and/or school (Durkin & Contri-Ramdden, 2014). It was likely that professionals with less frequent use of technology might have been more sceptical and were negatively inclined to the introduction of technology in autism (Sabayleh & Alramamneh, 2020).

2.2.2 The role of technology in autism

Recent studies, however, have shown that most autistic children show a natural affinity for technology and a disposition for using technology and learning through the use of computers (Lin et al., 2013; Valencia et al., 2019). The affinity of autistic children to technology might be attributed to its consistency and predictability in behaviour compared to humans (Diehl et al., 2012; Robins, Dautenhahn, & Dubowski, 2006) which in turn help autistic children adhere and maintain their routines (Wojciechowski & Al-Musawi, 2017; O'Neil et al., 2020). In 2010, John Gruber, a technology critic, commented the following: *“The iPad wasn't designed with autistic children in mind, but anecdotally, the results are seemingly miraculous”* (Knight, McKissick, & Saunders, 2013).

The introduction of smartphones, tablets, iPods, computers/laptops, virtual reality has transformed the learning experience in autistic children (Goldsmith & LeBlanc, 2004). The use of technology has served many functions to benefit autistic children including teaching children to read (Mechling, Gast, & Krupa, 2007), teaching mathematics using iPads (Burton et al., 2013), building and/or expanding social skills (Parsons & Cobb, 2011), improving activity scheduling (e.g., transition between activities, independent engagement) using a tablet (Fage et al., 2014), and using mobile phones for instructional purposes and for the purpose of supporting ongoing day-to-day task completion (Ayres et al., 2013). This list is not an exhaustive list of the contribution of technology in autism. However, these examples demonstrate the diverse application of technology use in autistic children.

The advance of technology aims to increase the sense of autonomy and enhance the well-being of people including autistic children (Comas-Gonzalez et al., 2020; Hedges et al., 2017; Knight et al., 2013; O'Neil et al., 2020). Gillspie-Lynch and colleagues (2014) suggested that technology allows social interaction for autistic adults to be less stressful and easier to navigate. Evidence from self-report studies report that autistic people prefer using social media and online forums because they have more time to prepare their response which is socially accepted in an online environment compared to pausing, thinking, and responding a few minutes/hours later in face-to-face communication (Gillspie-Lynch et al., 2014). Indeed, face-to-face communication is

more complex compared to online communication. Autistic people need to process multiple stimuli at the same time such as processing of information, interpret body language, look the person at the eyes, pay attention to the social partner and respond accordingly. These social skills present differently in autistic people who might benefit by having additional time to process information at their own pace. Usually, face-to-face social conversations take place in visually and audibly overwhelming environments which might make it harder to concentrate. Technology can filter out distractions which are challenging to process including eye-contact, loud noises, overstimulating lights. Where technology can simplify communication in such a way, it is perhaps unsurprising that autistic people show some affinity towards technology and online communication.

2.2.3. From other technology devices to SARs

Autistic children respond with affinity to technology-based support (Baron-Cohen, 2009; Colby, 1973; Fletcher-Watson, 2014; Fletcher-Watson & Durkin, 2015). There is evidence from literature and meta-analytic reviews of the potential benefits of technology-based support in the social understanding and interaction skills in autistic children (Grynszpan et al., 2013; Pennington, 2010; Ramdoss et al., 2011a, 2011b, 2012). As a result of the known advantages of technology in application to the autistic support needs, there has been a recent explosion in research on technology and autism over the years (Grynszpan, et al., 2013; Fletcher-Watson & Durkin, 2015). In 2010, a literature review of 11 studies summarised that computer-assisted instruction was effective in teaching literacy skills (e.g., vocabulary acquisition, spelling and reading instructions) in autistic children (Pennington, 2010). Ramdoss and colleagues (2011a, 2011b, 2012) summarised that computer-based support demonstrated mixed but promising results in the social, daily living and literacy support needs of autistic children. A meta-analysis of 10 studies about computer gaming software, virtual environment and interactive DVDs with autistic children reported a significant effect size in favour of technology-based support for overall learning of new skills at post-test ($d = 0.47$; CI: 0.08-0.86) (Grynszpan et al., 2013). The same study reported the age and cognitive capacity of autistic children were not significant moderators of the positive outcome in favour of technology-based support (Grynszpan et al., 2013).

Despite SARs being researched for over 30 years (Dautenhahn, 1999; Dautenhahn & Werry, 2004; Duquette, Mirchaud, & Mercier, 2008; Kennedy, Lemaignan, & Belpaeme, 2016; Panyan, 1984; Straten et al., 2018), they are less represented in systematic and meta-analytic reviews referring to technology-based support with autistic children. A meta-analysis of the use of technology-based support in autistic children from 1990 until 2011 reported that there was no study that had employed robots with autistic children (Grynszpan et al., 2013). Despite the potential of SARs in autism, significant gaps exist in the literature relating to robot-mediated support. Studies in the literature have mainly focused on reviewing the acceptability of SARs by therapists and autistic children and the short-term effectiveness that is frequently limited to the immediate effect following a session. The introduction of SARs in autism research, however, has gained more and more attention over the years with a rapid explosion of studies over the past decade (Cook et al, 2014; Huskens et al., 2015; Kumazaki et al., 2017; Yun et al., 2017).

Virnes and colleagues (2015) reviewed 255 articles related to technology use in autistic children published over a decade (2000 – 2010). The review reported the development and use of a wide range of technologies including computer and virtual reality games, interactive whiteboards, communication aids, mobile phones, wearable cameras, and robots. These technology devices were used to target different skills such as social and communication, academic, education and cognition with robots being the most used technology in autistic children. Following a review of 94 articles published between 2009 and 2019, Valencia and colleagues (2016) reported that the deployment of virtual reality, virtual agents and SARs was well accepted by autistic children and facilitated learning in domains of social and communication, emotional understanding, daily living skills (e.g., washing, bathing), and general skills including understanding the concept of money and maths. Finally, Syriopoulou-Deli & Gkiolnta (2020) reported that autistic children demonstrated positive immediate benefits in social and communication skills including joint attention, verbal communication, imitation, and recognition of specialised, focused, or intense interests following robot-mediated session.

Although research with SARs is still in its early stages, they have been used in research with autistic children (Scassellati, Admoni, & Mataric, 2012). Research with autistic children focuses on SARs either as behavioural models or facilitators with manualised tasks (Kim et al., 2012) and social play (Vanderboght et al., 2012). A critical review emphasised the potential advantages of using SARs in clinical settings with autistic children which encompass the robots' ability to repeat information, offer personalised training and appeal to children due to its novelty (Diehl et al., 2012). However, there is lack of robust evidence-based practice about the effect of SARs in autism because SARs research in autism is mainly based on small scale case studies (Robins, Dautenhahn, & Nadel, 2018; Robins et al., 2004). Individual case-series designs that recruit small sample sizes but collect rich demographic and participant data are also informative and useful in autism research (Green et al., 2013; Matson et al., 2012; Odom et al., 2016; Wendt & Miller, 2012). At the same time, the research community has suggested understanding autism at an individual level, rather than treating autism as a homogenous group, might aid service development and enhance the potential for individualised and personalised support (Lai et al., 2013). However, to address limitations with heterogeneity and better understand factors that predict better outcomes, autism research studies aim to recruit large sample sizes to increase their statistical power, methodological rigor and generalisability of findings (Lombardo et al., 2019). In addition, the current literature in autism and SARs is highly heterogeneous because each research team might develop its own robot and design its own session protocol that is not based on a standardised framework within which every practitioner and/or researcher can deliver a robot-mediated session with an autistic child. In summary, early access to support is beneficial but research for evidence-based support is still inconclusive and fragmented. These practices require robust evidence before they can be widely implemented. In the meantime, SARs are a logical, safe, personalised, and consistent technology device which in most cases brings joy and excitement as well as control in autistic children to learn and practice new learning of skills in an interactive way.

Chapter 3: Research programme

A mixed methods programme with quantitative and qualitative studies aim to enhance the knowledge and understanding of SARs in autism. Mixed methods have been described as the “third methodological movement” (Teddlie & Tashakkori, 2003) that allows the generation of new research questions that need to be explored, the confirmation of previous research findings to enhance their interpretation and the reframing of a research question from a different perspective (Tashakkori, Johnson & Teddlie, 2020).

There are different types of mixed methods design studies which include the following: 1. convergent parallel; 2. exploratory sequential; and 3. explanatory sequential (Dawadi, Shrestha & Giri, 2021). The convergent parallel mixed methods design describes the parallel collection of quantitative and qualitative data that are analysed separately. At a later stage, data will be integrated to explore the level of convergence or divergence to enhance the PhD candidate’s understanding and provide a comprehensive picture of the topic of interest. The exploratory sequential design begins with qualitative data with the view to develop a quantitative study on the variable of interest derived from the qualitative study. This design is useful when the research team aims to explore a topic with a small sample first and explore it further with a large sample size to enhance the generalisability of the study findings. The explanatory sequential design starts with quantitative data followed by qualitative data at different time points. This design is helpful when the researcher aims to further analyse a specific finding derived from the quantitative analysis. The challenge of this design is that the research team needs to shift from their own pre-conceived ideas that may influence their work (postpositivism; more flexible approach where facts and biases interact) and adopt a more constructivistic approach (e.g., construct new knowledge, reflect on experiences, and integrate it into the existing knowledge) to explore in depth the perspectives of others on the explored topic.

This research programme adopted a explanatory sequential design approach leading to a secondary analysis to initially collate data following a series of independent but connected studies while trying to generate evidence about the use of robots with

autistic children and its scope of benefit, if any, and allow the PhD candidate to explore the factors, patterns and look in depth at the perspectives and experiences of relevant key stakeholders to further the impact of SARs in the future. However, it should be acknowledged that there are multiple research approaches that can address the same aims, but mixed methods design and a logical flow was deemed advantageous to optimising use of available and new data.

A mixed methods design has been criticised because of the lack of clarity on its philosophical underpinning since it is mixing quantitative and qualitative methodologies with different theories (Ma, 2012). Quantitative research is associated with positivism (i.e., knowledge gained through objective and measurable facts) and empiricism (i.e., knowledge gained through observation) (Ma, 2012). It is often considered to be a rigorous (objective) scientific method because it relies on statistical methods to analyse data (Johnson, Onwueghuzie, & Turner, 2007). Qualitative research is associated with hermeneutics (i.e., “to interpret” written content), constructivism (i.e., collective knowledge as a result of social exchange and interaction of individuals within a social context), and relativism (i.e., reality and knowledge is socially and culturally constructed specific to the person experiencing it in a particular context) (Bogna, Raineri, & Dell, 2020; George, 2020; Luo, 2011). It is often perceived as a subjective methodology open to researchers’ interpretation generating relativistic findings (Ma, 2012). To address this conflicting paradigms, Creswell and Clark (2017) put aside philosophical and epistemological assumptions suggesting the following “stances”: 1. pragmatism (i.e., the primary objective is the priority regardless of the applied methodology and its philosophical underpinning); 2. multiple paradigms (i.e., acknowledgement that different paradigms may generate contradictory ideas and arguments that need to be valued by researchers); and 3. mixed methods is a just a method (i.e., the view that allows researchers to employ several philosophical foundations).

The introduction of the “stances” allows the researcher to take different stances and mix paradigms in mixed methods studies related to each research design. For example, when a research programme begins with a quantitative study design the researcher adopts a postpositivist paradigm but when moving to a qualitative study

the same researcher can shift towards a constructivist paradigm which allows the connection of new insights as a result of a mixed methods research design which mirrors the philosophical underpinning of the PhD candidate in this research programme. An invisible thread connects researchers and participants during data analysis and interpretation. After about a decade in this field, the PhD candidate took the position that autism researchers may make pragmatic decisions generating evidence for autistic children and their families while designing the most robust studies possible based on the available resources and funding. Therefore, this research programme of work adopted the “stances” of Cresswell and Clark (2017) taking into consideration the interpretivism and constructivism paradigms where reality and generated knowledge interact with each other.

The methodology of this research programme is summarised in this chapter. The overall aim of this thesis is to undertake a programme of work through a series of individual but connected studies that are designed to explore different elements about the role of SARs in autism intervention. This aims to support the development of a framework that can help understand ways in which future research can support the translation of robot-mediated sessions with autistic children into practice.

The increased availability of different autism specific support (see chapter 1.3) might make it difficult to understand how to best address the variable support needs of autistic children. Apart from researchers/clinical academics who develop and/or research robots to produce evidence and enhance the knowledge of the wider public and their community on the topic, there are some start-up companies (e.g., LuxAI, Moxie) across the globe selling robots to families of autistic children to use at home. They also sell these robots to schools including the UK. These robots cost from £600 to £1500. These companies have entered the market promoting their devices, as an educational tool. It is unclear if those working in start-up companies are experts or just informed of the support needs of autistic people. The use of robot-mediated support in autism warrants rigorous approaches to support the decision-making of different stakeholder members (e.g., parents, autistic adults, researchers, clinicians, educators etc.) about their effectiveness.

In addition, the concept of patient and public involvement (PPI) although well established in the UK, it might be in its infancy in some parts of Europe, and/or less widely implemented in parts of the USA. Research quality practices and procedures may be an uncharted territory for some researchers and start-up companies. Specifically, start-up companies mostly rely on anecdotal evidence (predominantly from their own case studies) reporting that autistic children demonstrate progress in multiple domains of development such as social, emotional, educational and communication following exposure to a robot. Therefore, there is a high risk that these companies may continue to evolve investing a lot on experts in Artificial Intelligence models and engineering with limited to no expertise in autism and the factors that may influence behavioural response. In line with this idea, the ethos of start-up companies is primarily driven by raising their capital to finance the operation of the company and to focus on new investments. That means that it is very likely to attempt to enter the market as a medical device as a result of upgrading their device(s). Finally, research on robot-mediated support has often been introduced as part of an already established psychosocial support programme (e.g., ABA) that has attracted a lot of criticism from the neurodivergent community (see chapter 1.3). Overall, these uncertainties may be a threat to the neurodiversity paradigm that is trying to empower the voices of all autistic individuals and their carers, break the stigma and societal myths around autism and raise awareness and understanding about autism.

This programme of work aims to make a robust and novel contribution to the field of autism and robot-mediated support. It should yield recommendations to inform the practices of researchers, clinicians, educators, and the wider autistic community (i.e., neurotypical parents of young autistic children, autistic parents of autistic children, policy makers) through exploring what is already known, what the preferences of parents/carers are, and how autistic children may benefit from one specific SARs platform. The following questions will be addressed over a programme of studies.

3.3.1 How have SARs been used with autistic children?

Quantitative research provides data to measure the impact of a support approach allowing to draw some generalisable conclusions (Jackson, Power & Walthall, 2023). A number of studies have been conducted over the past 20 years to explore the

feasibility and acceptability of robots in autistic children and practitioners (Dickstein-Fischer et al., 2018; Scassellati, Admoni, & Mataric, 2012). A recent review reported the acceptability of robots with autistic children (Pennisi et al., 2016). Another review reported that humanoid robots demonstrated positive outcomes in the the domains of social skills, gesture recognition, physical, mental, and verbal skills in autistic children and adults (Salimi, Jenabi, & Bashirian, 2021). To date, there was no meta-analysis to quantify the effect of robots in specific clusters of skill development (Salimi, Jenabi, & Bashirian, 2021). Therefore, a thorough synthesis of the literature was necessary to explore the way SARs have been used to date, in which settings, for how long and which skills have been targeted in the literature. Understanding the context in which SARs have been used so far can help shape future decisions about the design of robot-mediated sessions to maximise benefits for autistic children. At the moment, there is lack of robust evidence about the effect of SARs in autism, and a lack of a standardised framework within which every practitioner and/or researcher can design and deliver a robot-mediated session with autistic children.

3.3.2 What are parents'/carers' preferences about technology-based support including SARs with autistic children?

Mixed methods allow the generation of data to complement our understanding of the impact of a specific support with the view to draw some conclusions (Jackson, Power & Walthall, 2023). There are a number of technology-based support tools for autistic children (e.g., smartphones, tablets, virtual reality, robots (Kim et al., 2018). If robot-mediated support is found to be effective and implemented in practice, it is important that parents/carers find this technology acceptable. There is currently lack of evidence in the literature about parent's/carers' knowledge and preferences on technology-based support including robots. An online survey with open-ended questions was developed to understand their attitudes towards robots compared to other technology-based support (e.g., smartphones, iPods, tablets, virtual reality, other). This empirical study can shape researchers', clinicians', other professionals', and policy makers' decisions about whether it is worthwhile further investigating technology-based support.

3.3.3 What are parents' views on the way a humanoid robot might support autistic children in a session?

Qualitative research provides rich data about the experience, insights, and views of individuals on a topic (Jackson, Power & Walthall, 2023). The introduction of robots in autism is still not a well-known support option to parents/carers of autistic children. The majority of the literature has been focused on the acceptability of robots by professionals (Alcorn et al., 2019; Fridin & Belokopytov, 2014; Huijnen et al., 2017; Serholt et al., 2017; Westlund et al., 2016). There is currently very little information on the views of parents/carers of autistic children about how robot-mediated support might be structured, organised, and delivered to support their autistic child. Individual interviews and a focus group with parents of autistic children were conducted to explore their attitudes and views of using SARs with autistic children in a session. Understanding the context that robots might be used in and how they might be most effective as a support to autistic children is of paramount importance to researchers, families, and practitioners who are responsible for identifying suitable support and/or services to accommodate the needs of autistic children. Following diagnosis, it is common that parents/carers of autistic children access a range of specific support in an attempt to identify the one with optimal outcomes.

3.3.4 What is the effect of Kaspar, a humanoid SAR, in the joint attention skills of autistic children compared to a human therapist in a session?

A secondary analysis of existing data is a popular low-cost research methodology because new research can quickly be generated from existing data (Cheng & Phillips, 2014). In the current context, existing video recording data from autistic children were analysed to explore the effect of Kaspar on joint attention skills compared to autistic children who interacted with a human therapist only. There is evidence from feasibility and proof of concept studies that SARs may support the development of social and communication skills in autistic children. One question is whether a triadic interaction with SARs, a human therapist and an autistic child is more effective compared to a dyadic interaction with a human therapist and a child to practice joint attention skills. Answering this question helps to understand whether SARs when used as a mediator have a stronger effect on one aspect of social and communication skills in autistic

children via the scaffolding of interaction compared to human therapists themselves. This has implications for understanding whether interaction is driven by the child's motivation to socially engage with people or whether the novelty of SARs and affinity to technology for autistic children is more powerful.

Chapter 4: The use of SARs in autistic children: a systematic literature review and meta-analysis

4.1 Introduction

The introduction of Socially Assistive Robots (SARs) in autism research has gained more and more attention over the years with a rapid explosion of studies over the past decade (Cook et al., 2014; Huskens et al., 2015; Kumazaki et al., 2017; Yun et al., 2017). The emergence of humanoid, autonomous and mobile SARs brings hope that technology might assist the education and/or development of daily living, social communication, and behavioural skills in autistic children through playful activities.

The support for autistic children has progressively improved as a result of early diagnosis, better quality research and an ongoing focus on early access to autism specific support and/or services (Landa, 2018; Fuller & Kaiser, 2020; Hyman et al., 2020; Rogers et al., 2014; Volkmar et al., 2017). However, chapters 1.3 and 2.2 emphasise that long-term specific support is imperative because autistic experiences and characteristics vary and evolve over time. Language, social and communication skills, and behaviour that challenges are core areas in a child's development and support needs in these domains might impede the daily life of autistic individuals in adulthood (Magiati, Tay, & Howlin, 2014; Steinhausen, Mohr Jensen, & Lauritsen, 2016). Therefore, there is a need to examine innovative ways of addressing the specific autistic experiences and characteristics.

The use of SARs as an engaging mediator in a session with a therapist/adult play partner that allows autistic children to practise and develop skills (Scassellati et al., 2012; Valadão et al., 2016). Previous research emphasised that autistic children demonstrated some preference to non-social objects compared to social objects (Baron-Cohen, 2002, 2006; Klin et al., 2009). In line with this, recent studies have shown SARs to be well-accepted by autistic children who demonstrated better imitation skills, eye-contact, joint attention, and behavioural response (Pennisi et al., 2016; van den Berk-Smeekens et al., 2021). There is also a considerable amount of literature which reports that many autistic children interacted more effectively with SARs than humans (Begum et al., 2016; Diehl et al., 2012; Fong et al., 2003; Willemse

et al., 2018). A possible explanation might be that autistic children find stimulation through repetition and the gradual increase of challenge while interacting with a SAR (Dautenhahn, 2003; Diehl et al., 2012; Rudovic et al., 2017; van Straten et al., 2018).

SARs can take up different roles in a session (Huijnen et al., 2019). They can act as a “behaviour model” where the SAR teaches a skill and interacts directly with the child such as teaching an autistic child how to brush their teeth after each meal. Therefore, the robot adapts the role of the “trainer” that includes teaching the autistic child a skill so that the young person can learn it, transfer the benefits of the learning process across different environments and apply the new knowledge in different contexts with different people. For example, a SAR can play a turn-taking/problem-solving game with the autistic child that the child can replicate with an adult at home or a friend at school. Alternatively, SARs might be “reinforcers” of positive behaviour that make the learning during a session a rewarding procedure via social engagement. For instance, the SAR can reward the child via smiling and saying, “*Well done*” or “*I’m happy*”.

Over the years, there have been several attempts to explore the impact of SARs in autistic children during a session (Maglione et al., 2012). However, concrete evidence of the effectiveness of SARs is lacking. Despite the potential of using SARs with autistic children, significant gaps exist in the literature relating to robot-mediated support. Studies in the literature have mainly focused on reviewing the acceptability of SARs by therapists/adult play partners and autistic children and the short-term effectiveness that is frequently limited to the immediate effect following a session. Literature has neglected to examine the effectiveness of different SAR types used with autistic children (Pennisi et al., 2016; Rao et al., 2008; Sarrica, Brondi, & Fortunati, 2019). Additional components such as the setting in which a robot-mediated support is delivered and the number, frequency, and duration of sessions with a SAR have not been reported as a key factor of effectiveness in a session in the literature. It is imperative to examine the features in which robot-mediated sessions are most effective because autistic children often need support to generalise skills learnt in teaching environments such as a clinic room, a laboratory, or at home (Bellini et al., 2007; Rao et al., 2008). Monitoring children’s performance across settings might offer professionals an insight into the most effective environment to deliver a robot-

mediated session. Finally, the skills and outcomes that robot-mediated support have targeted in autistic children would inform professionals of future directions and gaps in the literature regarding SARs and autism.

4.1.2 Study objectives

The present systematic literature review and meta-analysis aims to explore the existing literature and provide an up-to-date synthesis of the evidence base regarding the use of SARs with autistic children and summarise the reported effects of robot-mediated support in autistic children. The objectives are as follows:

1. To identify the types of SARs that have been used to aid the development of autistic children
2. To identify the settings in which SARs have been used to support autistic children (e.g., school, home, clinic)
3. To specify the role of SARs in a training session
4. To determine the range of skills that robot-based sessions have targeted

4.2 Methods

The systematic literature review and meta-analysis has been completed adhering to the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-analyses) (Liberati et al., 2009). The review was also registered on the PROSPERO database (registration number: CRD42019148981).

4.2.1 Search strategy

A literature search of PubMed, Scopus, EBSCOhost, Google Scholar, Cochrane Library, ACM Digital Library and IEEE Xplore was conducted in April (6th) 2022. Grey literature was also searched using PsycExtra, OpenGrey, British Library eThOS, British Library Catalogue. The search strategy was developed by identifying relevant key terms, used in previous reviews with robots (Diehl et al., 2012; Pennisi et al., 2016) and was further developed in conjunction with professionals specialising in the field of robots and/or autism. The supervisory team and librarian monitored the process of developing search terms. A combination of free-text terms and medical subject headings (MeSH) were used in all databases. The PICO (population, intervention, control, and outcomes) framework was used to develop the search strategy which included the

following general search terms: ‘robot’ AND ‘autism’ AND ‘outcome-specific’ terms. The search strategy used in PubMed is presented in Table 4. 1. Search terms were combined using “OR” within the same concept and “AND” when different concepts were combined together. Databases were searched from inception for titles, abstracts, and keywords. Search terms were adjusted according to the subject headings of the remaining databases. Four key papers were identified and used to assess the reliability of the search results (Diehl et al., 2012; Kim et al., 2015; Marino et al., 2020; Pennisi et al., 2016). The author also conducted hand searches of the reference list of relevant papers. Study authors were contacted when access issues occurred.

Table 4. 1 Search strategy for systematic literature review

| Population | Intervention | Outcome |
|---|--|--|
| Autis* OR ASD OR ASC OR Asperger* OR “pervasive developmental disorder” OR PDD- NOS OR PDD- unspecified | Robot* OR “human-robot” OR “human- machine” OR “robot-mediated” OR “robot-based” OR “robot-assisted” OR robot* n3 interv* OR robot* n3 therap* OR robot* n3 train* OR robot* n3 treatment OR robot* n3 management OR robot* n3 care OR robot* n3 support OR robot* n3 education | Social OR emotion* OR communica tion OR educat* OR academ*OR behavio*r OR health |

*Truncated terms

4.2.2 Inclusion and exclusion criteria

Types of studies

All quantitative study designs were included in the review, including experimental (i.e., randomised control trial, crossover), quasi-experimental (i.e., pre-test and post-test within-subjects or between groups or matched pairs, post-test only), correlational and descriptive designs. Mixed-methods designs, single-subject case studies and multiple case studies were also eligible. Criteria for exclusion were: 1. lack of recording study procedures including number, duration, and frequency of sessions; 2. commentary papers, protocols, surveys, and reviews; 3. qualitative studies; 4. qualitative elements in mixed-method designs; 5. studies that were not published in English.

Participants

Participants were children up to the age of (including) 18 years with a primary autism diagnosis confirmed by internationally recognised criteria including the International Classification of Diseases (ICD-11) or the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). There were no limits on study participants in terms of gender, ethnicity, level of functioning, and co-occurring conditions. Studies of autistic children and co-occurring conditions were also included in the review. Co-occurring conditions (e.g., epilepsy, intellectual disability, anxiety etc.) were eligible regardless of a formal diagnosis. Criteria for exclusion were: 1. individuals 19 years old and over; 2. lack of separate presentation of study outcomes for autistic children.

Intervention

Any interventional study that used robots with autistic children as a mediator was eligible. The whole range of robots such as animaloid robots, humanoid robots, and toy robots were included in the review. Criteria for exclusion: 1. studies that focused on pharmacological interventions; 2. no reference to the robot type/model used in the intervention.

Control group

Any intervention comparison group was included such as children without autism, waitlist group, session delivered by humans or other robot.

Context

There was no limit on intervention settings (i.e., clinic, school, home). Studies from all countries were included but were restricted to those published in English.

4.2.3 Study selection

Identified records from all databases were imported into Mendeley reference management software (v1.19.8) and duplicates removed. The PhD candidate screened all originally identified records based on title and abstract. A second reviewer independently screened a random sample of 20% of the originally identified records based on title and abstract. Both reviewers used the pre-determined inclusion criteria to establish reliability for study selection. The full text of potentially relevant papers was retrieved and independently assessed for eligibility by the first reviewer. The

second reviewer independently screened for eligibility 20% of full text studies for quality assurance. There was 100% agreement between reviewers in the selection of studies which met the inclusion/exclusion criteria. Figure 4. 1 provides a flow diagram of the final number of included citations.

4.2.4 Data extraction

A data extraction framework was created in Excel, piloted with five studies and reviewed by the supervisory team. Relevant information from the full text papers were extracted into the data extraction table. General information extracted included the study title, publication year, authors, country of origin, funding source. Additional study information was extracted such as study aims, study design, inclusion/exclusion criteria, and recruitment procedures. Session characteristics extracted included session number, duration and frequency, robot type used, session procedures, comparison group, play partner, session location. Demographic information about the participants included data related to sample size, child's age, gender, ethnicity, additional diagnosis, intelligent quotient (IQ). Outcomes of the study such as study timescale, follow-up assessment, play partner of session delivery, outcome measures used, outcome data. A second reviewer independently extracted 20% of full text citations for quality assurance. Any disagreement between the two reviewers was resolved through discussion and/or by consulting a third reviewer from the supervisory team.

4.2.5 Quality assessment

The PhD candidate and a second reviewer independently measured the quality of the included studies using the Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project, 1998). All studies were appraised independently by the PhD candidate while 20% were reviewed by a second reviewer. The assessment tool assessed six components of study validity – selection bias, study design, confounders, blinding, data collection methods, withdrawals. Each component was rated as strong, moderate, or weak. Once the assessment tool was fulfilled, each paper received an overall mark ranging between “strong (no weak rating)”, “moderate (one weak rating)” and “weak (two or more weak ratings)”. The inter-rater reliability between the authors using Cohen's Kappa was good (0.870 agreement). Any disagreements

between the two reviewers were resolved through discussion or by consulting a third reviewer from the supervisory team. The results of the quality analysis were tabulated to identify any types of bias common to the included studies (see Table 4. 2 and Table 4. 3).

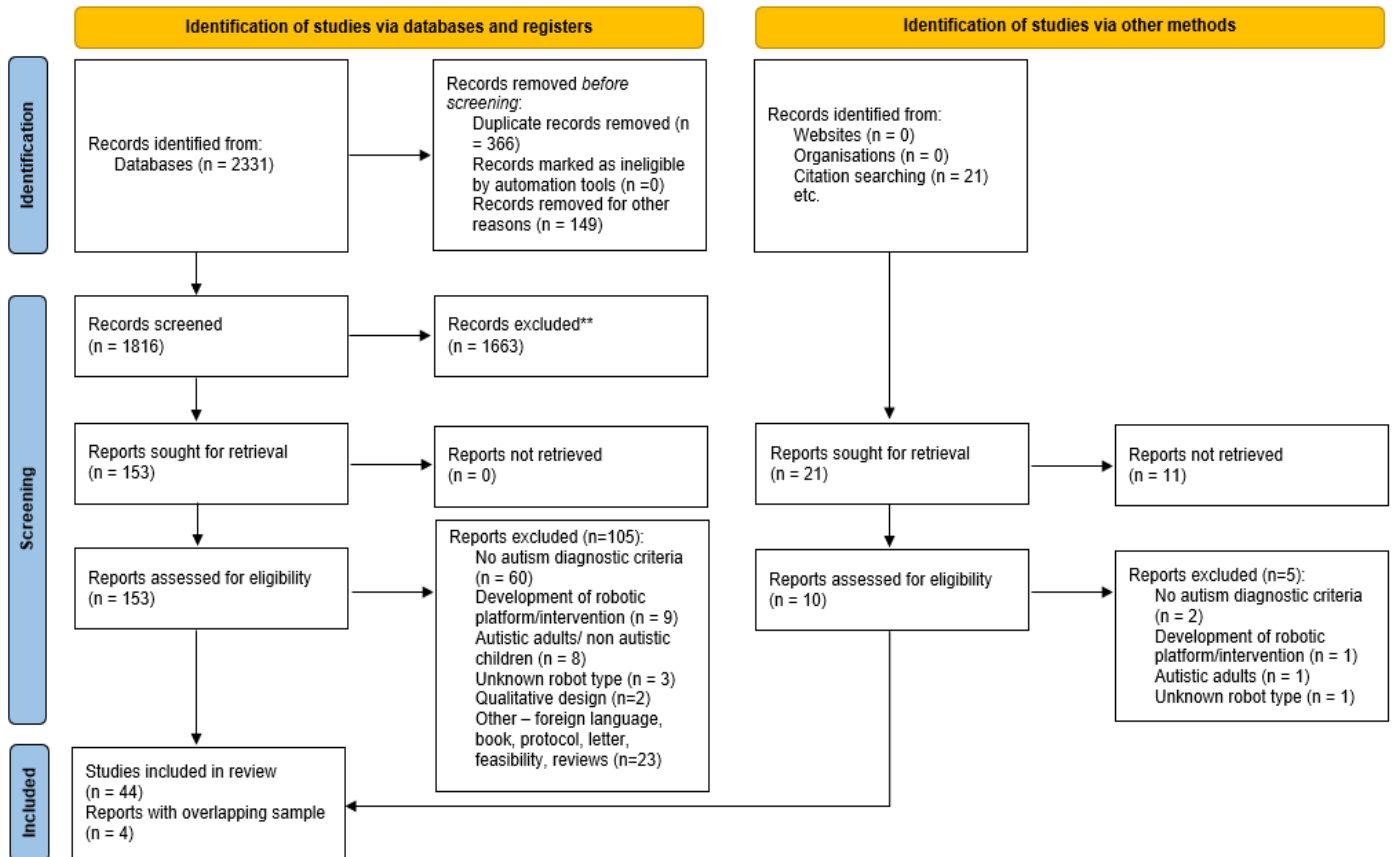


Figure 4. 2 PRISMA flow diagram of the study selection process

4.2.6 Data synthesis

A narrative synthesis (Popay et al., 2006) was used to summarise the relevant studies for inclusion. Session characteristics such as number and duration of sessions were reported numerically using means, percentages and standard deviations and other treatment characteristics such as the type of robot used, and treatment location were simplified into categorical variables for quantitative synthesis. This was to allow synthesis and integration of a large amount of data across the dataset. The quantitative data were imported into SPSS version 26.0 to compute means, percentages and standard deviations.

A meta-analysis was conducted using Comprehensive Meta-Analysis version 3.0 for Windows (Borenstein et al., 2021). Hedge’s *g* effect sizes (and 95% confidence

intervals) for end-of-trial data comparing robot-mediated support and control groups in randomised controlled trials (RCTs) were calculated. Hedge’s *g* adjusts effect sizes according to sample size. Comparisons were made for the primary outcomes of social and communication, emotional development, and motor skills, which emerged as the main clusters of outcomes in included RCTs. All meta-analyses used a random effects approach. Effect sizes were classified as small (0.2) medium (0.5) and large (0.8) according to Cohen’s nomenclature. Heterogeneity was assessed using the I^2 statistic, and for interpretation we followed Cochrane guidance (Higgins et al., 2019) where I^2 values were identified: 0% – 40% as might not be important; 30% – 60% as may represent moderate heterogeneity; 50% – 90% may represent substantial heterogeneity; 75% –100% representing considerable heterogeneity.

Table 4. 2 *Quality assessment breakdown of included studies (maximum number of studies = 44; RCT = 18 and non-RCT = 26)*

| Quality rating | Selection bias | Study design | Confounding variable | Blinding | Data collection | Withdrawal | Global rating |
|---|----------------|--------------|----------------------|----------|-----------------|------------|---------------|
| Strong | 4 | 8 | 6 | 4 | 23 | 27 | 8 |
| Moderate | 33 | 34 | 8 | 33 | 17 | 5 | 19 |
| Weak | 7 | 2 | 30 | 7 | 4 | 12 | 17 |
| RANDOMISED CONTROLLED TRIALS | | | | | | | |
| Strong | 2 | 7 | 3 | 2 | 14 | 12 | 6 |
| Moderate | 15 | 10 | 3 | 14 | 4 | 2 | 6 |
| Weak | 1 | 1 | 12 | 2 | 0 | 4 | 6 |
| NON-RANDOMISED CONTROLLED TRIALS | | | | | | | |
| Strong | 2 | 1 | 3 | 2 | 9 | 15 | 2 |
| Moderate | 18 | 24 | 5 | 19 | 13 | 3 | 13 |
| Weak | 6 | 1 | 18 | 5 | 4 | 8 | 11 |

4.3 Results

4.3.1 Overview of included studies

The search generated 2331 references of which 153 papers met the inclusion criteria. Following further review, 48 articles reporting 44 studies were eligible to be included in the systematic literature review. The most common reason for exclusion was the lack of information concerning diagnostic method for autism (n = 60) followed by studies which did not meet the inclusion criteria such as reviews, protocols, surveys, feasibility trials, opinion letters (n = 23). A smaller number of studies were excluded because of the following reasons: 1. a new robotic platform was developed (n = 9); 2. adults/children with diagnoses other than autism were examined (n = 8); 3. the robot name/type was missing (n = 3); 4. a qualitative study had been conducted (n = 2). See Figure 4. 1 for the PRISMA flow diagram.

4.3.2 Study characteristics

Table 4. 4 details the main methodological features of all studies. The description of the study characteristics is based on 44 studies because four articles (Kim et al., 2015; Srinivasan et al., 2015, 2016a, 2016b) had overlapping samples and were not included in the average sample size. The majority of the studies were non-RCTs (n = 26, 59%), followed by RCTs (n = 18, 41%). The majority of studies (n = 35, 79%) had more males than females, with percentage of males ranging from 67% to 100%. The majority of studies included in this review therefore seem to reflect the current literature about the rate of autism between males and females which was described in chapter 1.

The ethnic group of participants was reported in ten studies (23%) in which seven studies included Chinese participants (So et al., 2016, 2018a, 2018b, 2019a, 2019b, 2020a, 2020b) and two studies comprised of mixed ethnicities including Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, Mixed Caucasian, and Hispanic participants (Kim et al., 2013; Srinivasan et al., 2015a) and one study included Italian autistic children (Marino et al., 2020). Eighteen studies (41%) measured the cognitive capacity (intelligent quotient; IQ) of children. Of these, six studies reported that autistic children scored either above 60 or below 70 without providing further details. Autistic children were reported as having a mean IQ of 81 (SD = 18.29, range: 58 – 106) in the remaining studies. Further characterisation of

participants was generally poor. The age of autistic children ranged in age from 2 years to 16 years ($M = 7.3$, $SD = 2.99$).

The average sample size of autistic children across the studies was 10 ($n = 44$, $M = 10.61$, $SD = 7.09$, range: 1 – 30). The studies were published between 2008 and 2021 in Europe ($n = 21$, 48%) [i.e., Romania ($n = 7$), Italy ($n = 4$), the Netherlands ($n = 3$, Portugal ($n = 3$), France ($n = 2$), Luxembourg ($n = 1$), and Belgium ($n = 1$)] followed by the United States ($n = 12$, 27%). Some studies were based in East Asia ($n = 11$, 25%) including some studies in Hong Kong ($n=7$), Japan ($n = 3$) and Korea ($n = 1$). One study was conducted in Canada ($n = 1$). Since 2013, there has been an increase in studies in this area compared to previous years publishing five studies per year. This suggests the interest in robots and autism is increasing, especially from researchers based in the United States and Europe.

Only quantitative data were extracted for the purpose of the current review and meta-analysis. Thirty-nine studies (89%) utilised video data only to analyse the study findings. A further five studies used quantitative methods to supplement the analysis of video data including: 1. questionnaires to measure social and communication skills as well as emotional development skills completed by the therapist/adult play partner or the child after the session (Pop et al., 2013a, 2014; Simut et al., 2012); 2. a parent-completed online survey at the end of each session (Scassellati et al., 2018); and 3. an eye-tracker (Yoshikawa et al., 2019). Three studies used qualitative methods to augment the analysis of video recordings including qualitative notes from researchers (Pop et al., 2013b) and audio recordings (Kumazaki et al., 2018a; Scassellati et al., 2018). According to the exclusion criteria of the review, these qualitative data were not extracted. Five studies used standardised measures only to measure the desired outcome gain. Parents completed the Social Anxiety Scale for Children-Revised (SASC-R), Social Anxiety Scales for Adolescents (SAS-A) and Social Skills Improvement System (SSIS) (Kaboski et al., 2015) to examine social and communication skills. Researchers scored the child's performance in the session using the Test of Emotional Comprehension and Emotional Lexicon Test (Marino et al., 2020) to monitor emotional comprehension. The parent and teacher-reported Social Responsiveness Scale (SRS) was used to monitor social and communication skills (van den Berk-

Smeekens et al., 2021). The Early Social Communication Scale was rated by blind to allocation group healthcare professionals (Ghiglino et al., 2021). The Facial Emotional Recognition Task and the Basic Emotions Production Task was administered by researchers during video data coding (Lecciso et al., 2021).

Almost half of the robot-mediated sessions (n = 20, 45%) delivered brief training sessions which lasted on average for 10 minutes (range: 3 – 15 minutes). Robots were introduced to autistic children for a short-term session (Costa et al., 2018; Giannopulu et al., 2014; Kim et al., 2013; Kumazaki et al., 2018a, 2018b; Pierno et al., 2008; Pop et al., 2013a, 2013b, 2014; Puyon & Giannopulu, 2013; Silva et al., 2019, 2020; Simut et al., 2016) with a single session only. In addition, a few researchers only conducted a short-term pilot study (Pop et al., 2013b; So et al., 2020a; Srinivasan et al., 2015; Warren et al., 2015) to validate any preliminary observation or initial results. In total, four studies made explicit reference to the long-term benefits of robot-mediated support at two weeks (Huskens et al., 2013), four weeks (So et al., 2019a), 10 weeks (Ghiglino et al., 2021) and 12 weeks (van den Berk-Smeekens et al., 2021) following the end of the session. Finally, only Marino and colleagues (2020) reported that autistic children in both groups (robot and human) spontaneously practised the trained skills addressing generalisation issues.

4.3.3 Quality assessment and risk of bias in included studies

The quality of the studies in this review was found to be predominately moderate (n = 19) followed by weak (n = 17) whereas a few studies were found to be of strong quality (n = 8) (see Table 4. 2). A table was formulated to explore the reasons that studies were often of poor quality (Table 4. 3). The poor quality of the studies can be mainly attributed to the selection of participants resulting in the majority being rated as moderate in selection bias (n = 33, 75%). Reporting on ethnicity, age, family, or socioeconomic status of families was often poor with limited matching across study groups (n = 30, 68%). Matching samples was problematic in very few instances because studies compared adults with autistic children (n = 1) or neurotypical children with autistic children (n = 8) instead of similar aged autistic peers. This trend was comparable across both randomised and non-randomised studies. Assessors and/or participants were not blinded in 91% of the studies. This was as much a feature of

RCTs as non-RCTs. Effort was made to contact sixteen authors for further information. Five author responses were received which resulted in information being classified as missing and thus reducing study quality. It is, however, promising that the majority of studies (n = 40, 91%) used appropriate methods to collect data including video recordings as well as standardised assessment tools. Studies (n = 25, 56%) provided details about the position of the cameras and the use of at least two coders including inter-rater reliability between coders. Most studies (n = 32, 73%) also reported the number of participants approached, screened, and completed the session. Finally, outcome assessors (e.g., researchers) were not blinded in 81% (n = 36) of the studies including often in RCTs as well as non-RCTs. The reason for unblind coders was justified because the robot was visible during data coding of the session.

Table 4. 3 *Individual study quality assessment overview by study design and mostly used robot*

| Reference | Global rating | Selection Bias | Study design | Confounders | Blinding | Data collection methods | Withdrawals |
|------------------------------|---------------|----------------|--------------|-------------|----------|-------------------------|-------------|
| RANDOMISED CONTROLLED TRIALS | | | | | | | |
| De Korte et al., 2020 | Strong | Strong | Strong | Moderate | Strong | Strong | Strong |
| Huskens et al., 2013 | Moderate | Moderate | Moderate | Weak | Moderate | Strong | Strong |
| Marino et al., 2020 | Strong | Moderate | Strong | Weak | Moderate | Strong | Strong |
| So et al., 2018a | Weak | Moderate | Strong | Weak | Moderate | Moderate | Weak |
| So et al., 2018b | Weak | Moderate | Moderate | Weak | Moderate | Strong | Weak |
| So et al., 2019a | Weak | Weak | Moderate | Weak | Moderate | Strong | Weak |
| So et al., 2019b | Weak | Moderate | Moderate | Weak | Weak | Strong | Strong |
| So et al., 2020a | Weak | Moderate | Moderate | Weak | Weak | Strong | Strong |
| Srinivasan et al., 2015a | Moderate | Moderate | Strong | Weak | Moderate | Moderate | Weak |

| Reference | Global rating | Selection Bias | Study design | Confounders | Blinding | Data collection methods | Withdrawals |
|---|---------------|----------------|--------------|-------------|----------|-------------------------|-------------|
| Srinivasan et al., 2015b (overlapping sample) | Moderate | Moderate | Strong | Weak | Moderate | Moderate | Weak |
| Srinivasan et al., 2016a (overlapping sample) | Moderate | Moderate | Strong | Weak | Moderate | Strong | Strong |
| Srinivasan et al., 2016b (overlapping sample) | Moderate | Moderate | Strong | Weak | Moderate | Strong | Strong |
| van den Berk-Smeekens et al., 2021 | Strong | Moderate | Strong | Strong | Strong | Strong | Moderate |
| Zheng et al., 2020 | Weak | Moderate | Moderate | Weak | Moderate | Strong | Weak |
| So et al., 2020b | Moderate | Moderate | Moderate | Moderate | Moderate | Strong | Strong |
| Yun et al., 2017 | Strong | Moderate | Strong | Moderate | Moderate | Strong | Strong |
| Costescu et al., 2017 | Moderate | Strong | Strong | Weak | Moderate | Moderate | Strong |
| Pop et al., 2013a | Strong | Moderate | Moderate | Strong | Moderate | Strong | Strong |
| Pop et al., 2014 | Strong | Moderate | Moderate | Strong | Moderate | Strong | Strong |
| Simut et al., 2016 | Moderate | Moderate | Moderate | Weak | Moderate | Moderate | Moderate |
| Kim et al., 2013 | Moderate | Moderate | Moderate | Weak | Moderate | Strong | Strong |
| Kim et al., 2015 (overlapping sample) | Moderate | Moderate | Moderate | Weak | Moderate | Strong | Strong |
| NON-RANDOMISED CONTROLLED TRIALS | | | | | | | |
| Huskens et al., 2015 | Moderate | Weak | Moderate | Moderate | Moderate | Strong | Strong |

| Reference | Global rating | Selection Bias | Study design | Confounders | Blinding | Data collection methods | Withdrawals |
|---------------------------|---------------|----------------|--------------|-------------|----------|-------------------------|-------------|
| Kaboski et al., 2015 | Strong | Moderate | Moderate | Strong | Moderate | Strong | Strong |
| Korneder et al., 2021 | Moderate | Weak | Moderate | Moderate | Moderate | Moderate | Strong |
| So et al., 2016 | Weak | Weak | Moderate | Weak | Moderate | Weak | Weak |
| Tapus et al., 2012 | Moderate | Moderate | Moderate | Weak | Moderate | Weak | Weak |
| Warren et al., 2015 | Weak | Moderate | Moderate | Weak | Moderate | Moderate | Weak |
| Zheng et al., 2016 | Weak | Moderate | Moderate | Weak | Weak | Moderate | Weak |
| Kumazaki et al., 2018a | Moderate | Moderate | Moderate | Weak | Moderate | Moderate | Strong |
| Kumazaki et al., 2018b | Moderate | Strong | Moderate | Weak | Moderate | Strong | Strong |
| Yoshikawa et al., 2019 | Weak | Moderate | Moderate | Weak | Weak | Moderate | Strong |
| Srinivasan et al., 2013 | Moderate | Moderate | Moderate | Weak | Moderate | Strong | Strong |
| Srinivasan & Bhat, 2014 | Moderate | Moderate | Moderate | Weak | Moderate | Moderate | Strong |
| Costa et al., 2018 | Moderate | Moderate | Moderate | Strong | Moderate | Moderate | Weak |
| Duquette et al., 2008 | Weak | Weak | Moderate | Weak | Weak | Moderate | Strong |
| Lecciso et al., 2021 | Moderate | Moderate | Moderate | Weak | Moderate | Strong | Moderate |
| Scassellati et al., 2018 | Weak | Moderate | Moderate | Weak | Weak | Moderate | Strong |
| Pop et al., 2013b | Strong | Moderate | Strong | Strong | Moderate | Strong | Strong |
| Simut et al., 2012 | Moderate | Moderate | Moderate | Weak | Moderate | Moderate | Strong |
| Vanderborght et al., 2012 | Moderate | Moderate | Moderate | Weak | Moderate | Moderate | Strong |

| Reference | Global rating | Selection Bias | Study design | Confounders | Blinding | Data collection methods | Withdrawals |
|--------------------------|---------------|----------------|--------------|-------------|----------|-------------------------|-------------|
| Silva et al., 2018 | Weak | Moderate | Moderate | Weak | Weak | Weak | Weak |
| Silva et al., 2019 | Weak | Moderate | Moderate | Weak | Moderate | Strong | Weak |
| Silva et al., 2020 | Moderate | Strong | Weak | Moderate | Strong | Strong | Moderate |
| Puyon & Giannopulu, 2013 | Weak | Weak | Moderate | Weak | Moderate | Moderate | Strong |
| Giannopulu et al., 2014 | Weak | Weak | Moderate | Weak | Moderate | Moderate | Strong |
| Ghiglino et al., 2021 | Moderate | Weak | Moderate | Moderate | Strong | Strong | Moderate |
| Pierno et al., 2008 | Weak | Moderate | Moderate | Moderate | Moderate | Weak | Weak |

Table 4. 4 Summary of study characteristics by study design and mostly used robot

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|---|---|--|-----------------|----------------------------|-------------------|---|------------------------------|---|---|
| RANDOMISED CONTROLLED TRIALS | | | | | | | | | |
| De Korte et al., 2020; Netherlands; funded | N=24 (83% male); 3-8 years old | Parent Pivotal Response Treatment N=20 (85% male); 3- 8 years old | Not reported | NAO – Humanoid robot | Not reported | 20 sessions; 45 minutes; Home | Strong | Video recording | Improved self- initiation in robot- mediated Pivotal Response Treatment at 3-month assessment. |
| Huskens et al., 2013; Netherlands; funded | N=3 (100% male); 8-12 years old | Human therapist; N=3 (100% male); 8- 12 years old | 85-111 | NAO – Humanoid robot | Not reported | 5 sessions; 30 minutes; Clinic room | Moderate | Video recording | No significant differences in self- initiated questions at 19-21-week assessment. |
| Marino et al., 2020; Italy; funded | N=7 (86% male); 4-8 years old; Italian | Human therapist; N=7 (86% male); 4-8 years old; Italian | 82-121 | NAO – Humanoid robot | Not reported | 12 sessions; 90 minutes; Laboratory | Strong | Test of Emotional Comprehension & Emotional Lexicon Test | Improved emotional recognition and comprehension in robot group at 12- week assessment. |
| So et al., 2018a; Hong Kong; funded | N=7 (71% male); 6-12 years old; Chinese | Waitlist group robot sessions after research completion; N=6 (83% Males); 6- 12 years old; Chinese | 49-67 | NAO – Humanoid robot | Not reported | 24 sessions; 30 minutes; School | Weak | Video recording | Improved motor imitation (e.g., gestural accuracy) at 12-week assessment for robot group. |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|--------------------------------------|---|--|--------------|------------------------------------|----------------|--------------------------------------|------------------------|-----------------|--|
| So et al., 2018b; Hong Kong; funded | N=15 (87% male); 4-6 years old; Chinese | Waitlist group robot sessions after research completion; N=15 (93% Males); 4-6 years old; Chinese | Not reported | NAO – Humanoid robot | Not reported | 8 sessions; 30 minutes; School | Weak | Video recording | Improved motor imitation (e.g., gestural accuracy) at 10-week assessment for robot group. |
| So et al., 2019a; Hong Kong; funded | N=13 (85% male); 4-6 years old; Chinese | Waitlist group robot sessions after research completion; N=11 (93% male); 4-6 years old; Chinese | Not reported | NAO – Humanoid robot | Not reported | 12 sessions; 45 minutes; Clinic room | Weak | Video recording | Improved narrative skills at 12-week assessment for robot group. |
| So et al., 2019b; Hong Kong; funded | N=12 (83% male); 6-12 years old; Chinese | Human therapist; N=11 (91% male); 6-12 years old; Chinese | 46-74 | NAO – Humanoid robot | Not reported | 4-5 sessions; 30 minutes; School | Weak | Video recording | No significant between-group differences in motor imitation (e.g., gestural accuracy) at 10-week assessment. |
| So et al., 2020a; Hong Kong; funded | N=12 (83% male); 4–6 years old; Chinese | Waitlist group robot sessions after research completion N=11 (91% male); 4–6 years old; Chinese | Not reported | NAO – Humanoid robot | Not reported | 9 sessions; 45 minutes; Clinic room | Weak | Video recording | Improved joint attention in robot-mediated drama sessions at 9-week assessment. |
| Srinivasan et al., 2015; USA; funded | N=12 (92% male); 5-12 years old; Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, | Human therapist; N=12 (83% male); Comparison group (tabletop activities) N=12 (83% male); 5-12 years old; Caucasian, African American, Asian | Not reported | NAO – Humanoid robot & Rovio robot | Not reported | 32 sessions; 15 minutes; Home | Moderate | Video recording | Improved gestural imitation at 10-week assessment in robot group. |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|---|--|---|--------------|------------------------------------|----------------|-------------------------------|------------------------|-----------------|--|
| Srinivasan et al., 2015; USA; funded; (overlapping sample) | Mixed Caucasian and Hispanic N=12 (92% male); 5-12 years old; Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, Mixed Caucasian and Hispanic | Hispanic, Mixed African American and Caucasian, Mixed Caucasian and Hispanic Human therapist; N=12 (92% male); Comparison group (tabletop activities); 5-12 years old; Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, Mixed Caucasian and Hispanic | Not reported | NAO – Humanoid robot & Rovio robot | Not reported | 32 sessions; 15 minutes; Home | Weak | Video recording | Advanced specialised, focused, or intense interests at 10-week assessment for human therapist group. |
| Srinivasan et al., 2016a; USA; funded; (overlapping sample) | N=12 (92% male); 5-12 years old; Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, Mixed Caucasian and Hispanic | Human therapist; N=12 (83% male); Comparison group (tabletop activities) N=12 (88% male); 5-12 years old; Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, Mixed Caucasian and Hispanic | Not reported | NAO – Humanoid robot & Rovio robot | Not reported | 32 sessions; 45 minutes; Home | Moderate | Video recording | Improved social skills at 10-week assessment in robot group. |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|---|--|---|---|------------------------------------|---|--------------------------------------|------------------------|-----------------------------------|--|
| Srinivasan et al., 2016b; USA; funded; (overlapping sample) | N=12 (92% male); 5-12 years old; Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, Mixed Caucasian and Hispanic | Human therapist; N=12 (83% male); Comparison group (tabletop activities) N=12 (88% male); 5-12 years old; Caucasian, African American, Asian Hispanic, Mixed African American and Caucasian, Mixed Caucasian and Hispanic | Not reported | NAO – Humanoid robot & Rovio robot | Not reported | 32 sessions; 45 minutes; Home | Moderate | Video recording | Advanced specialised, focused, or intense interests at 10-week assessment for human therapist group. |
| van den Berk-Smeekens et al., 2021; Netherlands; funded | N=25 (80% male); 3-8 years old | Parent Pivotal Response (PRT) Treatment N=25 (88% male); 3-8 years old & TAU N=23 (83% male); 3-8 years old | PRT group M = 106; PRT & robot group M = 102; TAU M = 100 | NAO – Humanoid robot | Not reported | 20 sessions; 45 minutes; Clinic room | | Social Responsiveness Scale (SRS) | Improved social and communication skills in robot-mediated PRT compared to other groups at 3-month assessment. |
| Zheng et al., 2020; USA; funded | N=11 (gender not reported); 1.64–3.14 years old | Waitlist group robot sessions after research completion N=9 (gender not reported); 1.64–3.14 years old | M = 58.81 | NAO – Humanoid robot | Two children in waitlist and one child in robot group left at first session due to distress | 4 sessions; 10 minutes; Clinic room | Weak | Video recording | No difference in joint attention skills at 9-week assessment. |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|--|---|--|--------------|--------------------------------|----------------|---|------------------------|--|--|
| So et al., 2020b; Hong Kong; funded | N=18 – Tier** 1 (N=6 (67% male), Tier 2 N=6 (100% male), Tier 3 (N=6; 100% male); Tier 1 received the session earlier than Tiers 2 and 3); all 6-8 years old; Chinese | Not applicable | <70 | HUMANE – Humanoid robot | Not reported | 6 sessions; 30 minutes; School | Moderate | Video recording | Improved joint attention at 4-8 weeks assessment in all Tiers. |
| Yun et al., 2017; Korea; funded | N=8 (100% male); 4-7 years old | Human therapist; N=7 (100% male); 4-7 years old | >60 | iRobiQ & CARO – Humanoid robot | None | 8 sessions; 30-40 minutes; Unknown location | Strong | Video recording | No significant between-group differences in eye-contact at 10-week assessment. |
| Costescu et al., 2015; Romania; funded | N=12 (74% male); 6-12 years old | Human therapist; N=15 (74% male); 6-12 years old | Not reported | Keepon-humanoid snowman robot | Not reported | 6 sessions; 120 minutes; School | Moderate | Video recording | Improved emotional intensity and reduced frequency of irrational beliefs in robot group. |
| Pop et al., 2013a; Romania; funded | N=7 (100% male); 4-9 years old | Computer-based session; N=6/ control group no session; N=7; (100% male); 4-9 years old | Not reported | Probo – Mammoth robot | Not reported | 1 session; 10-15 minutes; Clinic room | Strong | Video recording and 7-point Likert scale | Decreased level of prompt in robot group. |
| Pop et al., 2014; Romania; funded | N=5 (100% male); 4-7 years old | Human therapist; N=6 (100% male); 4-7 years old | >70 | Probo – Mammoth robot | Not reported | 1 session; Unknown duration; Clinic room | Strong | Video recording and 7-point Likert scale | Improved level of engagement in robot group. |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|--|--|---|---------------------|-----------------------|-----------------------|---------------------------------------|------------------------|---|---|
| Simut et al., 2016; Belgium; funded | N=30 (90% male); 5 – 8 years old | Human therapist; N=30 (90% male); 5 – 8 years old | 70-119 | Probo – Mammoth robot | Not reported | 1 session; 15 minutes; School | Moderate | Video recording | No significant between-group differences in social skills (e.g., eye-contact, joint attention). |
| Kim et al., 2013; USA; funded | N=24 (87% male); 4 – 12 years old; white, two were black and two were Hispanic or Latino | Human therapist; N=24 (87% male); 4 – 12 years old; white, two were black and two were Hispanic or Latino | 72-119 | Pleo – Dinosaur robot | Not reported | 1 session; 6 minutes; Clinic room | Moderate | Video recording | No significant between-group differences in number of utterances. |
| Kim et al., 2015; USA; funded (overlapping sample) | N=24 (87% male); 4 – 12 years old | Human therapist; N=24 (87% male); 4 – 12 years old | 72-119 | Pleo – Dinosaur robot | Not reported | 1 session; 6 minutes; Clinic room | Moderate | Video recording | Improved level of enjoyment and number of words in robot group. |
| NON-RANDOMISED CONTROLLED TRIALS | | | | | | | | | |
| Huskens et al., 2015; USA; funded | N=3 pairs of 1ASD:1sibling (67% male); 5-10 years old | Not applicable | >80 | NAO – Humanoid robot | Aggression to sibling | 6-8 sessions; 30 minutes; Clinic room | Moderate | Video recording | No significant difference in collaborative behaviour at 12-week assessment. |
| Kaboski et al., 2015; USA; funded | N=8 pairs of 1ASD:1TD* (100% male); 12-17 years old | Not applicable | M ASD=106 M TD*=112 | NAO – Humanoid robot | Not reported | 5 sessions; 180 minutes; Robotic camp | Strong | Social Anxiety Scale for Children-Revised (SASCR), Social Anxiety Scale | Significant decrease in social anxiety for ASD group only. No significant changes in social skills for both |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|--|--|--|-----------------|----------------------------|-------------------|--|------------------------------|---|--|
| | | | | | | | | Adolescents (SAS-A), Social Skills Improvement System (SSIS) Video recording | groups at 2-week assessment. |
| Korneder et al., 2021; USA; funded | N=3 (100% male); 5 years old | Not applicable | Not reported | NAO – Humanoid robot | Not reported | 5 sessions; 3-15 minutes; Clinic room | | | Improved social and communication skills. |
| So et al., 2016; Hong Kong; not reported | N=20 (75% male); 6-12 years old; Chinese | Not applicable | 51-72 | NAO – Humanoid robot | Not reported | 8 sessions; 30 minutes; School | Weak | Unclear | Improved motor imitation (e.g., gestural accuracy) at 12–14-week assessment for robot group. |
| Tapus et al., 2012; Romania; not reported | N=4 (100% Male); 2-6 years old | Human therapist; N=4 (100% Male); 2- 6 years old | Not reported | NAO – Humanoid robot | Not reported | 23-26 sessions; 2-5 minutes with 10- minute break; unclear duration; Clinic room | Moderate | Video recording | Mixed results for eye-contact, initiations, attention between groups at 4- week assessment. Individual data presented per child. |
| Warren et al., 2015; USA; funded | N=6 (100% male); 2.5-4 years old | Not applicable | Not reported | NAO – Humanoid robot | Not reported | 4 sessions; unclear duration; Laboratory | Weak | Video recording | Improved attention at 2-week assessment. |
| Zheng et al., 2016; USA; not reported | N=6 (100% male); 2.5-4 | Not applicable | Not reported | NAO – Humanoid robot | Not reported | 6 sessions; unclear | Weak | Video recording | The robot attracted the attention at 8- month assessment. |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|--|----------------------------------|---|--------------|------------------------------------|--|--|------------------------|---|--|
| | years old; Caucasian | | | | | duration; Laboratory | | | |
| Kumazaki et al., 2018a; Japan; funded | N=11 (82% male); Mage=15.91 | Human therapist; N=11 (82% male) Mage=15.91 | Not reported | ACTROID-F & CommU – Humanoid robot | Not reported | 1 session; 5 minutes; Clinic room | Moderate | Audio recording | Improved in length self-disclosure statements in CommU (simple) robot group. |
| Kumazaki et al., 2018b; Japan; funded | N=16 (75% male); 5-6 years old | Human therapist; N=12 (58% male); 5-6 years old | >70 | CommU – Humanoid robot | One child in robot group distressed unable to complete session | 1 session; 15 minutes; Unknown location | Moderate | Video recording | Improved joint attention in robot group. |
| Yoshikawa et al., 2019; Japan; funded | N=4 (100% male); 15-18 years old | Human therapist; N=4 (100% male); 15-18 years old | Not reported | Actroid-F – Humanoid robot | Not reported | 5 sessions; one day; Laboratory | Weak | Video recording & eye tracker | Improved eye-contact in robot group. |
| Srinivasan et al., 2013; USA; not reported | N=1 (100% male); 7 years old | Child-led condition; N=1 (100% male); 7 years old | Not reported | Isobot – Humanoid robot | Not reported | 8 sessions; 30 minutes; Unknown location | Moderate | Video recording; Sensory Integration and Praxis Test (SIPT) | Improved motor imitation skills in robot group at 6-week assessment. |
| Srinivasan & Bhat, 2014; USA; funded | N=2 (100% male); 7-8 years old | Not applicable | Not reported | Isobot – Humanoid robot | Not reported | 8 sessions; 30 minutes; Home | Moderate | Video recording | Decreasing attention at 6-week assessment. |
| Costa et al., 2018; Luxembourg; funded | N=15 (100% male); 4-14 years old | Human therapist; N=15 (100% male); 4-14 years old | 80-120 | Qtrobot – Humanoid robot | Not reported | 1 session; 1.5-4 minutes; Laboratory | Moderate | Video recording | Improved attention and advanced specialised, focused, |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|---|---------------------------------|--|--------------|--------------------------|----------------|---|------------------------|--|--|
| Duquette et al., 2008; Canada; funded | N=2 (100% male); 4-5 years old | Human therapist; N=2 (50% male); 5 years old | Not reported | Tito – Humanoid robot | Not reported | 22 sessions; 3-4 minutes; Laboratory | Weak | Video recording | or intense interests in robot group. Mixed findings in imitation (e.g., verbal, motor, facial) skills between groups at 7-week assessment. |
| Lecciso et al., 2021; Italy; not reported | N=6 (100% male); 6-13 years old | Computer-based Training; N=6 (100% male); 6-13 years old | Not reported | Zeno – Humanoid robot | Not reported | 4 sessions; Unclear duration; Clinic room | | Facial Emotion Recognition Task (FERT) and Basic Emotions Production Task (BEPT) | No significant difference on facial emotional recognition and expression between groups. |
| Scassellati et al., 2018; USA; funded | N=12 (58% male); 6-12 years old | Not applicable | >70 | No name – Humanoid robot | Not reported | 30 sessions; 30 minutes; Home | Weak | Video and audio recording | Improved social skills (e.g., initiations, joint attention eye-contact, engagement) at 4-week assessment. |
| Pop et al., 2013; Romania; funded | N=3 (100% male); 5-6 years old | Not applicable | Not reported | Probo - Mammoth robot | Not reported | 1 session; Unclear duration; Clinic room | Strong | Video recording and qualitative notes | Improved emotional recognition. |
| Simut et al., 2012; Romania; funded | N=4 (50% male); 4-9 years old | Human therapist; N=4 (50% male); 4-9 years old | Not reported | Probo - Mammoth robot | Not reported | 6 sessions; 15 minutes; Clinic room | Moderate | 7-point Likert scale | Decreased level of prompt in robot group. |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|--|--|---|--------------|---------------------------|----------------|--|------------------------|---|--|
| Vanderborgh et al., 2012; Romania; funded | N=4 (50% male); 4-9 years old | Human therapist; N=4 (50% male); 4-9 years old | Not reported | Probo - Mammoth robot | Not reported | 6–8 sessions; 10-20 minutes; Clinic room | Moderate | Video recording | Decreased level of prompt in robot group at 4-week assessment. |
| Silva et al., 2018; Portugal; not reported | N=10 (100% male); 6-9 years old | Living dog; N=10 (100% male); 6-9 years old | Not reported | Zoomer – Dog robot | Not reported | 3 sessions; 10 minutes; Home | Weak | Video recording | Improved emotional regulation in living dog condition at 4-week assessment. |
| Silva et al., 2019; Portugal; funded | N=10 (100% male); 6-9 years old | Living dog; N=10 (100% male); 6-9 years old | Not reported | Zoomer – Dog robot | Not reported | 1 session; 3 minutes; Home | Weak | Video recording | Improved emotional regulation and social communication in living dog condition at 4-week assessment. |
| Silva et al., 2020; Portugal; funded | N=10 (100% male); 5-8 years old | Living dog N=10 (100% male); 5-8 years old | Not reported | Zoomer – Dog robot | Not reported | 1 session; unclear duration; Home | Moderate | Video recording | Improved imitation in living dog condition. |
| Puyon & Giannopulu, 2013; France; not reported | Game group; N=11 (72% male); 7-8 years old | No game group; N=11 (72% male); 7-8 years old | Not reported | "POL" – chicken robot | Not reported | 1 session; 10 minutes; Clinic room | Weak | Video recording | Improved eye-contact, number of words, better posture in game play robot condition. |
| Giannopulu et al., 2014; France; not reported | N=15 (73% male); 6-7 years old | Human therapist; N=15 (73% male); 6-7 years old | Not reported | "Pekoppa" – Other robot | Not reported | 1 session; 15 minutes; Clinic room | Weak | Unclear | Improved expressive language in robot group. |
| Ghiglino et al., 2021; Italy; funded | N=24 (79% male); 4-7 years old | Human therapist; N=24 (79% male); 4-7 years old | Not reported | Cozmo – toy (truck) robot | Not reported | Not reported; 10 | | Early Social Communication Scale (ESCS) | Improved social skills in robot-mediated |

| Reference; Country; Funding | Robot group | Control group | IQ | Robot type | Adverse events | Session details | Risk of bias (overall) | Measure | Outcome |
|--|--|---|-----------------|---|-------------------|--|------------------------------|-----------------|---|
| Pierno et al., 2008; Italy; funded | N=12 (50% male); 10-13 years old | Human therapist; N=12 (50% male); 10-13 years old | Not reported | Robotic arm – industrial robot | Not reported | minutes; Clinic room 1 session; 60 minutes; Laboratory | Weak | Video recording | training at 10-week assessment. Improved attention in robot-mediated group. |

*TD: typically developing, ** Tier: Tier 1 received session earlier than Tiers 2 and 3.

4.3.4 Robot types

In the studies included in the review, three robot types were employed that were characterised according to their appearance: humanoid, animaloid, and other.

A humanoid robot resembles the human body. Some humanoid SARs may have facial characteristics including eyes, nose, and mouth, a torso, two arms and two legs whereas other humanoids may model parts of the body from the waist up only including a torso with a face with distinct facial characteristics. Humanoid SARs were used in 68% (30 out of 44) of the included studies. The robot platforms that facilitated a session with autistic children were the following: NaO, qTrobot, CommU, ACTROID-F, Isobot, Tito, iRobiQ, Car, Keepon, Zeno and HUMANE. The most frequently used SAR was NAO which was used in 18 studies (Huskens et al., 2012, 2015; Kaboski et al., 2015; Korneder et al., 2021; Korte et al., 2020; Marino et al., 2019; So et al., 2016, 2018a, 2018b, 2019a, 2019b, 2020a, 2020b; Srinivasan et al., 2015; Tapus et al., 2012; van den Berk-Smeekens et al., 2021; Warren et al., 2015; Zheng et al., 2016, 2020). Studies used humanoid robots to examine a range of skills including social and communication skills and emotional development skills.

The use of animaloid (or animal-like) robots was examined in 25% of studies (11 out of 44) included in the review. Animaloid robots have taken the form of different animals such as an elephant, dinosaur, dog, and chicken. In this review, the Probo (elephant-like) was referenced in six studies (Pop et al., 2013a, 2013b, 2014; Simut et al., 2012, 2016; Vanderborght et al., 2012). Other animaloid robots were the dinosaur robot, Pleo, (Kim et al., 2013), the dog robot, Zoomer, (Silva et al., 2018, 2019, 2020) and POL, (chicken-like) (Puyon & Giannopulu, 2013). These robots facilitated sessions with autistic children focusing on social and communication skills.

The remaining “Other” robot category included a plant robot, called Pekoppa, a toy robot called Cozmo and a robotic arm. Pekoppa, the plant robot, was fully programmable with integrated sensors that allowed the robot to model a range of functions. Pekoppa was used with neurotypical children and autistic children to compare the differences in heart rate, verbal fluency, and emotional response (Giannopulu et al., 2014). Cozmo, the toy robot, is a small-size truck robot that moves around through tracked wheels to examine social and communication skills (Ghiglino

et al., 2021). The robotic arm that was used with autistic children to examine imitation and eye-contact (Pierno et al., 2008). A robotic arm consists of a manipulator arm designed to repeat tasks (Retrieved from <https://robots.ieee.org/learn/types-of-robots/>). The robotic arm was clustered as an industrial robot.

When exploring trends across study type, it appeared that humanoid robots were used in both RCTs (n = 14) and non-RCTs (n = 16), though proportionally, the RCTs more often included humanoid robots (14 out of 18; 77% versus 16 out of 26; 61% respectively). In particular, the robot NAO was utilised in 11 RCTs compared to seven non-RCTs (see Table 4. 4). Non-RCTs were therefore more likely to include a broader range of robot platforms.

4.3.5 Settings

Sessions with robots and autistic children took place in five different settings. The most common location was reported to be autism clinics/centres (n = 19, 43%) followed by home (n = 7, 16%), school (n = 7, 16%), laboratories (n = 7, 16%) and robotic camps (n = 1, 2%) (see Table 4. 5). Table 4. 5 uses the vote count methodology to map RCTs and non-RCTs by both their setting and whether or not individual studies reported development in targeted skills.

Table 4. 5 *Vote count mapping RCTs and non-RCTs by setting and session gain*

| Setting | Positive outcome (skills development) | | No significant difference | | Negative outcome | | Total |
|----------------------|--|---------|------------------------------|---------|------------------|---------|-------|
| | RCT | Non-RCT | RCT | Non-RCT | RCT | Non-RCT | |
| Autism clinic/centre | 5 | 8 | 3 | 3 | 0 | 0 | 19 |
| Home | 2 | 4 | 0 | 0 | 0 | 1 | 7 |
| Laboratory | 1 | 5 | 0 | 1 | 0 | 0 | 7 |
| School | 4 | 1 | 2 | 0 | 0 | 0 | 7 |
| Robotics camp | 0 | 0 | 0 | 1 | 0 | 0 | 1 |
| Not reported | 0 | 2 | 1 | 0 | 0 | 0 | 3 |

There was a trend for robot-mediated sessions in RCTs to be more likely to take place in autism clinics/centres (n = 8 out of 18; 44%) compared to non-RCTs (n = 11 out of 26; 43%) or in a familiar environment such as school (n = 6 out of 18; 33%) compared to non-RCTs (n = 1 out of 26; 4%). Sessions at home were more common in non-RCTs (n = 5 out of 26; 19%) compared to RCTs (n = 2 out of 18; 11%). Likewise, sessions in a laboratory were prevalent in non-RCTs (n = 6 out of 26; 23%) as opposed to RCTs (n = 1 out of 18; 5%). Sixty-six percent (n = 12) of RCTs and 77% of non-RCTs (n = 20) indicated a positive benefit of robot-mediated support. This indicates some consistency of learning gains across settings. Table 4. 6 further summarises the characteristics of a training session across all included studies.

Table 4. 6 *Summary of evidence from robot-mediated support in autistic children*

| Robot-mediated support characteristics | | |
|--|--------------------------------------|----|
| Mean number of sessions (SD; range) | 7.90 (8.34; range: 1 – 32 sessions) | |
| Mean duration of sessions (SD; range) | 32.1 (34.81; range: 3 – 180 minutes) | |
| Session frequency | <i>n</i> | % |
| Single session | 2 | 5 |
| Daily | 5 | 11 |
| Once a week | 10 | 23 |
| Twice a week | 11 | 25 |
| Three times a week | 1 | 2 |
| Varied frequency | 4 | 9 |
| Not reported | 11 | 25 |
| Play partner | <i>n</i> | % |
| Researcher | 27 | 62 |
| Child/Clinical Psychologist/ Psychotherapist | 13 | 29 |
| Parent | 1 | 2 |
| No play partner | 3 | 7 |

4.3.6 Robot's role and training session characteristics

During a session, robots took the role of a social interface. For example, some SARs moved their head and eyes to verbally express or non-verbally demonstrate emotions via facial expressions (e.g., happy, sad). Other SARs behaved as a storyteller or an imitation agent or an intermediate to attract the eye gaze of the autistic child or to facilitate collaboration within a small group of two children or an object where autistic children engaged in free play.

In most studies ($n = 42$, 95%), autistic children engaged in a triadic relationship with a therapist/adult play partner/sibling where the robot acted as a mediator in the interaction in the two parties. A typical session involved the therapist/adult play partner controlling the robot via a laptop/computer. Two studies used a fully autonomous robot to play independently without the guidance of a therapist/adult play partner (Giannopulu et al., 2014; Pyon & Giannopulu, 2013). The control group in nine RCTs was a human therapist engaging the child with the same or similar activities with the exception of five studies that used a waitlist as control who received the robot session after study completion. It was unclear whether the waitlist children in these studies were receiving no treatment at all or usual care that is part of education and community settings. The remaining four studies offered dyadic sessions with the robot and the autistic person alone in a room (Pyon & Giannopulu, 2013; Warren et al., 2015; Yoshikawa et al., 2019; Zheng et al., 2016).

The mean number of training sessions autistic children were offered with a robot was eight (SD: 8.34; range: 1 – 32) with each session itself lasting on average 32.1 minutes (SD: 34.81; range: 3 – 180 minutes) (see Table 4. 6). The first session was usually a familiarisation meeting with the child and/or the robot and/or therapist/adult play partner. The sessions were most frequently delivered twice a week (25%) or weekly (23%) over the session period, though there was considerable variability. Sessions tended to be longer in RCTs, with a mean of 37 (SD: 29.00; range: 6 – 120) versus 27 (SD: 38.56; range: 3 – 180) minutes in non-RCTs. The number of sessions was greater in RCTs with a mean of nine sessions (SD: 8.87; range: 1 – 32) compared to seven sessions (SD: 7.87; range: 1 – 30) in non-RCTs.

Autistic children had individual sessions apart from three studies where they collaborated with their neurotypical siblings (Huskens et al., 2015) or other neurotypical children in one-to-one play game activities where they worked in a group setting (Kaboski et al., 2015) or autistic children joined a group in a robot-mediated cognitive behaviour therapy (Costescu et al., 2017). The sessions were delivered by researchers experienced in autism (n = 27, 62%). Only 13 (29%) studies provided details on the professional background of the therapist/adult play partner which included child or clinical psychologists as well as psychotherapists. Detailed information is presented in Table 4. 6.

4.3.7 Targeted skills and outcomes

Studies included in this review targeted a number of skills that are clustered in three categories: 1. social and communication skills including narrative skills (n = 1), self-initiated questions (n = 4), engagement (n = 5), self-disclosure (n = 1), collaborative play (n = 1), level of prompting (n = 3), eye-contact (n = 6), imitation (n = 7), joint attention (n = 14); 2. emotional development such as recognition and/or understanding (n = 3), emotional regulation (n = 4); and 3. motor skills including (n = 3). The targeted skills which showed improvement in eye-contact, emotional recognition and regulation, joint attention, imitation (e.g., gesture and facial recognition and verbal production), verbal skills (e.g., self-disclosure, initiations, narrative skills, expressive language), level of prompting, engagement, collaborative play, and specialised, focused, or intense interests due to robot-mediated support. Outcomes showing little, if any, significant improvement were motor imitation skills.

More than two-thirds (n = 28; 63%) of the studies reported a positive impact of robot-mediated support in autistic children. Only 27% (n = 12) of studies reported no difference in comparison to traditional autism specific support in the performance of autistic children using a robot. Five studies (11%) reported a positive impact of the non-robot session. Finally, one study reported a decline in attention skills during the session period (Srinivasan & Bhat, 2014). Detailed information is listed in Table 4. 4.

The majority of the targeted skills were measured through the examination of video recordings and coding procedures completed by researchers whereas only five studies (Ghiglino et al., 2021; Kaboski et al., 2015; Lecciso et al., 2021; Marino et al., 2020; van

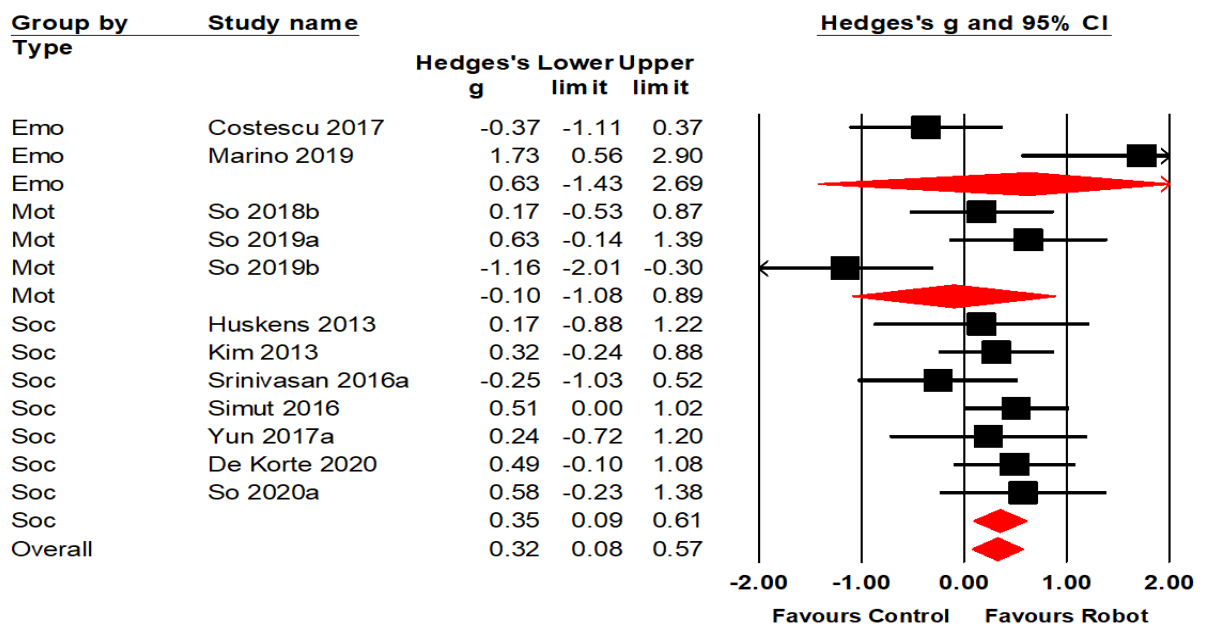
den Berk-Smeekens et al., 2021) used standardised assessment tools to examine social and communication skills and emotional development skills (see Table 4. 4). Eleven studies (Ghiglini et al., 2021; Marino et al., 2020; Pop et al., 2013a; So et al., 2018a, 2018b, 2019a, 2019b, 2020a; Srinivasan & Kaur, 2015; van den Berk-Smeekens et al., 2021; Yun et al., 2017) used researchers blind to allocation to administer the questionnaires and one study (Kaboski et al., 2015) relied on unblinded parent-reported outcomes. Another three studies (Pop et al., 2013a, 2014; Simut et al., 2012) utilised child self-report methods and one used eye-tracking in conjunction with video recordings (Yoshikawa et al., 2019). Four studies made explicit reference to the benefits of robot-mediated support at two weeks (Huskens et al., 2013), four weeks (So et al., 2019a), 10 weeks (Ghiglini et al., 2021) and 12 weeks (van den Berk-Smeekens et al., 2021) following the end of the session. Finally, Marino and colleagues (2020) reported that autistic children in both groups (robot and human) spontaneously practised the trained skills addressing generalisation issues. No studies included evaluation of health economics related to session delivery.

4.3.8 Meta-analysis

Hedge's g was calculated for RCTs examining outcomes relating to social and communication ($k = 7$), emotional development ($k = 2$) and motor ($k = 3$) skills and for all three areas combined ($k = 12$). This provided a total of 346 participants (175 assigned to robot and 171 assigned to control conditions). Ten RCTs were excluded from the analyses because of: 1. overlapping samples (Kim et al., 2015; Srinivasan et al., 2015a, 2015b; 2016b); and 2. use of waitlist group and/or no reporting (or sharing when contacted directly) of means, standard deviations, or effect sizes (Pop et al., 2013a, 2014; So et al., 2018a, 2020b; van den Berk-Smeekens et al., 2021; Zheng et al., 2020). The included RCTs had quite good quality ratings: strong ($k = 4$), moderate ($k = 6$) and weak ($k = 3$). All three of the weak ratings were for the studies by So and colleagues (So et al 2018b, 2019a, 2019b) and all were assessing motor skills.

RCTs providing sufficient data for emotional development skills to be examined revealed a non-significant effect size ($g = 0.63$ [95%CI -1.43 to 2.69]; $k = 2$). Heterogeneity was high ($I^2 = 88.65$). For trials assessing motor skills, the effect size was again non-significant ($g = -0.10$ [95%CI -1.08 to 0.89]; $k = 3$) and heterogeneity was

again high ($I^2 = 79.63$). For social and communication skills, the effect size was significant ($g = 0.35$ [95%CI 0.09 to 0.61; $k = 7$) and heterogeneity was low ($I^2 = 0.00$). When we combined all three sets of outcomes to assess any pooled benefit of robot-mediated support (see Figure 4. 2), the effect size was significant ($g = 0.33$ [95%CI 0.08 to 0.57; $k = 12$) and heterogeneity was moderate and significant ($I^2 = 54.48$). Visual analysis of funnel plots did not suggest any asymmetry and evidence of obvious publication bias (see Figure 4. 3).



Note. Emo, Mot and Soc= emotion, motor and social outcomes

Figure 4. 3 Forest plot showing efficacy of robot-mediated support on emotional, motor and social outcome variables

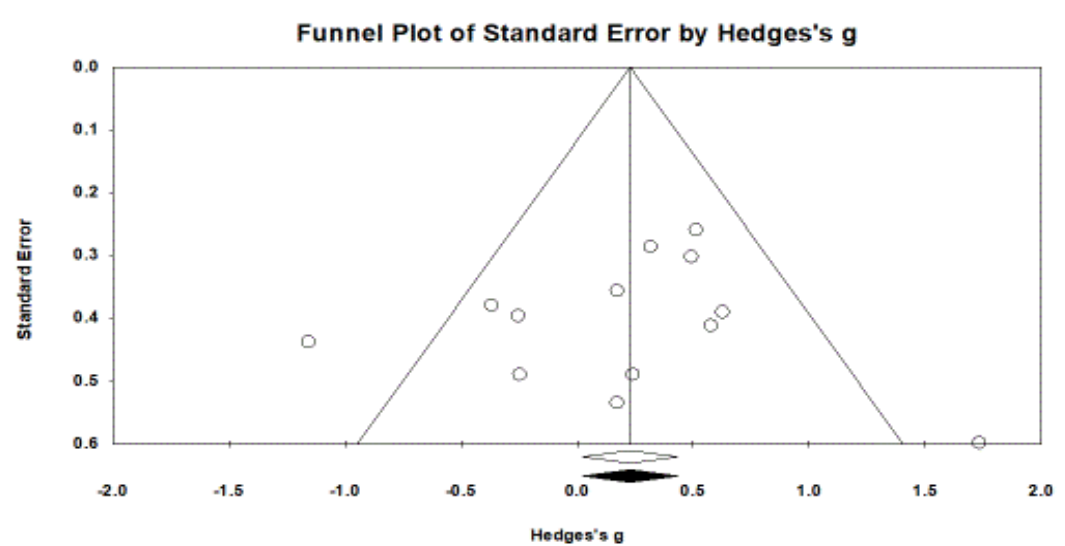


Figure 4. 4 Funnel plot exploring publication bias

Although there is no definitive minimum number of studies required for meta-regression, the general recommendation of at least 6 to 10 studies for a continuous variable was followed (Higgins et al., 2019). Meta-regression was used to assess various possible moderators across all 12 RCTs in the meta-analysis. The age of the autistic child was found to be a significant moderator ($z = -1.97$, $df = 12$, $p = .02$) with effect sizes being significantly larger in younger samples aged 4 – 7 years (see Figure 4. 4). Indeed, age accounted for nearly a third of the variance in effect sizes (analog $r^2 = .32$). None of the other continuous variable moderators examined were significant including: 1. total length of time in sessions ($z = 0.40$ $df = 12$, $p = .35$); 2. proportion of male participants ($z = 0.97$, $df = 12$, $p = .17$); and 3. IQ ($z = 1.44$ $df = 8$ $p = .07$). The current meta-analysis revealed a trend toward greater effect sizes in autistic children with higher IQ. Nonetheless, the current meta-analysis had missing data from four studies and the samples were rather bimodal with two studies having a mean IQ in the 50 to 60 range and the rest being 90 to 105. Sub-group analysis was also used to see if the context (e.g., home, school, clinic) impacted effect sizes across all RCTs. This analysis showed a significant impact of robots in the clinic ($g = 0.57$ (95%0.16 to 0.98; $k = 5$) with low heterogeneity ($I^2 = 21.96$). By contrast robots were not efficacious in either the home $g = 0.16$ (-0.56 to 0.89; $k = 2$; $I^2 = 55.55$) or in school $g = -0.16$ (-0.85 to 0.53; $k = 4$, $I^2 = 75.19$).

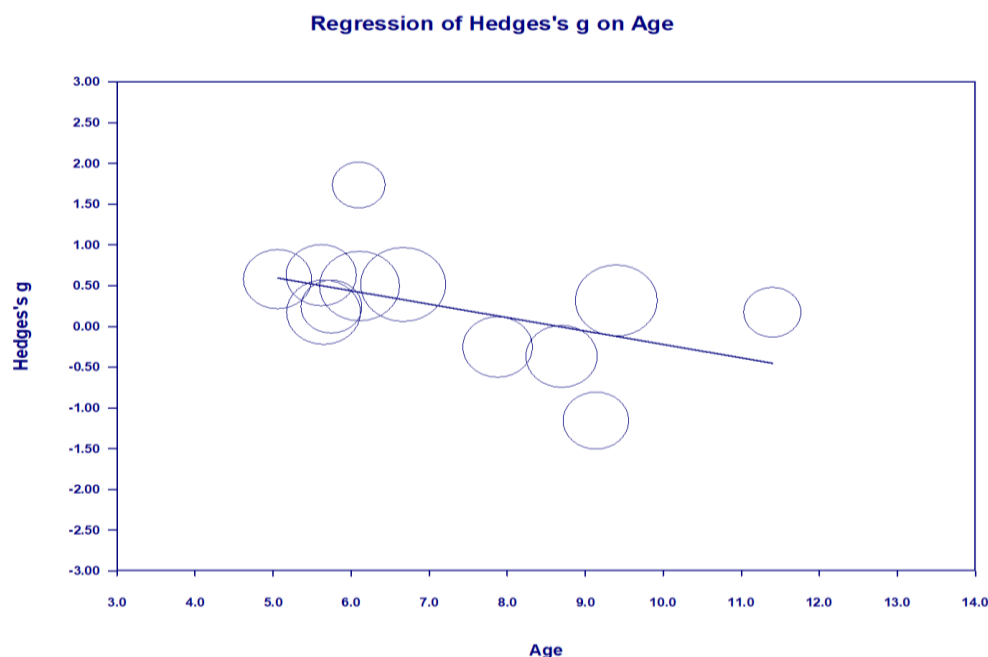


Figure 4. 5 *The impact of age on effect size for robot-mediated support*

4.4 Discussion

This systematic literature review and meta-analysis intended to summarise available evidence on the use of robots with autistic children. It aimed to understand the typology of included robots, the settings of robot-mediated support, the function of the robot during sessions and the specific skills targeted for gain in autistic children aged up to 18 years. This is the first review to include a meta-analysis estimating the efficacy of robots to bring about meaningful gains, particularly in social and communication skills. The meta-analysis of RCT data highlighted some key factors that moderate effect sizes. These include age, with younger individuals appearing to benefit more and with effects being significantly larger in autism clinics/centres. In addition, the systematic literature review and meta-analysis reported that the benefits associated with robots were not moderated by the session length, cognitive capacity (IQ), or the proportion of males per sample. These findings support the use of robot-mediated support as an evidence-based, relatively brief form of support (most protocols include an average of 8 sessions each lasting approximately 30 minutes) with meaningful skills development, in particular, for social and communication skills at least in the immediate post session period. Longer-term follow-up was lacking and limited the extent to which the generalisation of skills in daily life can be examined, and expectations managed, for example amongst parents, about the sustainability of development. For example, of the included RCTs, the median duration of follow-up data reported was 12 weeks since baseline assessment. Longer-term data are essential to better understand retention of learned skills, support commissioning decisions and parent expectations about session outcomes and gains.

The majority of studies in the systematic literature review focused on evaluating the usefulness of humanoid robots, with a minority also including animaloid ones. Both robot types benefit from the capacity to represent familiar social cues to autistic children in a controlled environment, for example, facial features such as eyes. For humanoid robots, in particular, technological advances have enabled them to engage in a range of human-like functions where, importantly for autistic children, perceptual processing between human and objects appears to be similar (Kaiser et al., 2010). This

supports the use of robots in general as mediators. The most often studied outcome of interest were three clusters, with the majority of studies concentrating on social and communication or emotional development skills in keeping with the social nature of the robots and a few on motor imitation skills. For example, eye-contact, joint attention, collaborative play behaviours, imitation, engagement, specialised, focused, or intense interests, and engagement, emotional recognition. In most cases, outcome measures were captured via video recordings compared to standardised assessment questionnaires. Nevertheless, 81% of coders were not blinded in studies collecting outcome measures via video recordings. The reason for unblind coders was justified because the robot was visible during data coding of the session. Future studies should use blind researchers to the allocation of groups coding sessions in a naturalistic environment (e.g., free play) to evaluate the long-term effect of gained skills.

Interestingly, the majority of studies made use of autism clinics/centres and research laboratories for session delivery with few studies based in everyday learning environments such as the child's home or school. A recent qualitative study found that educators are not uncritically approving of the use of robots in schools (Alcorn et al., 2019). Although the appeal of robots has been reported in the literature (e.g., engaging, consistent, motivating, predictable), educators request protocols on the way and the reason robots should be used to facilitate learning. Taken with the findings of the meta-regression that showed an overall non-significant effect of session based in the school environment, this suggests that future research should focus far more on the clarity with regards to the theory of change underpinning the use of robots in therapy and optimising the effect of robot-mediated support manuals, session training, technical support throughout the delivery of sessions and their practicability in this setting. However, autism clinics/centres appear to be the most beneficial location, naturalistic settings are arguably more convenient locations to embed a robot-mediated support and may indeed also be more cost effective. Though no studies included a health economic evaluation of robot-mediated sessions to support this assertion. Nonetheless, for evidence-based autism specific support to reach the community at the most developmentally appropriate time, school environments offer a mechanism for more children to benefit. Other researchers have also suggested that the use of everyday settings is less represented in autism research (Stahmer et al.,

2019). The examination of a naturalistic environment for the autistic child though might bring benefits in autism research because different professionals will be working towards a shared goal of improving everyday functioning and outcomes for autistic children and their families (Stahmer et al., 2019). It is imperative to translate research into practice by effective ways of integrating robots across a range of community settings.

There were encouraging findings with the majority of studies ($n = 28$; 63%) reporting that robot-mediated support was beneficial in bringing gain either compared to no session at all or as compared to sessions with a human therapist/adult play partner alone. The latter suggests that robots have an augmentative impact on learning. Indeed, in 95% of the studies, robots had taken the role of a mediator between the autistic child and the therapist/adult play partner who typically controlled the robot through a keypad. That is to say that robots were used to assist the interaction between the autistic child and therapist/adult play partner in the main, as opposed to the robots acting as an independent therapist. Although there are autonomous robots (e.g., NAO), therapists/adult play partners use robots as an attractive toy to engage autistic children in the session to support social needs (Robins, Dautenhahn, & Dubowski, 2006; van Straten et al., 2018). In addition, therapists/adult play partners used robots with autistic children to facilitate imitation of hand gestures and/or facial expressions which in turn preserved energy and time in therapists/adult play partners (Aresti-Bartolome & Garcia-Zapirain, 2014; Diehl et al., 2012) whilst autistic children benefited from the robot's consistency to repeat the same movement and/or facial expression multiple times. It is perhaps unsurprising therefore that the literature review findings highlight the advantage of robot-mediated support in social and communication skills such as the alignment of theoretical underpinning with outcomes of interest. The meta-analysis also provides evidence for a small to moderate benefit of robots for social and communication skills. By contrast, the evidence of impact on emotional development and motor skills was harder to obtain, largely because of the small number of RCTs, and the large heterogeneity associated with those outcomes – which would undoubtedly reduce the power to detect any emotion or motor effects. Indeed, to detect the average effect size reported here (0.35), a sufficiently powered future trial would require 100 per group (robot and

human). The effect size of 0.35 may seem quite small; however, this needs to be considered in the context that such effects may have huge benefits for the children themselves and potentially a cumulative effect over time. The latter will require future research to also conduct longer follow-up analyses.

Using the Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project, 1998), the majority of studies were rated as either moderate or weak in terms of risk of bias assessment. Only eight (18%) studies were rated as strong, and this related mainly to RCTs which would be expected to score highly given standards of rigour for this type of study design and reporting criteria. Selection bias [k = 40 (91%); 16 RCTs; 24 non-RCTs] and reporting on confounding variables [k = 40 (91%); 16 RCTs; 24 non-RCTs] were both identified as common issues. Other researchers have also expressed concern about selection bias in autism studies, specifically the exclusion of autistic children with intellectual disability (Russell et al., 2019). Transparency in reporting full sample characteristics as well as the implementation of more randomised study designs (currently accounting for almost a third of studies in the review) will likely help address poor study risk of bias ratings.

Of excluded articles, over 50% were due to no reporting on the diagnosis of included children. Importantly, a better understanding of study samples will help to address questions such as who is more likely to benefit from robot-mediated support. At a minimum, knowing the age, sex assigned at birth, ethnicity, autism diagnosis and method of diagnosis, as well as details of co-occurring conditions, family structure and deprivation would help provide important information about potential moderators and mediators of observed therapeutic impact. Researchers in the field of robots and autism are encouraged to consider these attributes in future study designs. The majority of studies also did not include baseline cognitive assessment (IQ) of included autistic children. This further limit the understanding of for whom robot-mediated support may be more beneficial or further help with developmental tailoring. The current meta-analysis revealed a trend toward greater effect sizes in autistic children with higher IQ. Nonetheless, the current meta-analysis had missing data from four studies and the samples were rather bimodal with two studies having a mean IQs in the 50 to 60 range and the rest being 90 to 105. In future studies, transparency and

consistency in reporting sample characteristics is critical. This will allow improved targeting and adaptation of session protocols for those for whom robot-mediated support is more effective.

Lastly, since 2008, the number of studies in this area has increased, as has the proportion of studies that have received funding, indicating that the interest in autism and robots is increasing, especially from researchers based in the United States and Europe. The relative scarcity of international research on autism and robots may indicate the need for broader global perspectives on human-robot interaction and cultural impacts on autism session design (Hashim & Yossuf, 2017). Hashim and Yussuf (2017), for example, stated that robots should be humanised, assist ethical, spiritual, and religious learning, hence increasing autism research's cross-cultural appeal. We support approaches that strive to modify sessions for cross-cultural benefit, based on the findings of the current meta-analyses.

4.4.1 Strengths and limitations

This is one of the first systematic literature reviews that is preregistered on PROSPERO and provides the first meta-analysis of evidence on robot-mediated support for autistic children. In addition, the search of the grey literature generated articles that are included in this review and offers a more balanced picture of the current literature, minimising potential for publication bias. Evidence from the meta-analysis did not point to any obvious publication bias amongst RCTs. In doing so, key insights into the nature of research in this area, including novel dimensions missing from the few other available reviews have been summarised (Pennisi et al., 2016; Salimi, Jenabi, & Bashirian, 2021). This includes the scope of robot types, their roles in a session, the settings in which sessions are typically based, and assessment of bias across individual studies. This evidence will be helpful to researchers, clinicians, educators, and the autistic community especially as the field of technology-assisted learning in autism is seeing an expansion (Chia et al., 2018; Virnes et al., 2015; Wong et al., 2015; Zervogianni et al., 2020).

Still, there are some limitations of the review to acknowledge. This review excluded qualitative studies (n=2) that were case studies of observations from two and three autistic children, respectively, evaluating exposure to a robot-based session.

Qualitative studies were not in scope because it was anticipated that they may be methodologically distinct to those designed to be undertaken with large groups and these differences may matter for the review findings. Nonetheless, from the identified studies, exclusions based on this method selection were minimal. A number of articles (n = 97) were excluded mainly due to poor reporting on autism diagnosis. It should be highlighted that children up to (and including) 18 years old who were self-identified as autistic were excluded from this review which limits the merit of this review to those with a confirmed diagnosis and fails to address the more generic overview of the use of robots in autism. Systematically excluding this data was intentional as per the review inclusion criteria but may have introduced nuances as we cannot rule out that these studies included data from the true population of interest. Further, the evidence from meta-analysis should be considered with the caveat that we could derive data from a few studies (only 12 RCTs out of 18), although this constitutes data from almost two-thirds of the trials. In addition, it should be noted that the examination of moderator variables was limited to analyses that were pooled across all three outcomes (e.g., social and communication, emotional and motor) in order to obtain sufficient data points. Despite such limitations, the findings for social and communication skills appeared to be particularly promising, while those relating to emotional development and motor skills will require further research. Only three studies reported adverse events including aggression to a neurotypical sibling during the session (Huskens et al., 2015) and distress which led to ending the session (either in the robot group or the waitlist) (Kumazaki et al., 2018b; Zheng et al., 2020). So, it was not possible to report adverse events as this data was poorly reported in studies which indicates that ethical considerations were not prioritised in SARs research. In addition, small sample sizes with fewer than 10 participants were noted in more than 50% of the studies. The small sample size may be influenced by the marked variance seen in individual abilities and support needs of autistic children. Besides, studies reported children's level of cognitive functioning (IQ) in 18 studies which impeded further analysis of the effect of robot-mediated support based on additional needs for this population group. Finally, as previously stated, the research studies included in this review focused on the outcome of brief exposure and its impact in the immediate post session or short follow-up period. As a result, while robot-mediated support

appears promising, it is uncertain the extent to which skills are retained and generalised over time into everyday life.

4.4.2 Future recommendations

This systematic literature review and meta-analysis suggest that there is considerable interest in the evaluation of clinical effectiveness of robot-mediated support for autistic children. Robots are suggested being appropriate to personalisation, scalability and cost-effectiveness and hence offer enormous potential as an alternative autism specific support (Boccanfuso et al., 2017; Huijnen et al., 2017). However, greater reporting across study designs on sample recruitment and characteristics and adverse events, as well as further standardisation of outcome measures are required to maximise session benefits. A recent study on adverse events reporting in autism research with children presented that only 7% of studies (11 out of 150) reported adverse events (Bottema-Beutel et al., 2021). Adverse events reporting in autism research is imperative to ensure participants' safety is prioritised. The repeated lack of adverse events reporting in autism research indicates that quality research and ethical considerations might be disregarded while designing a research study. There is evidence that transparency in research procedures is valued not only by researchers to enhance their knowledge and critically review a work but from the autistic community that aims to contribute to high quality autism research (Gowen et al., 2021; Nicolaidis et al., 2019). Monitoring of adverse events reporting in autism research is key to outweigh the advantages of specific support compared to its disadvantages. In addition, clinical effectiveness will be restricted unless it is evaluated using randomised designs that offer evidence of immediate and long-term specific support benefits, safely. The importance of implementing specific support consistently across settings has also been emphasised (Koegel & Koegel, 2006). Further, multiple professionals should engage in collaborative work to support autistic children increase the likelihood of greater specific support benefits and rapid progress (Koegel & Koegel, 2006). A multidisciplinary approach to harnessing technology improvements, methodological issues, and evaluation of behavioural and psychological effects would benefit robotic study design and evaluation. Furthermore, gaining consensus among the robotics research community on session evaluation would be beneficial, and it would be possible to draw on current methodologies that

have informed comparable frameworks in autism specific support (Dawson-Squibb & de Vries, 2019). Training of advanced skills with more complex activities in a naturalistic environment appears to be the next step of robot-mediated sessions. Finally, if there is evidence of the effectiveness of SARs, then research could expand to evaluate the possibility of easily programmed personalised specific support for autistic children.

4.5 Conclusions

Humanoid robots were the most widely applied form of robots to support social and communication skills for autistic children. With little heterogeneity, the effect size for social and communication skills was considerable. Session protocols were often brief and executed at autism clinics/centres, then at home, in schools, and in laboratories, with robots serving as a mediator. The current meta-analysis indicated that when trials are conducted in autism clinics/centres rather than at home or in schools, the effects are larger, and for younger children there is a better developmental match. The number of robot studies published from 2013 compared to previous years suggests the popularity of robots is increasing. It is encouraging that robot-mediated support has attracted the attention of professionals, researchers, and funding bodies. However, research findings were often tentative and should be interpreted cautiously because of a lack of high-quality evidence from randomised study designs. More research evidence gathered from experimental designs is needed to improve assessment of clinical effectiveness, as well as transparent reporting on sample selection, features, and adverse events, as well as assessment of the effect of specific support beyond the immediate study period.

Chapter 5: Parents'/carers' knowledge and preferences about technology-based support for autistic children: An international online survey

5.1 Introduction

The explosion of technology in the last 20 years has stimulated interest in the ways that autistic children and young people are using technology devices. Digital technology in the form of smartphones, iPods, tablets, virtual reality, and robots have become widespread making some of them more affordable, transportable, and easily accessible among autistic children in daily life (Alzrayer, Banda, & Koul, 2014; Brunero et al., 2019). According to recent data from the Office for National Statistics 90% of the adult population in the United Kingdom (UK) are familiar internet users while 96% of households have access to the internet (ONS, 2020). Many autistic children are experts in the use of the internet, in online gaming, in social media, forums which is indicative of their interest and familiarity with technology. Previous work demonstrated that parents report a high level of tablet use by their autistic children (mean age = 7 years) with some using them 50 – 94 minutes per day (Clark, Austin, & Craike, 2015). Similarly, parents of neurotypical children (mean age = 6.27 years) reported they usually spent 1 – 2 hours per day (Oliemat, Ihmeideh, & Alkhawaldeh, 2018).

Autistic children and young people can use these platforms to connect to people with similar interests, socialise and make online friends, get information, or exchange ideas about a topic of interest (Oliemat, Ihmeideh, & Alkhawaldeh, 2018). Therefore, they might use it more as a playing tool rather than learning (Oliemat, Ihmeideh, & Alkhawaldeh, 2018). The coronavirus pandemic increased the use of technology for extended periods of time, particularly in education. In March 2020, England went into lockdown and most children were using technology devices (e.g., laptop, tablets, computers, smartphones) more frequently and in a different way compared to the pre-pandemic period including to attend school online, connect with the class teacher and their peers as well having online meetings with healthcare professionals, if needed. The coronavirus pandemic gave an additional dimension to technology use in

school-aged autistic children and their parents/carers. This might be considered as an opportunity to leverage the use of technology in the future.

As described in chapter 2.2, technology has characteristics particularly attractive to autistic children (e.g., predictable formats of information delivery, self-paced usage, highly motivating) (Dautenhahn, 2003; Diehl et al., 2012; Fong et al., 2003). There is substantial evidence that autistic children have demonstrated a special interest in technology (Grynszpan et al., 2014; Hedges et al., 2018; Kuo et al., 2014; MacMullin, Lunsy, & Weiss, 2016; Mazurek & Wenstrup, 2013). Stone and colleagues (2019) conducted an ethnographic case study with three autistic boys aged 9 – 10 years and three teachers in one school. The research team observed the autistic boys playing Minecraft at home (frequency not specified) via cameras for 90 minutes and interviewed their teachers at a later point. The study concluded that autistic children exhibited more social initiations and maintained social interactions with peers either in real or virtual life after playing the online game with co-player(s) (Stone et al., 2019).

The educational opportunity of these new technologies (e.g., smartphones, iPods, tablets, virtual reality, robots) is under investigation and recent research activity highlights that more and more specific support have introduced varied technologies in sessions with autistic children (Fletcher-Watson et al., 2016; Grynszpan et al., 2014; Hedges et al., 2018; Penissi et al., 2016; Sandbank et al., 2020). Although research suggests that autistic children respond well to different technology devices, there is little evidence to support their effectiveness to enhance the development of their skills (Costescu, Vanderborght, & David, 2014; Kouroupa et al., 2022; Sandbank et al., 2020; Soares et al., 2021). While some studies have focused on parents' attitudes to technology by measuring the time autistic children spent with varied technologies (Laurie et al., 2019; Stiller & Mobile, 2018), it is equally imperative to understand the way autistic children and young people might benefit by the use of technology. Touch screens including smartphones, iPods and tablets have been introduced in sessions with autistic children to facilitate learning (e.g., word picture pairing, picture pairing) or facilitate the social and communication support needs of autistic children operating as speech generating devices, facilitating the learning of Picture Exchange Communication System (PECS) and other communication specific applications

operating via these devices (Alzrayer, Banda, & Koul, 2014; Brunero et al., 2019; Hillier et al., 2016; Kellems & Morningstar, 2012). Virtual reality and avatars support autistic children working on a range of realistic scenarios in a controlled virtual environment to practise social and communication skills via role play, share their experiences and capture perceptual and cognitive differences via their senses (Bellani et al., 2011; Ghanouni et al., 2019). Finally, robots can educate and train autistic children targeting a range of social and communication, emotional development, or motor skills (Begum et al., 2016; Diehl et al., 2012; Marino et al., 2020).

Nowadays, it is common that autistic children have their own tablet. The purpose autistic children using tablets remains vague (e.g., educational, specific support or for fun). The efficacy of iPad applications (i.e., FindMe app) as an educational tool for social and communication skills in autism has been questioned in the current literature (Fletcher-Watson et al., 2016; Maglione et al., 2012). There is, however, evidence that parents/carers often use a trial-and-error system of specific support for their autistic child rather than waiting for them to be empirically supported in an attempt to identify the optimal outcome (Christon, Mackintosh, & Myers, 2010). On average, parents of autistic children use seven different approaches (Green et al., 2006). As such, parents/carers of autistic children might be keen to seek alternative multimodal methods (Brady et al., 2015; White et al., 2013). This is a usual phenomenon following autism diagnosis which diminishes when parents/carers become more knowledgeable and confident with their child's diagnosis, strengths, and needs (Grant et al., 2015).

Parents/carers of autistic children are usually influenced by a diverse array of sources including books, professionals, and recommendations by other parents (Miller et al., 2012). A constellation of factors plays a role in the decision-making of an autism specific support including the child's age, the child's progress, the parents' understanding of autism and their parenting style (Carlton et al., 2013; Dinora et al., 2017; Grant et al., 2015; Hebert, 2014). Parents' attitudes related to technology-based support is also likely to be shaped by their child's use of technology. A recent exploration of technology use in autistic adolescents revealed that access to smartphones, tablets, computers, and laptops increased the child's sense of independence, reduced anxiety, and created social opportunities with adults and/or

peers (Hedges et al., 2018). Despite the growing use of technology, there is limited information about the knowledge and preferences of families as likely gatekeepers of access to technology to support and develop the skills of their autistic child. Developing a comprehensive understanding of parents'/carer's preferences around technology-based support and their decision-making process would allow professionals to partner and negotiate with families the complex world of specific support for their autistic children via information materials and decision-making aids. In addition, raising awareness of parental knowledge will support professionals' future work, especially those who develop new practices with the use of technology. It is critical to explore the issue further to ensure that parents/carers are provided with the guidance and support they find most helpful in deciding how best to support their autistic child.

5.1.1 Study objectives

This study aims to take a step towards addressing a series of gaps related to parents' current knowledge of the use of technology-based sessions in autism, their preferences among different technology-based sessions (i.e., smartphone, iPod, tablet, virtual reality, robot, other) and the reasons behind their choice. The aims of this research are as follows:

1. To identify the range of specific support parents/carers have accessed
2. To identify the number of parents/carers who know about technology-based sessions and which device(s) they prefer
3. To identify reasons driving preference for a specific technology device
4. To explore any associations between parents'/carer's and child's demographic characteristics and technology preferences
5. To report parents'/carer's attitudes about technology-based support

5.2 Methods

This study was reported according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines (Eysenbach, 2004, 2012) (Appendix A: Checklist for Reporting Results of Internet E-Surveys).

5.2.1 Participants and recruitment

A convenience sampling method was adopted in this study. Parents/carers of autistic children were approached online via posts in third-sector settings (i.e., autism specific charities, organisations), parenting groups and public accounts on social media (i.e., autism support groups on Facebook and Instagram). Potential participants were provided with a paragraph explaining the study and a hyperlink taking them to a survey website (Qualtrics: <https://qualtrics.herts.ac.uk>). After consent was obtained participants were granted access to the online survey. The 54-item questionnaire was carried out entirely online with no face-to-face contact between participants and the experimenter.

Parents/carers of autistic children were invited to complete the online survey if they had a child with a formal diagnosis of autism, had been referred to a clinic for a diagnosis or self-identified their child as autistic. Parents/carers whose children had additional needs [i.e., attention deficit hyperactivity disorder (ADHD), intellectual disability] were also eligible to complete the survey. In total, 280 parents/carers participated in the study. After excluding incomplete survey responses (>60% of missing data), the final sample comprised of 267 participants.

5.2.2 Questionnaire

The online survey (Appendix B: Copy of the Parents, Autism, Technology (PATH) participant information sheet, consent form and survey) was developed in English by the PhD candidate and the supervisory team. After the development of the survey was complete, the PhD candidate followed the Delphi method (Linstone & Murray, 1975) to ensure readability of the survey items. Piloting the survey (including the participant information sheet and consent form that were embedded in the survey) before launching the study minimised any subsequent problems related to terminology, misinterpretation, or misleading items. In the piloting phase, an online version of the survey was created and a link to the survey was sent to three parents of autistic

children identified online, the Public Involvement in Research Group (PIRG) at the University of Hertfordshire and experienced professionals in autism. After they all completed the online survey, there was the opportunity to ask questions and/or give any constructive feedback via written communication (e.g., email, text messages) with the PhD candidate. From the questions that arose and the changes that were suggested, alterations were made to improve ease of access and understandability for participants. These changes ranged from spelling/grammatical and punctuation errors to rearrange the order of questions in the survey. Edits were made in one question that allowed parents to add multiple responses.

The participant information sheet and consent form were embedded in the online survey (Appendix B: Copy of the Parents, Autism, Technology (PATH) participant information sheet, consent form and survey). All participants completed their participation within one sitting (approximately 15 – 20 minutes). Survey data were a mix of pre-set options (e.g., “What is your child’s spoken language”) and free-text sections (e.g., “Why would you most like your child to have a session with a robot?”). Participants answered multiple-choice questions, some with the opportunity to provide multiple responses to determine all factors in decision-making and other pre-set questions to provide information regarding the singular most important factor of preference. For questions for which the answer “Other” was provided as a choice, participants were given the opportunity to provide a free-text response.

The survey was divided into four sections including different sets of questions focused on both parents’/carers’ (section one) and child’s demographic (section two) information (i.e., gender, ethnicity, age, etc.), autism specific support (section three), access to technology platforms and preferences (section four). In total, the survey contained 54 questions with 1 – 4 items per page over 23 pages and participants were able to review and change their responses via clicking the back button. The survey collected data about respondent’s demographics (e.g., relationship to the child, age, gender, educational level). In the second section, descriptive information about children (e.g., number of children in household, number of autistic children, gender, age of diagnosis) was collected. The survey also asked about the child’s reading and language skills, and the response options were compiled using a combination of

evidence-based practices for autistic children informed by a literature review of relevant articles (Nation et al., 2006; Wei et al., 2014; Westerveld et al., 2016).

In the autism specific support section, respondents were asked questions relating to any current or recent (over the past six months) autism specific support for their child as well as any specific support that had been received since diagnosis. A list of 17 types of autism specific support was provided based on Green and colleague's (2006) previous work and participants were asked to select those which their child has/had received or report another specific support. The location of session delivery and the number of professionals accessed to support the decision-making of the autism specific support approach were also requested in this section.

In the technology preference section, respondents were asked to select which of the listed technology-based support they were aware of being used in autism, if their child had ever engaged with any of the listed technologies, if they would consider any of the listed technology-based support, their most/least preferred technology, and the reasoning of their choice. Finally, the influencing factors that would play a role in considering a technology-based session and the technology devices their autistic child had access to were also asked in this section.

5.2.3 Procedures

Ethical permission from the Health, Science, Engineering and Technology Ethics committee with Delegated Authority (ECDA) from the University of Hertfordshire Ethics Committee was granted prior to recruitment commencing (Protocol number: LMS/PGR/UH/04164) (Appendix C: University of Hertfordshire ethical approval for conducting a survey). Following ethical approval, the online survey was launched in May (21st) 2020. The survey was advertised through a variety of social media outlets including websites of charities (i.e., Scottish Autism) and via the mailing list of Autistica. Last, the PhD candidate requested membership in four parenting support group pages on Facebook. Once membership was approved, the PhD candidate was able to either contact the group page owners to post the survey description and link on the PhD candidate's behalf or the PhD candidate was able to post directly to the group.

Participation was voluntary and anonymous unless respondents shared their contact details to receive a copy of the published work or participate in future research. There was no financial incentive in completing the survey. The survey was launched during the first national lockdown necessitated by the COVID-19 health emergency. The study link was available online for 14 weeks (i.e., May – August 2020 and October – November 2020). The decision to relaunch the survey in autumn 2020 was made when Autistica contacted the PhD candidate (following her application in Spring 2020) to offer support with recruitment after the study was originally closed in August 2020. A pragmatic decision was made to relaunch the survey in October 2020 and increase the number of recruited participants in the survey so the analysis would have more power and more generalisable study findings. Responses were automatically entered into the Qualtrics database upon completion of the questionnaire. When the survey was closed, data were downloaded in .csv format, reviewed and prepared for analysis.

Parents/carers were asked to create a user Participant Identifier (PID) which gave respondents the option to contact the PhD candidate and ask to delete their responses from the online survey for whatever reason. Although a small number of respondents stopped the survey at an early point, none of the respondents requested their responses to be deleted. When the database was downloaded, the personalised user PID and the Internet Protocol (IP) address automatically collected via Qualtrics were deleted to protect the anonymity of the study participants. The IP address was also reviewed to avoid duplicate entries from the same participant. None identified.

5.2.4 Data analysis

Descriptive statistics (means, standard deviations, percentages) were used to describe the sample characteristics. For descriptive analysis, a number of responses were collated into broader categories due to the small number of frequencies in some items and following review of free-text descriptions. Free-text descriptions under additional diagnoses for autistic children confirmed by a healthcare professional were collated in the following categories: Intellectual disability, ADHD, sleep, anxiety, communication problems, chromosomal disorders, incontinence, eating problems, no additional needs and prefer not to say. The total number of additional needs was computed by aggregating children's different diagnoses into a numeric variable.

Children's verbal ability (language skills) was condensed into three main categories – learning, fluent and non-verbal autistic children. For instance, babbling, word approximations, single words, and two-words together formed the “learning” group and the other options of short phrases, multi-part sentences, wh-questions, complex grammar, using pronouns appropriately and fluent formed the “fluent” group. Free-text descriptions provided under the “Other” option were reviewed by and if the reason provided could be assigned to a different category, responses were transferred. The remaining qualitative data were coded and created a third category described “non-verbal” autistic children.

The reading ability of autistic children was also categorised into sub-groups including learning reader, fluent reader, and non-reader. The “learning” group included the following items: look at pictures, know how to hold a book, respond by sounds, recognise letters, retell a story using pictures, start reading, read at a slower pace. “fluent” readers were those who described the plot of a story, identified themes, and demonstrated advanced skills. The same approach, as described for children's verbal skills, was adopted for the “Other” option to categorise the reading skills of autistic children. The “non-reader” group was formed following review of the free-text descriptions which were reviewed by the PhD candidate. Finally, if parents had reported two or more locations where their child had received a session that was computed and presented as multiple locations.

A repeated measures analysis of variance (ANOVA) examined specific support tried, knowledge about technology-based support, most and least preferred technology-based support, decision-making factors, and age group (e.g., young children under 5 years old, children and teenagers) as between-subject factors. The correlation of parent characteristics with preferred technology was explored. For regression analyses, Pearson's correlations were used to rule out multicollinearity between independent variables (Pearson's $r = < 0.05$). As this topic is new and very few correlations were observed between the dependent variable (preference for technology-based support) and the independent variables, the initial approach was to add all predictors within the regression analysis model to explore the relationship among variables and not the direction only. The Spearman correlation was used to

explore which independent variable/coefficients significantly contributed to a given model and to compare contributions of coefficients across models. Statistical significance was set at $p = < 0.05$. Table 5. 16 provides the correlation coefficients among the variables in the study with the independent variable per technology-based support.

Binary logistic models were used to analyse the relationship among parent/carer (e.g., age, ethnicity, country of living, socioeconomic deprivation), child demographic characteristics (e.g., child's gender, child's age, age of child's diagnosis, child's language and reading skills, any additional diagnosis, receipt of autism specific support) and most preferred technology as dependent variable. A socioeconomic deprivation composite was created by summing three binary indicators: educational level (below university versus university education), employment status (not employed versus employed) and household income (up to £40,000 versus above £40,001) in line with the approach suggested by Diemer and colleagues (2013). The financial threshold about household income decision was adopted following review of the recent Office for National Statistics data for 2020 (ONS, 2020). Diemer and colleagues (2013) have provided in-depth guidance for conceptualising and measuring socioeconomic deprivation in psychological research which includes the following three variables. The socioeconomic deprivation score ranged from 0 to 3 with higher score indicating more deprivation.

Variables with more than two items and low responses in each category were collapsed into binary categories for multinomial logistic regression to increase the number of responses in each category and to aid interpretation. Therefore, a multivariable ordinal representation for ethnicity (White versus other), country of living (UK versus other), child's gender (male versus other), child's language and reading skills (fluent versus other), confirmed autism diagnosis (yes versus no), presence of additional needs (yes versus no), receipt of autism specific support (yes versus no) was used in the analyses. Regression models were estimated with robust standard errors, and exponential coefficients. Exponential estimates derived from the regression model, which are interpreted as odd ratios (OR; Knol et al., 2012) with 95% confidence intervals (CI). Statistical analysis was performed using IBM Statistical

Package for Social Sciences (IBM SPSS. version 27.0). For qualitative analysis, parents/carers reported the reason(s) of the most and least preferred technology-based support approach. Data were coded by the PhD candidate, but the codes and coding scheme were reviewed by the supervisory team. A bottom-up approach was followed to derive themes within the data. The codes were summarised into overarching themes (broad categories) based on the principles of conceptual content analysis (Graneheim, Lindgren, & Lundman, 2017; Lindgren, Lundman, & Graneheim, 2020; Schreier, 2012). Data were stored and analysed using NVivo version 12.

5.3 Results

5.3.1 Participants

There were 267 respondents including 208 respondents from the UK (184 from England, 11 from Wales, seven from Northern Ireland and six from Scotland). Thirty-one parents/carers from other European countries participated in the survey including Greece (n = 19), Cyprus (n = 7), Slovakia (n = 2), Spain (n = 1), Germany (n = 1), and Republic of Ireland (n = 1). Finally, 19 responses came from parents/carers in the United States (US) of America, six from Australia, two from Canada and one from Malaysia.

Participants were split into three groups based on the child's age: young children aged 5 years and younger (n = 71, 27%), children aged between 6 – 12 years (n = 149, 56%) and teenagers aged between 13 – 18 years (n = 47, 17%). The demographic characteristics of parents/carers are shown in Table 5. 1. Parents/carers were asked to report their age, gender, educational level, employment status, and annual family household income.

Mostly mothers responded to the survey (n = 241, 91%) with 12 fathers (4%). The mean age of respondents was 39 years old (SD = 7.98, range: 22 – 68 years old). Approximately 90% of parents/carers (n = 238, 89%) were of White ethnic origin. The ethnic group of the parents/carers was categorised following the recommended categorisation of the Office for National Statistics comprising five ethnic groups which are White, Mixed/Multiple ethnic groups, Asian/Asian British, Black/African/Caribbean/Black British, and other ethnic group. The White ethnic category included White English/Welsh/Scottish/Northern Irish, White Irish, and any

other white background. Similarly, the Mixed/Multiple ethnic groups included White and Black Caribbeans, White and Black Africans, White and Black Asians and any other mixed/multiple ethnic groups. The next ethnic group category comprised of Black/African/Caribbean/Black British individuals from Africa, the Caribbean, and any other Black/African background. Asian/Asian British covered those from the countries of India, Pakistan, Bangladesh, China as well as those from any other any other Asian background. Finally, any other background included Arabs and any other ethnic group.

Table 5. 1 *Parent/carer demographic characteristics*

| Characteristics | <i>n</i> | % |
|---------------------------------------|----------|-----|
| Full sample | 267 | 100 |
| Relationship to the child | | |
| Mother | 242 | 91 |
| Father | 12 | 4 |
| Carer (e.g., sibling, foster carer) | 13 | 5 |
| Gender | | |
| Female | 248 | 93 |
| Male | 14 | 5 |
| Gender diverse | 3 | 1 |
| Prefer not to say | 2 | 1 |
| Ethnic group | | |
| White | 238 | 89 |
| Mixed/Multiple ethnic groups | 11 | 4 |
| Black/African/Caribbean/Black British | 5 | 2 |
| Asian/Asian British | 7 | 3 |
| Other ethnic group | 6 | 2 |
| Level of education | | |
| GCSEs | 32 | 12 |
| A/AS levels | 5 | 2 |
| Higher education | 79 | 30 |
| Foundation degree | 8 | 3 |
| Undergraduate degree | 63 | 24 |
| Postgraduate degree | 52 | 20 |
| Doctorate/PhD | 8 | 3 |

| Characteristics | <i>n</i> | % |
|--------------------------------------|----------|----|
| Prefer not to say | 20 | 6 |
| Below degree educated | 136 | 51 |
| Above degree educated | 131 | 49 |
| Employment status | | |
| Full-time | 56 | 21 |
| Part-time | 81 | 31 |
| Full-time carer | 54 | 20 |
| Unemployed not looking for work | 38 | 14 |
| Student | 8 | 3 |
| Retired | 5 | 2 |
| Career break | 12 | 4 |
| Disabled | 3 | 1 |
| Prefer not to say | 9 | 4 |
| Not employed | 130 | 49 |
| Employed | 137 | 51 |
| Family Income | | |
| Up to £20,000 | 64 | 24 |
| £20,001-£40,000 | 62 | 23 |
| £40,001-£60,000 | 46 | 17 |
| £60,001-£80,000 | 22 | 8 |
| £80,001-£100,000 | 15 | 6 |
| £100,001+ | 16 | 6 |
| Prefer not to say | 42 | 16 |
| Up to £40,000 | 168 | 63 |
| Above £40,000 | 99 | 37 |
| Socioeconomic deprivation (deprived) | 32 | 12 |

Autistic children were predominantly boys ($n = 173$, 73%). The mean age of autistic children in the study was 8.7 years ($SD = 4.03$; range: 2 – 18 years). The mean age of autism diagnosis in children was reported being 5.5 years ($SD = 3.23$; range: 1 – 17 years). Although most parents/carers ($n = 147$, 55%) reported their children had no other additional diagnosis diagnosed by healthcare professionals outside of autism, 43% ($n = 114$) of parents/carers shared their child had an additional diagnosis followed

by 2% (n = 6) parents/carers who preferred not to disclose. Most children with additional diagnoses confirmed by a healthcare professional had one more diagnosis (M = 1.2; SD = 1.54; range: 0 – 6 diagnoses). The most frequent additional condition was intellectual disability (n = 100, 37.5%) followed by anxiety (n = 55, 21%) and sleep problems (n = 47, 18%). Most of the children were verbally fluent (n = 186, 70%). Approximately 50% of autistic children were in the process of learning to read (n = 129, 48%) followed by fluent readers (n = 120, 45%). A detailed summary of the child’s characteristics per age group is presented in Table 5. 2.

Table 5. 2 Demographic characteristics of children by age group

| Characteristics | Young children | Children | Teenagers | Full sample |
|---|----------------|----------------|-----------------|--------------|
| | 2-5 years old | 6-12 years old | 13-18 years old | |
| | n = 71 | n = 149 | n = 47 | n = 267 |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> |
| Gender | | | | |
| Male | 49 (69) | 114 (77) | 30 (64) | 193 (73) |
| Female | 20 (28) | 35 (23) | 14 (30) | 69 (26) |
| Other (e.g., non-binary) | 0 | 0 | 3 (6) | 3 (1) |
| Prefer not to say | 2 (3) | 0 | 0 | 2 (<1) |
| Diagnosis from healthcare professional | | | | |
| Yes | 55 (78) | 136 (92) | 42 (90) | 233 (88) |
| No, awaiting diagnosis | 11 (15) | 9 (5) | 2 (4) | 22 (8) |
| No, ASD suspected | 5 (7) | 4 (3) | 3 (6) | 12 (4) |
| Additional needs | | | | |
| No | 42 (59) | 78 (53) | 27 (57) | 147 (55) |
| Prefer not to say | 1 (2) | 5 (3) | 0 | 6 (2) |
| Yes | 28 (39) | 66 (44) | 20 (43) | 114 (43) |
| Intellectual Disability | 27 (38) | 56 (38) | 17 (36) | 100 (37.5) |
| Epilepsy | 1 (2) | 2 (1) | 1 (2) | 4 (1.5) |
| ADHD | 13 (19) | 16 (11) | 9 (19) | 38 (14) |
| Sleep problems | 14 (20) | 27 (18) | 6 (13) | 47 (18) |
| Anxiety | 8 (12) | 29 (20) | 18 (39) | 55 (21) |
| Communication problems | 12 (17) | 12 (8) | 8 (17) | 32 (12) |
| Deaf | 1 (2) | 1 (1) | 0 | 2 (<1) |

| Characteristics | Young children | Children | Teenagers | Full sample |
|-----------------------|----------------|----------------|-----------------|--------------|
| | 2-5 years old | 6-12 years old | 13-18 years old | |
| | n = 71 | n = 149 | n = 47 | n = 267 |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> |
| Chromosomal disorders | 6 (9) | 10 (7) | 4 (8) | 20 (7.5) |
| Dyspraxia | 2 (3) | 6 (4) | 5 (11) | 13 (4.5) |
| Eating problems | 10 (14) | 6 (4) | 4 (9) | 20 (7.5) |
| Language ability | | | | |
| Learning | 35 (50) | 20 (14) | 5 (11) | 60 (22) |
| Fluent | 23 (33) | 122 (82) | 41 (87) | 186 (70) |
| Non-verbal | 13 (17) | 7 (4) | 1 (2) | 21 (8) |
| Reading ability | | | | |
| Learning | 48 (68) | 67 (45) | 14 (30) | 129 (48) |
| Fluent | 10 (14) | 78 (52) | 32 (69) | 120 (45) |
| Unable to read | 9 (12) | 3 (2) | 1 (1) | 13 (5) |
| Prefer not to say | 4 (6) | 1 (1) | 0 | 5 (2) |

5.3.2 Access to autism specific support

Most parents/carers (n = 179, 67%) reported their children were currently receiving or had received an autism specific support in the past six months followed by 26% who had no access to any specific support at the time of survey completion. Likewise, 80% of parents/carers reported their children had received sessions to support their child's needs since diagnosis (Table 5. 3). Almost half of parents/carers (n = 129, 49%) reported their children had received an autism specific support in at least two of the listed settings. Among those parents/carers who selected a single choice, the most frequent session location was school (n = 62, 23%).

The type of specific support that children had accessed were chosen from a list of multiple choices. Parents/carers reported their children had accessed on average three different autism specific support approaches (M = 3.03, SD = 2.28, range: 0 – 14). Forty-one (16%) parents/carers reported having tried one autism specific support approach, 44 (17%) had accessed two different autism specific support approaches and 149 (56%) had accessed more than three autism specific support approaches.

Thirty-two (12%) parents/carers reported their child had never used any of the listed autism specific support approaches.

Table 5. 3 Access autism specific support and location of delivery

| | Young children 2-5 years old n = 71 n (%) | Children 6-12 years old n = 149 n (%) | Teenagers 13-18 years old n = 47 n (%) | Full sample n = 267 n (%) |
|---|--|--|---|---------------------------------|
| Autism specific support (at present or past 6 months) | | | | |
| Yes | 56 (79) | 96 (65) | 27 (57) | 179 (67) |
| No | 12 (17) | 42 (28) | 16 (34) | 70 (26) |
| On a waiting list | 3 (4) | 11 (7) | 4 (8) | 18 (7) |
| Autism specific support since diagnosis | | | | |
| Yes | 61 (86) | 114 (76) | 39 (83) | 214 (80) |
| No | 10 (14) | 35 (24) | 8 (17) | 53 (20) |
| Location | | | | |
| National Health Service (NHS) | 3 (4) | 6 (4) | 5 (11) | 14 (5) |
| School | 11 (16) | 34 (23) | 17 (36) | 62 (23) |
| Private | 6 (8) | 5 (3) | 3 (6) | 14 (5) |
| Home | 6 (8) | 2 (1) | 3 (6) | 11 (4) |
| Multiple | 41 (58) | 74 (50) | 14 (30) | 129 (49) |
| Not applicable | 4 (6) | 28 (19) | 5 (11) | 37 (14) |

Most parents/carers reported their child was receiving early support. All age groups had received occupational and speech and language therapy. There was, a statistically significant difference between groups as determined by one-way ANOVA ($F(2) = 9.937, p < .001$) for speech and language therapy with more 2 – 5 years old children accessing this therapy compared to children aged 6 – 12 years and teenagers aged 13 – 18 years. A statistically significant difference between groups ($F(2) = 5.752, p = .004$) was also noticed in social skills training with more teenagers having accessed it compared to younger age groups. Lego therapy was statistically significant different

($F(2) = 5.535, p = .004$) among different age groups of children with more 6 – 12 years old having accessed it. There were no significant differences in any other evidenced-based specific support approaches (see Table 5. 4).

Table 5. 4 *Types of specific support tried by parents/carers by age group*

| Specific support | Young children | Children | Teenagers | Full sample | p-value |
|--|-------------------------|---------------------------|------------------------------|--------------|---------|
| | 2-5 years old n = 71 | 6-12 years old n = 149 | 13-18 years old n = 47 | | |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | |
| Speech & Language therapy (SLT) | 60 (84) | 100 (67) | 22 (47) | 182 (67) | <.001* |
| Occupational therapy (OT) | 37 (52) | 80 (54) | 19 (41) | 136 (51) | .279 |
| Applied Behaviour Analysis (ABA) | 11 (15) | 26 (18) | 6 (13) | 43 (16) | .741 |
| Discrete Trial Training (DTT) | 2 (3) | 1 (<1) | 1 (2) | 4 (1) | .440 |
| Functional Communication Training (FCT) | 3 (4) | 5 (3) | 0 | 8 (3) | .389 |
| Cognitive-Behavioural Therapy (CBT) | 6 (8) | 12 (8) | 9 (19) | 27 (10) | .077 |
| Social Skills Training | 7 (10) | 40 (27) | 16 (34) | 63 (23) | .004* |
| Lego therapy | 2 (3) | 25 (17) | 3 (6) | 30 (11) | .004* |
| Pivotal Response Training (PRT) | 2 (3) | 1 (<1) | 0 | 3 (1) | .269 |
| Picture Exchange Communication System (PECS) | 25 (35) | 51 (34) | 11 (24) | 87 (33) | .334 |
| Floortime | 3 (4) | 5 (4) | 0 | 8 (3) | .392 |
| Play therapy | 1 (1) | 4 (3) | 0 | 5 (2) | .472 |
| Music therapy | 0 | 1 (<1) | 0 | 1 (<1) | .675 |
| Sensory Integration (SI) | 8 (12) | 28 (19) | 9 (19) | 45 (17) | .343 |

| Specific support | Young children | Children | Teenagers | Full sample | p-value |
|------------------------------|-------------------------|---------------------------|------------------------------|--------------|---------|
| | 2-5 years old n = 71 | 6-12 years old n = 149 | 13-18 years old n = 47 | | |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | |
| Social stories | 7 (10) | 62 (42) | 16 (34) | 85 (32) | <.001* |
| Nutritional Supplements | 9 (13) | 6 (6) | 5 (11) | 23 (9) | .227 |
| Gluten- and Casein-Free Diet | 4 (6) | 5 (3) | 4 (8) | 13 (5) | .340 |
| Art therapy | 0 | 3 (2%) | 2 (4) | 5 (2) | .246 |
| Animal therapy | 0 | 0 | 2 (4) | 2 (<1) | .009* |
| Hydrotherapy | 0 | 0 | 2 (4) | 2 (<1) | .009* |
| Sign Language | 7 (10) | 13 (9) | 4 (8) | 24 (9) | .955 |
| None | 4 (6) | 19 (13) | 9 (19) | 32 (12) | .079 |
| Portage | 11 (15) | 7 (5) | 4 (8) | 22 (8) | .025* |

*p<.05

There was a statistically significant difference between age groups of children for the use of social stories which were more frequently reported in children aged 6 – 12 years ($F(2) = 5.752, p = <.001$). There was also a statistically significant difference between groups in both the use of animal therapy ($F(2) = 4.834, p = .009$) and hydrotherapy ($F(2) = 4.722, p = .009$). These specific support approaches, however, had been accessed by a very small number of autistic teenagers only and should be cautious about the outcome (Table 5. 4).

Other autism specific support that parents/carers reported having accessed in a free-text box included portage home visitors. Portage home visitors is a home scheme that works in partnership with pre-school aged children with special needs and the family through making parents/carers more effective teachers of their children (Cossins, 2009). It originated in the US in the 1960s, in Portage, Wisconsin, and was introduced into the UK in 1976 (Cossins, 2009). A significant between groups difference ($F(2) = 3.772, p = .025$) was observed in young children aged 2 – 5 years having used Portage

compared to older aged groups of children (e.g., aged 6 – 12 years and teenagers aged 13 – 18 years) (Table 5. 4).

Respondents were asked how many professionals they had contact with to obtain support for the child. As can be seen from Table 5. 5, 41% of those surveyed reported having contact with four or more professionals.

Table 5. 5 *Number of professionals parents/carers consulted about autism specific support*

| Number of professionals | Young children | Children | Teenagers | Full sample |
|-------------------------|-------------------------|---------------------------|---------------------------|--------------|
| | 2-5 years old n = 71 | 6-12 years old n = 149 | 13-18 years old n = 47 | |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> |
| 1 – 3 | 37 (52) | 70 (47) | 24 (51) | 131 (49) |
| 4 – 6 | 27 (38) | 43 (29) | 11 (24) | 81 (31) |
| 7 – 9 | 4 (6) | 9 (6) | 3 (6) | 16 (6) |
| 10+ | 0 | 9 (6) | 3 (6) | 12 (4) |
| None | 3 (4) | 18 (12) | 6 (13) | 27 (10) |

5.3.3 Knowledge about technology-based support

Parents/carers were asked about their prior knowledge of technology-based support available for autistic children (e.g., Which technology-based intervention have you heard about for autistic children?). A multiple-choice option was presented in the survey including smartphone, iPod, tablet, virtual reality headset, robot, none, other. No respondent selected “Other”. Most parents/carers (n = 164, 61%) had heard of the use of tablets as a technology-based support. Parents/carers (n = 53, 75%) with young children aged 2 – 5 years had more frequently reported awareness of the use of tablets in autism compared to older age children, and this between groups difference was statistically significant ($F(2) = 3.788, p = .024$). Similarly, there was a statistically significant difference ($F(2) = 3.544, p = .030$) among parents/carers of children who selected none of the listed technologies were known to them across different age groups. More parents/carers of children aged 6 – 18 years had no knowledge of these

technology-based approaches. Table 5. 6 and Figure 5. 1 shows the patterns of responses by age group.

Table 5. 6 Parents'/carers' knowledge about technology-based support

| Technology | Young children | Children | Teenagers | Full sample | p-value |
|-----------------|----------------|----------------|-----------------|--------------|---------|
| | 2-5 years old | 6-12 years old | 13-18 years old | | |
| | n = 71 | n = 149 | n = 47 | n = 267 | |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | |
| Smartphone | 28 (39) | 50 (34) | 16 (34) | 94 (35) | .683 |
| iPod | 9 (13) | 17 (11) | 5 (11) | 31 (12) | .938 |
| Tablet | 53 (75) | 86 (58) | 25 (53) | 164 (61) | .024* |
| Virtual Reality | 5 (7) | 20 (13) | 8 (17) | 33 (12) | .229 |
| Robot | 12 (17) | 20 (13) | 4 (9) | 36 (13) | .426 |
| None | 15 (21) | 56 (38) | 19 (40) | 90 (34) | .030* |

*p<.05

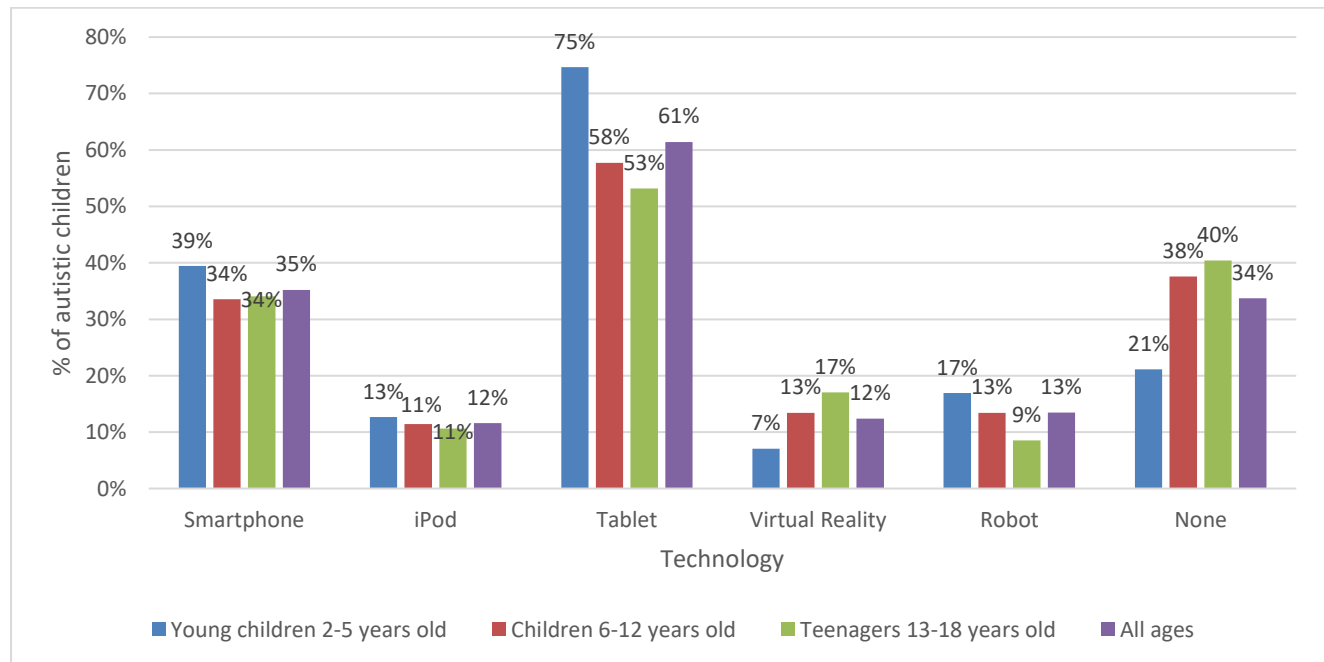


Figure 5. 1 The proportion of respondents reporting an awareness of different technology-based support by age group

5.3.3.1 Engagement with technology-based support

Parents/carers were asked if their autistic child had engaged with a technology-based support (e.g., Has your child engaged with an autism intervention that uses any of the listed technologies?). A multiple-choice option was presented in the survey including smartphone, iPod, tablet, virtual reality headset, robot, none, other. No parents/carers selected “Robots” or “Other”. Most parents/carers (n = 152, 57%) reported that their children had engaged with none of the listed technology-based support and 38% (n = 100) reported their children had engaged with a tablet. There was no significant difference in parents/carers of children in different age groups. Table 5. 7 shows the differences in the patterns of responses by age group.

Table 5. 7 *Number of parents/carers whose children engaged with technology-based support*

| Technology | Young children | Children | Teenagers | Full sample | p-value |
|-----------------|----------------|----------------|-----------------|--------------|---------|
| | 2-5 years old | 6-12 years old | 13-18 years old | | |
| | n = 71 | n = 149 | n = 47 | n = 267 | |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | |
| Smartphone | 14 (20) | 28 (19) | 11 (23) | 53 (20) | .787 |
| iPod | 4 (6) | 2 (1) | 1 (2) | 7 (3) | .172 |
| Tablet | 28 (39) | 56 (38) | 16 (34) | 100 (38) | .838 |
| Virtual Reality | 0 | 3 (2) | 1 (2) | 4 (2) | .479 |
| None | 35 (49) | 88 (59) | 29 (62) | 152 (57) | .301 |

5.3.3.2 Interest in technology-based support

Parents/carers were asked if they were seeking an autism specific support for their child, whether they would consider a technology-based session (e.g., Which of the following technology-based devices, if any, you are most interested in using with your child with ASD? Select more than one option). More than half of the sample (n = 184, 69%) said they would and an additional 26% (n = 69) of parents/carers would potentially consider (responded maybe) any/some of the listed technology-based approaches for their children. Only 5% (n = 14) of the sample said they would not consider the use of technology-based support with their autistic children.

Finally, parents/carers reported which of the available technology-based support they would be most interested in using with their autistic child. This was a multiple-choice question including the option to select “None” or “Other”. Nobody selected “iPods” or listed another technology-based support. Most parents/carers (n = 229, 86%) reported they would be interested in using a tablet. There was a statistically significant difference, as indicated by one-way ANOVA, between parents/carers of children with different ages regarding smartphones ($F(2) = 5.033$, $p = .007$). Mostly parents/carers (n = 31, 66%) of teenaged children reported more interest in smartphones compared to parents/carers of children aged 2 – 12 years. Likewise, more parents/carers (n = 16, 34%) of autistic teenagers reported their interest to use a virtual reality headset compared to children aged 6 – 12 years (n = 10, 14%) and young children aged 2 – 5 years (n = 40, 27%) ($F(2) = 3.487$, $p = .032$). Table 5. 8 shows the differences in the patterns of responses by age group.

Table 5. 8 *Number of parents/carers interested in technology-based support*

| Technology | Young children | Children | Teenagers | Full sample | p-value |
|-----------------|----------------|----------------|-----------------|--------------|---------|
| | 2-5 years old | 6-12 years old | 13-18 years old | | |
| | n = 71 | n = 149 | n = 47 | n = 267 | |
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | |
| Smartphone | 26 (37) | 70 (47) | 31 (66) | 127 (48) | .007* |
| iPod | - | - | - | - | - |
| Tablet | 65 (92) | 124 (83) | 40 (85) | 229 (86) | .253 |
| Virtual Reality | 10 (14) | 40 (27) | 16 (34) | 66 (25) | .032* |
| Robot | 14 (20) | 28 (19) | 15 (32) | 57 (21) | .148 |
| None | 3 (4) | 10 (7) | 1 (2) | 14 (5) | .425 |

* $p < .05$

5.3.4 Most preferred technology-based support

Parents/carers were asked to report the most preferred technology-based support for their autistic child (e.g., Which alternative would you MOST like your child to take part in? Only one option is available). A single-choice option was offered in the survey among seven options. Parent’s/carer’s responses were analysed by age group. Among all age groups, the most preferred technology appeared to be the tablet (n = 158,

59%). The second most preferred technology was a smartphone (n = 47, 18%). The use of other technology-based support including virtual reality headset (n = 24, 9%) and robots (n = 15, 6%) were selected by some parents of autistic children. Approximately 5% (n = 14) of parents/carers reported none of the listed technologies were most preferred for their autistic child to have any engagement with and only eight (3%) parents/carers preferred other technologies including computer/laptop. The use of iPod was scarcely selected by parents/carers (n = 1, <1%). There were no statistically significant differences among age groups. Information by age group is shown in Table 5. 9 and Figure 5. 2.

Table 5. 9 Number of parents/carers selected most preferred technology

| Technology | Most preferred technology | | | Full sample n = 267 | p-value |
|-------------------------|---------------------------|----------------|-----------------|------------------------|---------|
| | Young children | Children | Teenagers | | |
| | 2-5 years old | 6-12 years old | 13-18 years old | | |
| | n = 71 | n = 149 | n = 47 | | |
| | n (%) | n (%) | n (%) | n (%) | |
| Smartphone | 12 (17) | 24 (16) | 11 (23) | 47 (18) | .511 |
| iPod | 1 (<1) | 0 | 0 | 1 (<1) | .250 |
| Tablet | 48 (68) | 86 (58) | 24 (51) | 158 (59) | .174 |
| Virtual Reality | 3 (4) | 15 (10) | 6 (13) | 24 (9) | .223 |
| Robot | 1 (<1) | 10 (7) | 4 (9) | 15 (6) | .178 |
| None | 4 (6) | 10 (7) | 0 | 14 (5) | .195 |
| Other (computer/laptop) | 2 (3) | 4 (3) | 2 (4) | 8 (3) | .855 |

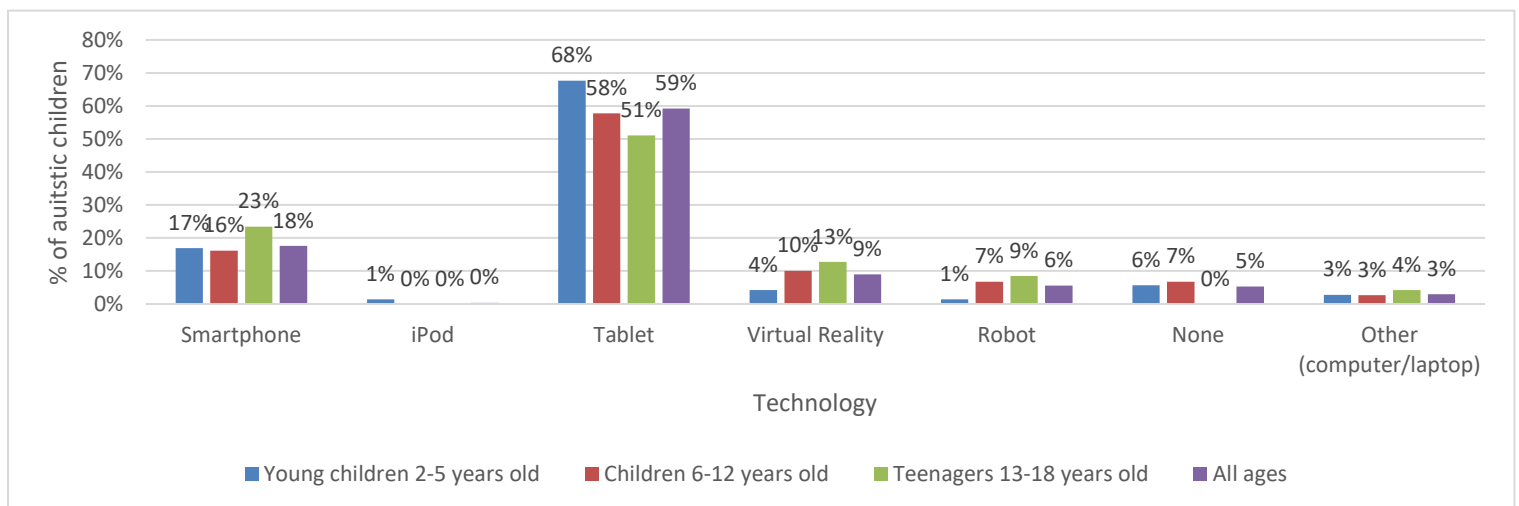


Figure 5. 2 Percentage of parents/carers selected most preferred technology

5.3.5 Parent's/carer's attitudes about most preferred technology-based support

Table 5. 10 presents the reasons parents in the study mostly preferred the selected technology-based support. The variability of facilitators per technology highlights the variable perspectives of parents/carers per different technology-based support. A detailed description is provided in the following sections.

Table 5. 10 *Reasons for most preferred technology-based support*

| Technology-based support | Reason for most preferred |
|--------------------------|--|
| Tablet (n = 158) | Special features (n = 109) Availability (n = 49) |
| Smartphone (n = 44) | Special features (n = 29) Accessibility (n = 19) |
| Virtual reality (n = 24) | Characteristics (n = 20) Previous experience (n = 4) |
| Robot (n = 17) | Engaging nature (n = 10) Child's interest in technology (n = 7) |
| None (n = 8) | Technology addiction (n = 4) Personal view about technology (n = 4) |
| iPod (n = 1) | Used in PECS (n = 1) |

5.3.5.1 Parent's/carer's attitudes about the use of tablets

Parents/carers were asked to state their reason for the preference selected. One hundred fifty-eight parents/carers responded in brief sentences. Content analysis of the data revealed that parents appeared to prefer a tablet because it is an attractive choice due to its special features and availability.

Special features

A number of parents/carers (n = 109) reported that their children enjoy using tablets because they have a large screen compared to smartphones that might be equally available in a household.

"It has a large screen, and he understands how to use it... It provides a better visual experience than a phone and has a variety of uses."

Parents/carers shared that a tablet can be controlled by autistic children independently giving them the means to communicate their needs in a different way compared to other devices because they tap or drag with fingers.

“He is able to control the iPad with his finger which results in less frequent melt downs as he struggles with tv because he cannot tell us what he wants on.”

“Easy for him to navigate as phones are small and I don’t want him near my Macbook air.”

It is worth mentioning that parents/carers made special reference to tablets being portable that allows both parents/carers and the autistic child to carry it in multiple places and use it according to the needs of the child. For example, parents/carers could use it to distract the attention of the child from a stressful occasion or engage them in a fun activity while the parent/carer is busy.

“I feel that they would engage more with their tablet and can take it to a quiet space so they wouldn’t be distracted by other things. Also, it’s something we could take with us if going somewhere that they are uncomfortable with.”

Moreover, the tablet can also be used during a session such as occupational therapy or to facilitate interaction via alternative means of communication.

“Through school he is using PECS on an iPad with clicker app.”

“My son uses ProLoQuo2Go on an iPad to speak. It is his voice.”

Finally, parents/carers stated that the tablet is an engaging device with several available applications that might facilitate learning and kid movies to entertain them.

“Because she’s familiar with iPads, enjoys the interaction with the apps and potentially it could be a valued item of support for her. Many applications that can be accessed to help with learning and interaction.”

“He already comfortably uses a tablet for playing games.”

Availability

Availability was reported as a facilitator by 49 parents/carers. Parents/carers in the study reported that their children appear to be already familiar with the use of a tablet because it is available in most households nowadays and children tend to own tablets from a very young age (Figure 5. 3). They said their child used a tablet daily and often carry it with them when they leave the house.

“It is a familiar piece of equipment. He is very comfortable with his iPad and takes it everywhere he goes.”

As a result, it is a device that autistic children feel comfortable and confident to use, especially during the coronavirus lockdown where several autistic children might have been educated remotely.

“It is the most accessible option. He already has a tablet and enjoyed doing his home schoolwork on it during lockdown.”

Parents/carers also shared that their children may not engage freely with any other technology which is less familiar.

“We already have one and it is user friendly and easy to hold. He may not engage freely with anything else.”

5.3.5.2 Parent’s/carer’s attitudes about the use of smartphones

Forty-eight parents/carers reported they preferred a smartphone due to its special features and accessibility.

Special features

Parents/carers (n = 29) described smartphones as easy to use and hold which offered a variety of activities that might engage autistic children in fun activities to reinforce learning and/or relaxation.

“He uses the smart phone to play games during the day and it’s his independent time to explore and teach himself.”

Accessibility

Parents/carers (n = 19) stated that autistic children like using smartphones because they are easily accessible in most households these days (if children don't own one already) and are familiar devices to navigate. As a result, children were described as confident users of a smartphone.

"It's easy to use and familiar. We both own one; he uses this for all the time."

"My child is a confident smartphone user and enjoys finding new ways for his phone to help him negotiate life."

5.3.5.3 Parent's/carer's attitudes about the use of virtual reality headset

Twenty-four parents/carers said that virtual reality headset was mostly preferred as a technology-based support in a session due to its characteristics and previous experience.

Characteristics

A small number of parents/carers (n = 20) thought the immersive environment of virtual reality might be beneficial because autistic children might be able to remain focused longer and enable interaction in a social context without additional pressure.

"I think that he would benefit from feeling completely immersed in the experience as can be distracted easily."

Previous experience

Some parents/carers (n = 4) had previously tried a virtual reality headset with their autistic children and felt confident that it might be a useful technology-based support in a session.

"My son has had only one experience of using a virtual headset but really seemed to enjoy it."

Finally, one parent described their child has expressed an interest in getting a virtual reality headset and thought it would be beneficial for their child.

"I think it would be something which he would engage with as he has asked previously for a VR [virtual reality] headset."

5.3.5.4 Parent's/carer's attitudes about the use of robots

Seventeen parents/carers reported a preference for the use of robots due to its engaging nature and the child's interest in technology.

Engaging nature

Parents/carers (n = 10) described being keen to observe their autistic child interact with a non-human which might involve simple interaction. They described the robot acting as a "teacher" and/or "friend" might attract the attention of the child.

"A robot could be a game and a teacher at the same time for him. I feel my child would engage to a robot better than a human."

"Think would be a good middle ground between human and learning but a 'friend' too."

One parent/carer described that their autistic child is usually distracted at school by the use of a tablet and the robot appeared to be a preferred solution while still effective tool to support the child.

"She has to have an iPad for school, and it affects her behaviour. I feel a robot would interest her without the shift in behaviour."

Child's interest in technology

Parents/carers (n = 7) were directed by their child's interest into technology and described a robot might be an innovative and engaging tool for their child. Additionally, autistic children demonstrated a preference to robotic shows and/or movies and might be keener to interact with a robot without experiencing the pressure to respond quickly during a social occasion.

"I think she would find it interesting and engage more. She loves technology and loves the idea of robots."

"He enjoys robots and robotics and would likely engage with this well."

5.3.5.5 Parent's/carer's attitudes about none most preferred of the abovementioned technologies

The eight parents/carers who selected none of the presented technology-based support expressed concerns about technology addiction and reported an overall negative view about technology.

Technology addiction

Parents/carers (n = 4) expressed their concerns about technology-based support because their children get addicted to technology, and they need to restrict its use.

"He can get fixated with technology and then it's hard to get him to do anything else after."

"We currently limit the use of screen time. It has its purpose and we do use it but, in my experience, autistic children can become heavily reliant/obsessed with screen time with a negative effect."

Personal views about technology

Parents/carers (n = 4) reported that they prefer human interaction compared to technology-based support. Similarly, parents/carers reported having a negative perception of using technology in general and, in particular, with their child.

"I don't always agree that technology is the best for my child."

"I prefer human intervention."

5.3.5.6 Parent's attitudes about the use of iPods

Only one respondent selected the iPod as a preferred technology-based approach because it had been used to facilitate PECS in the past.

5.3.6 Least preferred technology-based support

Parents/carers were also asked to report the least preferred technology-based support for their autistic child. A single-choice option was offered in the survey among seven options. Overall, the least preferred technology appeared to be the virtual reality headset (n = 74, 28%). There was a statistically significant difference as determined by one-way ANOVA ($F(2) = 4.822$, $p = .009$) in virtual reality as a least preferred technology-based support in young children aged 2 – 5 years compared to

children aged 6 – 18 years. The next least preferred technology was reported to be a robot (n = 69, 26%). For older children aged 6 – 12 years the use of a robot was the least preferred technology-based support as per parents’/carers’ responses (Figure 5. 3). A number of parents/carers (n = 45, 17%) reported they did not least prefer any of the listed technologies followed by 12% (n = 31) of parents/carers of autistic children who reported the use of iPod to be least preferred. Smartphones were least preferred by 9% (n = 23) of parents/carers of autistic children and 2% (n = 6) of parents/carers least preferred other technologies including computer/laptop. Detailed information by age group is shown in Table 5. 11 and Figure 5. 3.

Table 5. 11 Number of parents/carers selected least preferred technology

| Technology | Young children | Children | Teenagers | Full sample | p-value |
|----------------------------|----------------|----------------|-----------------|-------------|---------|
| | 2-5 years old | 6-12 years old | 13-18 years old | | |
| | n = 71 | n = 149 | n = 47 | n = 267 | |
| | n (%) | n (%) | n (%) | n (%) | |
| Smartphone | 7 (10) | 14 (9) | 2 (4) | 23 (9) | .499 |
| iPod | 4 (6) | 19 (13) | 8 (17) | 31 (12) | .135 |
| Tablet | 7 (10) | 8 (5) | 4 (9) | 19 (7) | .442 |
| Virtual Reality | 29 (41) | 37 (25) | 8 (17) | 74 (28) | .009* |
| Robot | 14 (20) | 45 (30) | 10 (21) | 69 (26) | .185 |
| None | 8 (11) | 24 (16) | 13 (28) | 45 (17) | .062 |
| Other (computer/laptop) | 2 (3) | 2 (1) | 2 (4) | 6 (2) | .467 |

*p<.05

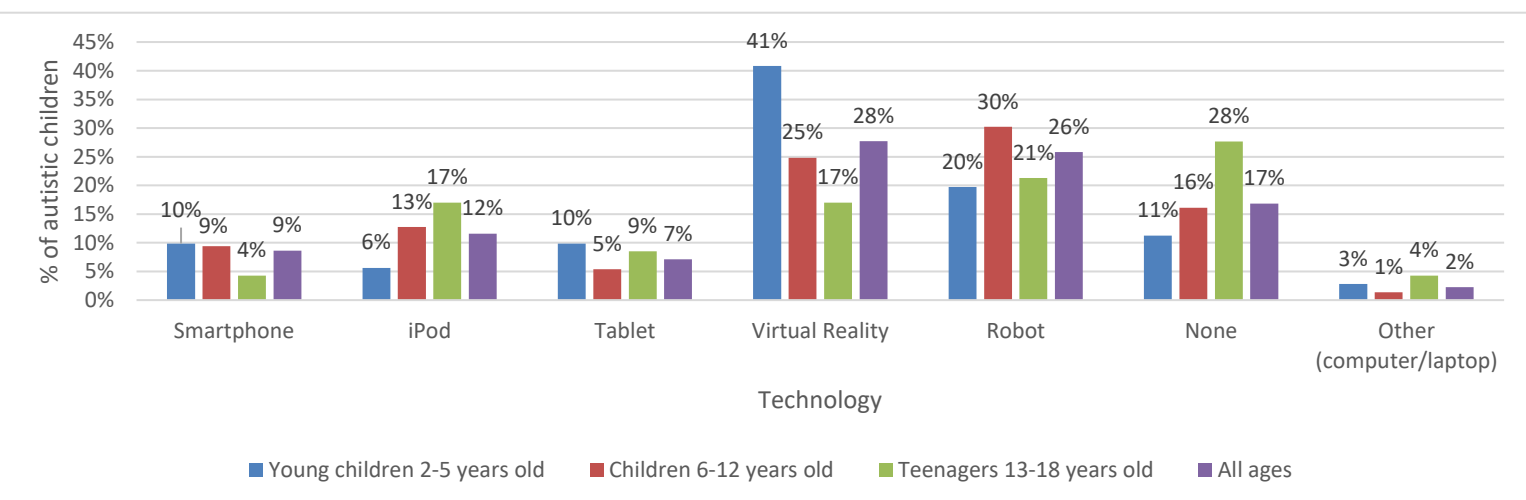


Figure 5. 3 Percentage of parents selected least preferred technology

5.3.7 Parent's/carer's attitudes about least preferred technology-based support

Table 5. 12 presents the reasons each technology-based support was least preferred by parents/carers of autistic children in the study. The structural and special characteristics of each technology was the most common reason for least preferring a virtual reality, a robot, and a smartphone. In addition, the cost of virtual reality and a robot and the young age of children for using a smartphone and a tablet were the second most frequently reported reasons that these technology-based approaches were least preferred by parents/carers. A detailed description is provided in the following sections.

Table 5. 12 *Reasons for least preferred technology-based support*

| Technology-based support | Reason for least preferred |
|--------------------------|---|
| Virtual reality (n = 76) | Characteristics (n = 73) Cost (n = 3) |
| Robot (n = 61) | Physical appearance (n = 32) Unknown technology (n = 21) Cost (n = 5) Structural characteristics (n = 3) |
| iPod (n = 32) | Old-fashioned (n = 32) |
| Smartphone (n = 23) | Age of the child (n = 19) Special characteristics (n = 4) |
| Tablet (n = 15) | Age of the child (n = 15) |

5.3.7.1 Parent's/carer's attitudes about the use of virtual reality

Seventy-six parents/carers reported that a virtual reality headset was the least attractive technology alternative due to its characteristics and cost.

Characteristics

The immersive environment of virtual reality appeared to be of concern to parents/carers as well. Seventy-three parents/carers repeatedly expressed that it is an unnatural environment that will cause confusion, distress autistic children, and widen the gap with the real world. The sensory overload that autistic children might experience in a virtual reality session was the most frequent reason parents/carers

gave for selecting this as the least attractive technology. Parents/carers described it as “intolerable”, “claustrophobic”, “unrealistic”, “scary”, “weird”.

“My child already has the ability to be “be in his own world” acting things out and moving around quickly as he does this. I feel a virtual headset would be too much for him and that is if he would even put it on his face in the first place, which is highly unlikely.”

In particular, the use of virtual reality might trigger behaviour that challenges in autistic children who find it difficult to control the expression of emotions.

“He struggles with video games as he is unable to distinguish between life and fiction sometimes. For example, if he plays Minecraft, he will then start smashing things in his room. A VR [virtual reality] headset I believe would only enhance the distancing from the actual world.”

“I would be concerned about the effects on him emotionally blurring lines between reality and virtual reality...he may find it difficult to separate it using this kind of technology.”

The fact that a virtual reality headset allows minimal control from the user was another reason parents/carers reported it was the least preferred technology-based alternative for a session with an autistic child.

“He doesn’t like anything he isn’t in control of so he would hate something on his ears / eyes.”

Cost

A small number of parents/carers (n = 3) reported the financial burden of buying a virtual reality headset would put off them trying it with their autistic child stating: *“They are expensive to buy.”*

5.3.7.2 Parent’s/carers’ attitudes about the use of robots

Robots were less appealing compared to other technology-based support by 61 parents/carers due to their physical appearance, structural characteristics, cost and being an unknown technology.

Physical appearance

Respondents (n = 32) described robots as being “scary”, “cold”, “daft”, “creepy”, “unnatural”, “odd” and “impersonal”. These descriptions were reported by parents/carers who shared that robot might not be appropriate for young autistic children and too intimidating to use in a session.

Unknown technology

It appears that robots remain an “unknown territory” for some parents/carers (n = 21) to consider using with their children.

“It is new technology. I have no information on how this would work.”

Parents/carers shared their concerns that as a new technology there is still limited evidence to establish robots are effective in autistic children.

“I guess because I don’t trust robots or feel there cannot be much evidence to show its effectiveness.”

One parent/carer reported being very sceptical about the use of robots and its effect with autistic children stating: “My child is not an experiment”. Another parent/carer reported: “My child is a human”.

In addition, parents/carers challenged the rationale of using a robot with autistic children thinking it may have a negative impact some autistic characteristics.

“His condition makes human interaction problematic, especially regarding empathy, I don’t think a robot session is going to ameliorate that.”

Consequently, parents/carers preferred more conventional approaches such as a human therapist to work with their child.

“Prefer more familiar ways such as human interaction.”

“I would rather a real human model with human skills.”

Cost

The cost of having a robot was also described as a barrier by five parents/carers who might need to buy one to practice different skills at home or other settings with their autistic child reporting: *“I assume it would be expensive”*.

Structural characteristics

Only three parents/carers shared their concerns about the practicality of using a robot with autistic children referring to the structure of the robot. The *“size”* of the robot was commonly referenced as a barrier as being *“Inconvenient to carry around”* followed by *“space”* that might be needed to store it. Therefore, parents/carers described that the fact that a robot is not easily portable and difficult to store adds to the inconvenience of considering it as a technology-based support.

5.3.7.3 Parent’s/Carer’s attitudes about the use of iPods

Old-fashioned

Thirty-two parents/carers described iPods as *“outdated”* *“not common anymore”* or reported the following: *“I’m not opposed but it has limited use versus the other options”*.

The *“inconvenient”* and *“impractical”* size of iPods was frequently referenced by parents/carers followed by comments as *“Screen is too small”*.

One parent/carer was an opponent of buying products designed by the Apple company saying: *“Don’t use apple products.”*

Finally, parents/carers described their children as being able to process more easily visual compared to oral information and that an iPod device does not accommodate the needs of their autistic children.

“He would lose concentration because he relies on visual aids.”

“I’m not sure it was gain enough of his attention. He relies on visual aids.”

“Difficulty with auditory issues.”

5.3.7.4 Parent's/carer's attitudes about the use of smartphones

Very few parents/carers (n = 23) selected smartphones as the least preferred technology among those listed. Parents/carers voiced their concerns related to age and its special characteristics.

Age of the child

Parents/carers (n = 19) repeatedly reported that autistic children who own a smartphone rely on it describing it as “*addiction*”. In addition, parents/carers considered the use of a smartphone not appropriate for young autistic children who are not owners of a smartphone yet.

“Smartphones already create addiction to him risky to connect it with therapy.”

“He gets stuck to the phone all day and won’t pay attention to our words.”

“Phones are not always meant for kids. Smart phones open your child up to bullying and at 9 I feel my child is too young for one.”

Special characteristics

A small number of parents/carers (n = 4) referred to the characteristics of a smartphone being less of an attractive choice to use with their autistic child. For example, parents/carers shared technologies, such as a tablet, are easier to monitor the activity of their child’s use including the download of applications or video watching because they are shared.

“Not as easy to monitor than iPad.”

In addition, smartphones tend to have smaller screens which make them less attractive to use compared to other easily available technology devices.

“Screens are too small.”

Finally, one parent/carer reported that smartphones are fragile devices to use especially with autistic children who present with behaviour that challenges.

“He often breaks them.”

5.3.7.5 Parent's/carer's attitudes about the use of tablets

Very few parents/carers (n = 15) shared their thoughts regarding the use of tablets as a least preferred technology-based support with autistic children. Those parents/carers who selected the tablets justified the reasons being the age of children.

Age of the child

Parents/carers repeatedly reported that autistic children become “*addicted*” to the tablet and not appropriate for young children.

“I don’t want him to use technology for learning at this age.”

“He becomes addicted to screens.”

5.3.8 Decision-making factors

Once parents/carers reported their preferences, they were asked to report the decision-making factors that might influence their choices in relation to accessing technology-based support for their autistic children (e.g., Which factors influence your decision to access technology-based support for your child’s treatment choice for ASD (select more than one option)?). A list of multiple-choice options was presented in the survey allowing parents/carers to select the most suitable option for their child. There were no significant differences in parent’s/carer’s responses between age groups. As illustrated in Table 5. 13, healthcare professionals (n = 167, 63%) was the most common response followed by the autistic community (n = 137, 51%). A small number of parents/carers (n = 41, 15%) reported not being influenced by any of the listed influencing factors. Finally, parents/carers were asked to report the technology their autistic child has access to from a list of prespecified items (e.g., Which technology devices does your child with ASD have access to (e.g., smartphone, tablet, Wii, PlayStation, Nintendo, Xbox)?). The highest number of parents/carers (n = 130, 49%) reported that autistic children predominantly have access to a tablet. The parents/carers of young children aged 2 – 5 years reported their child having access to a tablet more frequently than teenagers (see Figure 5. 4). Gaming platforms including PlayStation, XBOX, Wii, Nintendo were more accessible to children and

teenagers aged 6 – 18 years. Detailed information by age group is shown in Table 5. 14 and Figure 5. 4.

Table 5. 13 *Decision-making factors to access technology-based support by age group*

| | Young children 2-5 years old n = 71 | Children 6-12 years old n = 149 | Teenagers 13-18 years old n = 47 | Full sample n = 267 | p-value |
|--------------------------|---|---------------------------------------|--|------------------------|---------|
| | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | |
| School | 23 (32) | 65 (44) | 15 (32) | 103 (39) | .163 |
| Media/Books | 22 (31) | 50 (34) | 15 (32) | 87 (33) | .925 |
| Workshops | 13 (18) | 39 (26) | 12 (25) | 64 (24) | .426 |
| Healthcare professionals | 41 (58) | 100 (67) | 26 (55) | 167 (63) | .215 |
| Autistic Community | 37 (52) | 78 (52) | 22 (47) | 137 (51) | .793 |
| None | 13 (18) | 22 (15) | 6 (13) | 41 (15) | .684 |

Table 5. 14 *Number of children with access to technology devices*

| | Young children 2-5 years old n = 71 | Children 6-12 years old n = 149 | Teenagers 13-18 years old n = 47 | Full sample n = 267 |
|--|---|---------------------------------------|--|------------------------|
| Technology | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> | <i>n (%)</i> |
| Smartphone | 4 (6) | 14 (10) | 8 (17) | 26 (10) |
| Tablet | 49 (69) | 70 (48) | 11 (23) | 130 (49) |
| Gaming platform (e.g., PlayStation, Nintendo, Xbox, Wii) | 6 (8) | 38 (26) | 10 (21) | 54 (25) |
| Computer | 1 (1) | 8 (5) | 3 (6) | 12 (5) |
| All of the above | 3 (4) | 13 (9) | 7 (15) | 23 (9) |
| None | 4 (6) | 1 (<1) | 0 | 5 (2) |

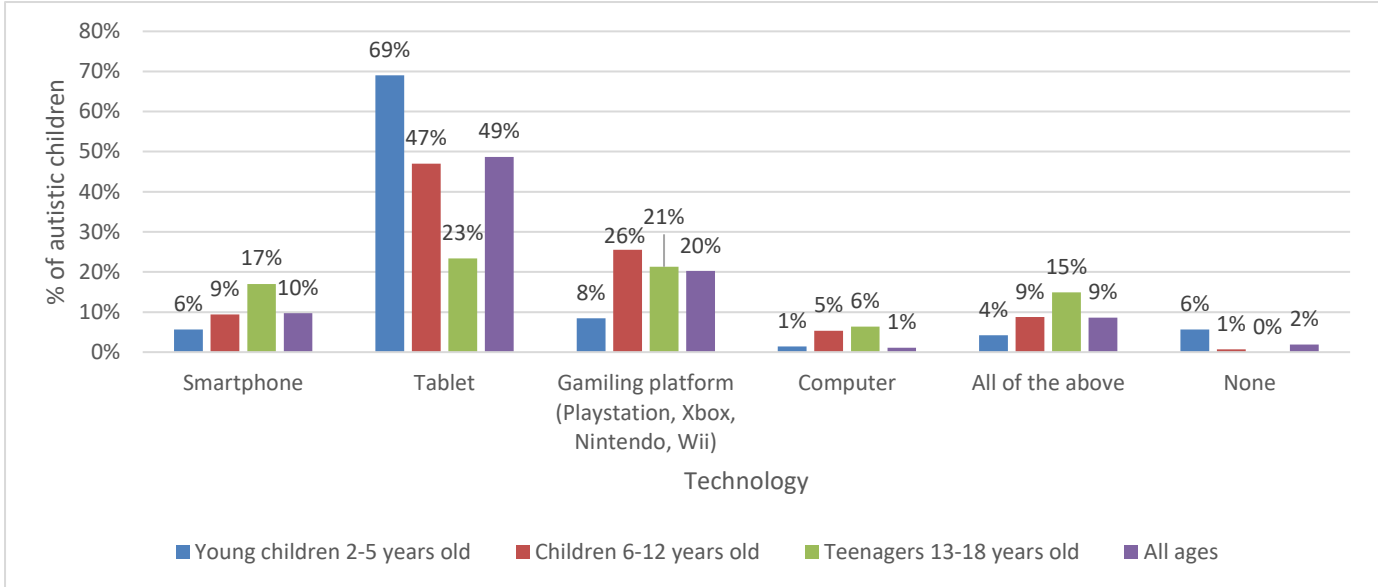


Figure 5. 4 Access to technology devices

5.3.9 Parent/carer, child characteristics and mostly preferred technology-based support

A descriptive presentation only of the demographic characteristics of respondents with technology preferences is set out in Table 5. 15. Frequencies, percentages and means give a first overview of the profile of respondents who selected their mostly preferred technology-based support.

The mean age of parents/carers who selected a tablet, as a mostly preferred technology-based support, to engage their child in a session was 38 years old. This was the youngest mean age of parents/carers compared to the rest of technology-based support. Parents/carers of a White background expressed an equal preference across all different technology-based support. Parents/carers who selected a virtual reality headset as a preferred technology-based support for their children were from higher socioeconomic status.

In addition, 82% of parents/carers from the UK reported a tablet as a mostly preferred technology-based support which is the highest value across the rest of preferred technology-based support. A virtual reality headset as a mostly preferred technology-based support was selected by 92% of parents/carers whose child was verbally fluent and by 59% of parents whose child was fluent in reading. A robot or other technology as a mostly preferred support was chosen by 100% of parents/carers whose children had a confirmed autism diagnosis.

A smartphone was selected as a mostly preferred support by 52% of parents/carers whose autistic children presented with additional needs. Other technology-based

support (e.g., computer, laptop) was selected by 50% of parents/carers of autistic children with additional needs. Other (e.g., computer/laptop) as a technology-based support was selected by 75% of parents/carers of children already in receipt of an autism support.

A robot was chosen as a mostly preferred technology-based technology approach by 74% of parents/carers of children already in receipt of an autism specific support. None of the listed technology-based support, as a mostly preferred approach, were selected by 86% parents/carers with male autistic children. Virtual reality and robots were selected by parents/carers of children whose mean age was 10 years old.

Finally, other technology-based support (e.g., computer/laptop) were chosen by parents/carers of autistic children whose mean age of diagnosis was approximately 7 years old.

Table 5. 15 Presentation of most preferred technology-based approach by demographic characteristics

| | Smartphone | Tablet | Virtual Reality | Robot | Other (e.g., computer/laptop) | None |
|--|--------------|--------------|-----------------|--------------|----------------------------------|--------------|
| | n = 47 | n = 158 | n = 24 | n = 15 | n = 8 | n = 14 |
| Parent/carer age (mean, SD) | 40.57 (8.49) | 37.82 (7.82) | 40.21 (7.24) | 41.47 (6.63) | 40.88 (11.76) | 39.57 (7.09) |
| Parent/carer is White (n, %) | 44 (94) | 137 (87) | 22 (92) | 13 (87) | 7 (87) | 14 (100) |
| Socioeconomic deprivation (mean, SD) | 1.46 (0.80) | 1.45 (0.81) | 1.33 (0.81) | 1.46 (0.91) | 1.87 (0.83) | 1.85 (1.02) |
| Child lives in the UK (n, %) | 37 (79) | 130 (82) | 17 (71) | 9 (60) | 5 (62) | 9 (65) |
| Child is fluent speaker (n, %) | 32 (68) | 108 (69) | 22 (92) | 10 (67) | 5 (62) | 9 (65) |
| Child is fluent reader (n, %) | 20 (42) | 69 (44) | 14 (59) | 7 (50) | 4 (50) | 6 (43) |

| | Smartphone | Tablet | Virtual Reality | Robot | Other (e.g., computer/laptop) | None |
|---|-------------|-------------|-----------------|--------------|----------------------------------|-------------|
| | n = 47 | n = 158 | n = 24 | n = 15 | n = 8 | n = 14 |
| Child has a confirmed autism diagnosis (n, %) | 43 (92) | 135 (86) | 19 (80) | 15 (100) | 8 (100) | 12 (86) |
| Child has additional needs (n, %) | 25 (52) | 66 (42) | 9 (37) | 5 (34) | 4 (50) | 4 (29) |
| Child has/had received autism support (n, %) | 30 (64) | 107 (68) | 15 (62) | 11 (74) | 6 (75) | 9 (65) |
| Child is male (n, %) | 34 (73) | 115 (73) | 17 (71) | 11 (74) | 4 (50) | 12 (86) |
| Child age (mean, SD) | 9.36 (4.73) | 8.22 (3.86) | 10.25 (3.52) | 10.13 (3.77) | 9.75 (4.83) | 7.29 (2.67) |
| Childs age of autism diagnosis (mean, SD) | 6.21 (4.01) | 5.01 (2.80) | 5.65 (2.70) | 5.73 (2.91) | 7.25 (4.13) | 6.50 (4.23) |

5.3.10 Correlation analyses

Before running a regression model, the correlations between all parent/carer and child characteristics and technology preferences were explored (Table 5. 16). There was no significant correlation between smartphones with any of the listed parent and child factors.

Similarly, there was no significant correlation between iPods and any of the listed family and child factors.

Parent/carer age, child living in the UK, child's age and child's age of autism diagnosis were all found to be significantly (positively) correlated with a preference for a tablet. As a result, older parent/carer and older autistic children were more likely to mostly prefer a tablet. Similarly, the older the age of the child's autism diagnosis, parent/carer were more likely to mostly prefer a tablet.

Child being a fluent speaker was negatively correlated with virtual reality being mostly preferred technology-based support. A positive correlation was identified between child's autism diagnosis with virtual reality being mostly preferred technology-based support. Therefore, parent/carer were more likely to prefer a virtual reality headset if children had received an autism diagnosis as they got older.

Robots, as a mostly preferred technology-based support was not correlated with any of the listed parent/carer or child characteristics.

Finally, there was no correlation between family and child characteristics with other (e.g., computer/laptop) or none selected as a mostly preferred technology-based support.

Table 5. 16 Spearman's correlations among parent/carer and child characteristics with most preferred technology

| | Smartphone | | iPod | | Tablet | | Virtual Reality | | Robot | | Other | | None | |
|---------------------------------------|------------|-----|-------|-----|--------|--------|-----------------|------|-------|-----|-------|-----|-------|-----|
| | r_s | p | r_s | p | r_s | p | r_s | p | r_s | p | r_s | p | r_s | p |
| Parent/carer age | .09 | .16 | -.06 | .33 | -.14 | .04* | .06 | .38 | .03 | .60 | .08 | .20 | .06 | .34 |
| Parent/carer is White (ethnic group) | -.07 | .28 | -.02 | .73 | .09 | .13 | -.03 | .68 | .02 | .75 | .01 | .88 | -.08 | .18 |
| Socioeconomic deprivation | .01 | .81 | -.10 | .10 | -.04 | .53 | -.05 | .37 | .01 | .93 | .08 | .20 | .09 | .13 |
| Child lives in the UK | -.01 | .88 | -.03 | .60 | -.13 | .04* | .05 | .38 | .11 | .09 | .07 | .29 | .08 | .21 |
| Child is fluent speaker | .02 | .80 | .09 | .13 | .03 | .58 | -.15 | .01* | .02 | .80 | .03 | .66 | .03 | .65 |
| Child is fluent reader | .02 | .72 | .06 | .37 | .03 | .62 | -.08 | .17 | -.01 | .89 | -.02 | .77 | .01 | .87 |
| Child has additional needs | -.10 | .11 | -.07 | .25 | .02 | .71 | .03 | .59 | .05 | .45 | -.03 | .67 | .07 | .27 |
| Child has/had received autism support | .03 | .61 | -.04 | .48 | -.02 | .78 | .03 | .62 | -.03 | .60 | -.03 | .63 | .01 | .82 |
| Child is male | .00 | .99 | .10 | .11 | -.01 | .83 | .01 | .87 | -.01 | .93 | .09 | .15 | -.07 | .25 |
| Child age | .09 | .16 | -.08 | .21 | -.17 | .001** | .07 | .26 | .09 | .14 | .03 | .65 | .04 | .57 |
| Child age of autism diagnosis | .05 | .46 | -.06 | .33 | -.14 | .02* | .14 | .02* | .10 | .12 | .04 | .54 | -.07 | .24 |

*Correlation is significant at the 0.05 level (2-tailed). **Correlation is significant at the 0.01 level (2-tailed).

5.3.11 Logistic Regression model

A simple binary logistic model was used to analyse the relationship among parent's/carer's age, child's country of living, child's age, child's age of diagnosis and the tablet as the most preferred technology (yes or no) as dependent variable. Parent/carer and child predictors were included in the regression model. Regression analysis was chosen to do be conducted to predict if there is a relationship between parent/carer and child characteristics over choosing the tablet as a mostly preferred technology-based support. The correlation table indicated the direction among some of these variables. However, an observed correlation is not a guarantee of a causal relationship among variables (Schober et al., 2018). Two variables may or may not exhibit a degree of correlation but can at the same time disagree substantially (Schober et al., 2018). Virtual reality was unable to be fitted in a binary regression model due to low sample size. Riley and colleagues' (2020) approach (pre-specified formula) for binary models requires at least 54 responses to test for one predictor with a small margin of error ($<.05$). Virtual reality included 48 responses. The remaining technology-based support was not tested in a regression model due to low sample sizes and lack of correlations as indicated in table 5. 16.

Parent's/carer's age was found to be a significant predictor of mostly preferring a tablet as a technology-based support. As parent/carer age increased, they were 4% more likely to mostly prefer a tablet ($\beta = .042$; $p = .010$). Similarly, the child living in the UK was a significant predictor of parents/carers preferring a tablet. Parents/carers whose children was living in the UK were 84.5% more likely to select a tablet as a mostly preferred technology-based support ($\beta = .613$; $p = .039$). Children's age was also found to be a significant predictor of parents/carers mostly preferring a tablet. As children get older, parents/carers were 7.5% more likely to select a tablet as a mostly preferred technology-based support ($\beta = .072$; $p = .021$). Finally, child's age of receiving an autism diagnosis was a significant predictor of parents/carers mostly preferring a tablet. That finding indicated that as autistic children get diagnosed older, parents/carers were 11% more likely to select a tablet as a mostly preferred technology-based support ($\beta = .106$; $p = .012$).

A multiple regression model was then used to predict the combined value of these four independent variables (e.g., parent/carer age, child living in the UK, child's age, and child's age of diagnosis) with a tablet being the mostly preferred technology-based support and

explore if they will remain significant predictors when all predictors are in the same model. To determine the adequacy of the sample size for the four predictors in this exploratory study, the pre-specified formula of Riley and colleagues' (2020) was used. This approach indicated that a sample size of 197 was required to model this binary outcome with a small margin of error (<0.05). For three predictors, a sample size of 151 participants required which was closer to the total sample size of parents/carers who had selected tablets (n = 158).

A multicollinearity test was conducted to observe the level of additional variance was explained by each predictor of interest. Multicollinearity of predictor variables was checked by computing the variance inflation factor (VIF) and the tolerance statistic for each analysis. Values of VIF and of tolerance were below cut-off criteria (VIF \geq 2.5; Johnston, Jones & Manley, 2018) in all analyses suggesting there was no multicollinearity among the four variables. According to a recent literature review (Wilson et al., 2018) that examined the factors related to parent's/carer's (e.g., psychosocial, alternative, pharmacological) specific support decisions for their autistic child, child's age, child's age of diagnosis and parent/carer age were among the factors that offered mixed but important results about their choices. Country of living was not identified in the literature as a decision-making factor for selecting autism specific support. Based on that review (Wilson et al., 2018) and the power analysis from Riley's approach (2020), the multiple regression model was used with three outcome predictors which were parent's/carer's age, child's age, and child's age of diagnosis. The model was statistically significant [$\chi^2(3) = 9.662, p = .022$]. Table 5. 17 presents the odd ratios per covariate and shows that no significant predictor was identified to describe parents' preferences towards tablets as a mostly preferred technology-based support.

Table 5. 17 *Covariates between parent/carer, child socio-demographic characteristics and tablet as a mostly preferred technology*

| Predictor | B | OR (95% CI)* | p-value |
|-------------------------------|------|-------------------|---------|
| Parent age | .03 | 1.03 (0.99, 1.07) | .11 |
| Child age | .08 | 1.09 (0.99, 1.20) | .10 |
| Child age of autism diagnosis | -.01 | 0.99 (0.92, 1.08) | .89 |

*OR: odd ratios; CI: confident interval.

5.3.12 Concerns about technology use in general

In total, 251 parents/carers responded to the question “What are your concerns, if any, of using technology-based support with children with ASD?”. A third of the total number of parents/carers (n = 74, 30%) reported they had no concerns about the use of technology in autism. The remaining shared their views which are presented below.

Dependent on devices

Parents/carers (n = 149) of autistic children shared their concern that there should be a balance in the use of technology because autistic children tend to spend too much time on it to the extent that parents/carers described their children getting “*addicted*”. In addition, the time autistic children dedicated on technology devices limited social opportunities, as parents/carers described. Parents/carers also had concerns that prolonged exposure to technology devices might impact the child’s physical health (e.g., eyesight).

“Dependency. My son has started taking his tablet to the dinner table. I worry about his eyes too. Very tricky to get them off of it.”

In addition, parents/carers reported that prolonged exposure on technology might hinder skill development of autistic children in other areas.

“Need for development of skills around nonverbal communication, obsessive tendencies around technology, potential for social isolation.”

“I would be concerned that it may reduce her interaction with others, and she will stay in her 'bubble' for longer periods of time if she's absorbed in a device.”

Safety

Some parents/carers (n = 30) raised a point about the safety of the digital world (e.g., cyberbullying). Therefore, especially parents/carers of young autistic children reported monitoring devices regularly compared to parents/carers of autistic teenagers.

“Safety of children as easily led. Cyberbullying.”

Online advertisement was also reported as a challenge from parents/carers of autistic children as they felt their children were not appropriately trained to access technology; they are just immersed into the digital world of 2021. Parents/carers reported it was necessary to

ensure their child have access to age-appropriate content but at the same time they are aware they might not always be able to monitor their child's online activity.

"No awareness of safety or knowledge not to access stuff not allowed to."

"Understanding of web adverts and safety."

Obstacles of telecommunication

Two parents/carers of autistic children reported that technology allows space for misunderstanding which is an area that parents/carers often described as challenging for autistic children in face-to-face communication. Parents/carers described that online contact was likely to exacerbate this phenomenon between people due to being hidden behind a screen.

"That there can be miscommunication and my child would not understand fully."

5.3.13 Attitudes about technology use during the pandemic

Most parents/carers (n = 256) responded to the final question in the survey. A third of the total number of parents/carers (n = 77, 30%) reported they had no concerns about the use of technology during the coronavirus pandemic saying "None", "No concerns", "None, we've used technology to assist her for years". Most parents/carers, however, shared their views about technology use with autistic children during the pandemic reporting an overall positive (remote) learning experience and a calming routine.

Positive (remote) learning experience

Parents/carers (n = 61) shared that their autistic children welcomed the introduction of virtual learning and adjusted quickly to online platforms which facilitated learning and remote school attendance (e.g., Moodle).

"Technology really helps my children to see what is happening in the world and is also what we have been using for home schooling as they engage better with visuals."

"My daughter loves zoom because it gives her one-on-one time with the teacher."

It has also been reported that children appeared to be more settled at home and coped better compared to being in a typical school environment. Parents/carers described the experience of their children as "fun" and "engaging way of interaction". As a result, autistic children

appeared to receive of a more tailored and inclusive programme that acknowledged their needs. In return, children appeared to enjoy the process and be in better mental health.

“I have found that the online lessons have worked best for us. Also due to sensory issues typing her answers on a keyboard have helped massively rather than writing which affects her physically.”

“She seems a lot happier using technology to do her homework rather than paper based.”

In addition, the use of a technology device to facilitate new learning appeared to be more attractive compared to the child being physically present in class.

“By using online educational Platforms such as Moodle has helped autistic individuals to facilitate their educational needs whilst they were at home. It has shown he is willing to engage with online learning, as long as it's fun.”

Finally, parents/carers of autistic children valued that technology assisted their children to stay connected and communicate with friends.

“We value the interaction he can have with his friends through technology - otherwise he would be very isolated. It can help with his social skills - conflict resolution, communication etc on games with his friends.”

Calming effect

Parents/carers (n = 46) of autistic children described the use of technology to be an important feature describing it as a “life saver” in their daily routine. During the first lockdown (March – May 2020 in the UK) nationally and internationally, parents/carers in the study reported having limited resources to keep their children engaged. Accessing technology was reported by respondents in the survey as a safe and secure environment for children to avoid meltdowns. Children remained calm and engaged in activities allowing parents/carers either to focus on themselves or dedicate time to complete additional duties and responsibilities.

“I feel very grateful to have the access to technology to calm my son especially during this time. It is something he enjoys, and it occupies him which gives me a break.”

“We have no choice but to let him use technology more. The meltdowns that ensue otherwise are very stressful for us all.”

“My child suffers really badly socially but with technology he is really good.”

Independence

Three parents/carers described how access to technology assisted the development of different skills in their children. For example, one parent/carer reported that technology use supported the imagination and creativity of their autistic children (e.g., drawing on the tablet) while acknowledging that learning how to use a technology device is an important life skill in the 21st century.

“Spending time at home, the tablet helped her be more creative by drawing. Using her imagination is a big step I think.”

“He can now navigate a laptop fairly confidently which is a good life skill.”

“Before COVID-19 my son wouldn’t use the mouse pad on the laptop to get to what he wanted on YouTube, he will now control the laptop using the mouse pad without help.”

Other parents/carers discovered the direct benefits of technology use in their children who developed, practised, and established new knowledge because of spending more time on devices and educational applications. Parents/carers reported that technology is brilliant and can help autistic children excel, if used appropriately.

“It has helped him on labelling things by going through pictures on the tablet.”

“My child has really benefited from using maths apps to learn. He has found this easier than being taught by a parent.”

Maintain routine

The operational restrictions to respond to the coronavirus health emergency impacted support sessions with autistic children. Parents/carers shared their views about the cessation of autism specific support sessions or the attempt of having teletherapy. Ten parents/carers described the experience of using remote platforms to maintain the continuity of their child sessions. Six parents/carers described that their children were engaged in teletherapy which should be considered in the future as an option, so families avoid cancelling sessions.

“He responded well to that way of working. It also shows how therapy could be more accessible to families who might have difficulties getting to appointments in person, even if all returns to normal.”

The remaining parents/carers of autistic children recognised the value of in-person sessions. They described the use of teletherapy as problematic although important for a short period of time and for certain types of autism specific support.

“Not at all, was suggested video therapy for speech but he would not engage. Been having face to face therapy for a month now in my opinion its better.”

“We had to move our SALT online and it's far less effective, as it can be as interactive. OT** was fine for a bit, but again, so limited. I don't think it's helpful, I think face to face therapy is CRITICAL for ASD.”*

** SALT: Speech and Language Therapy; ** OT: Occupational Therapy*

Increased screen time

Parents/carers equally acknowledged that abrupt dependency on technology in young autistic children might be *“harmful if not used in moderation”*. A small number of parents/carers (n = 17, 6%) were alarmed by the increased use of technology during the first coronavirus lockdown in the UK when schools were closed, and activities stopped.

“COVID-19 affected our children, because we were closed in the house for two months. Children became more addicted to technology.”

Parents/carers observed their autistic children relied a lot on technology devices and gaming platforms which was a great concern to parents/carers in conjunction with the national lockdown which meant that social opportunities were very limited.

“Our use of technology has increased during the lockdown. Schooling, screen time, gaming, learning apps. We have noticed that he is less interactive and interested in interacting with real-life when using technology.”

“My daughter has become obsessive around Roblox, Minecraft. She has used zoom and WhatsApp but is harder to regulate emotional input and output.”

5.4 Discussion

This cross-sectional online survey study considered parents'/carers' knowledge and preferences about technology-based support for their autistic child. Given the explosion of technology over the past few decades, there has been more opportunity for its integration in everyday life with autistic children making it important to explore which technology-based support parents/carers are aware of, willing to engage with, and prefer as key decision-makers for their children.

The study findings indicated that speech and language therapy, occupational therapy, ABA approaches and sensory integration were most in use by autistic children following diagnosis. Similar findings have been reported in the literature (Goin-Kochel et al., 2007; Green et al., 2006; Monz et al., 2019; Salomone et al., 2016). This suggests that early support is predominantly based on a multidisciplinary approach to support the social and communication, attention, play, emotional regulation and acknowledge the sensory needs of the autistic child through structured activities. The current study described that 15% of parents/carers reported accessing at least one autism specific support and on average three autism specific support (mean = 3.03, SD = 2.28, range: 0 – 14) which aligns with a recent internet-based parent survey (Denne, Hastings, & Hughes, 2018). Denne, Hastings, & Hughes (2018) reported that parents in the UK (n = 160) were accessing 2.7 different autism specific support per child with a range from 0 to 11. Similarly, a survey study with parents of autistic children (n = 479) reported they were currently using on average five autism specific support (range: 0 – 15) and about eight autism specific support had been tried in the past including pharmacological, emotional/psychosocial, and dietary approaches (Goin-Kochel et al., 2007). Parents in that study were sampled internationally including England, Ireland, Canada, Australia, and New Zealand although 77% (n = 371) of parents/carers were based in the US which might have affected the results (Goin-Kochel et al., 2007). In 2006, Green and colleagues reported that autistic children were using on average seven autism specific support and had tried about eight autism specific support from 111 listed approaches. The discrepancy in the mean number of autism approaches is because in our study we only listed 19 autism specific support compared to Green and colleagues (2006) which adapted a more comprehensive approach including medication, combined programmes, alternative treatments. Finally, the slight difference of our study with Green and colleagues (2006) and

Goin-Kochel and colleagues (2007) (3 versus 5 or 7 autism specific support respectively) may be explained by the fact that 15 years ago there was less guidance and information about the appropriateness of autism specific support compared to today which might suggest that parents/carers were likely to be open to trial-and-error autism specific support in an attempt to identify the most suitable one to address the needs of their autistic child.

Notably, parents/carers in the current study reported their children having accessed support early, but autism support tends to decrease in adolescence. For example, 84% of parents/carers of children aged 2 – 5 years and 67% of parents/carers of children aged 6 – 12 years had tried speech and language therapy compared to 47% of parents/carers of children aged 13 – 18 years. Similarly, 52% of parents/carers of children aged 2 – 5 years and 54% of parents/carers of children aged 6 – 12 years had tried occupational therapy compared to 41% of parents/carers of children aged 13 – 18 years. A similar finding was recently reported in a US study that examined the patterns of autism specific support (Monz et al., 2019). In our study, occupational therapy and speech and language therapy were utilised across all age groups. Literature indicates that speech and language therapy and occupational therapy are indeed conventional non-drug autism specific support approaches (Monz et al., 2019; Salomone et al., 2016). However, in our study speech and language therapy was slightly more frequently used compared to occupational therapy. Data from the US and Europe confirm that speech and language therapy is frequently utilised by autistic children (Becerra et al., 2017; Monz et al., 2019; Salomone et al., 2016). This is not a surprise given that social and communication support needs are a core characteristic of autism. Similarly, this study found that social and communication support for autistic children (e.g., social stories, social skills training) were most popular in the teenage group. Social skills training increased from 27% in autistic children aged 6 – 12 years to 34% in those 13 – 18 years old. Monz and colleagues (2019) reported a higher overall figure of 37% in an overall sample of 3,471 of autistic children aged 3 – 17 years. Finally, this study reported that 20% – 26% of autistic children had no access to an autism specific support since diagnosis and/or at the time of survey completion and/or over the past 6 months, respectively. Similar rates ranging from 9% to 30% have been reported internationally (Salomone et al., 2016; Xu et al., 2019) which is addressing the lack of availability of autism specific support across the globe including the UK.

It should be acknowledged that social expectations increase as children get older (Lerner, 1985). Interpersonal skills and social connection play a critical role for the acquisition of social competence (Vernon et al., 2018) and determine the autistic child's subjective well-being (Park, 2004). Studies also indicate that positive peer relationships and supportive social network of friends may be important protective mechanisms of resilience in autism (Graber, Pichon, & Carabine, 2015). Our study findings revealed that schools were among the most common location where autistic children had accessed autism specific support. This finding aligns with a study with parents in the US who reported that autistic children with a mean age of 9 years old received speech and language and occupational therapy in schools (Monz et al., 2019). That fact that school was chosen as a frequent response for delivering an autism specific support might indicate the progress in implementing autism specific support in schools (Hodges, Cordier, & Joosten, 2021; Kasari & Smith, 2013). It remains unclear though whether there is a better infrastructure in schools with easier access to specialist professionals. It could be argued that there is good collaboration among the school, the family and private or public educational settings that provide their personnel in school to accommodate the needs of autistic children in a natural setting.

In the current study, parents/carers reported consulting numerous information resources during the decision-making process about their child's support plan such as multiple professionals, the autistic community, and media which aligns with the literature (Gibson, Kaplan, & Vardell, 2017; Grant et al., 2015; Hartley & Schultz, 2015; Hebert, 2014; Miller et al., 2012). This is an important finding which emphasises the importance of professionals being in close contact with the autistic community, media, and researchers. So that they can support parents/carers of autistic children to identify the right autism specific support. Evidence in autism should inform and influence parents'/carers' choice. However, some parents/carers might choose not to use evidence-based autism specific support (Green, 2007; Green et al., 2006; Miller et al., 2012).

There is strong evidence that early autism specific support is imperative not only to the child's better adaptive functioning but on family's well-being (Estes, Swain, & MacDuffie, 2019). Literature suggests that the child's autistic characteristics, parental stress, and beliefs about autism are implicit factors associated with the use of autism specific support (Wilson et al., 2018). Behaviour that challenges was associated with medication and alternative approaches

(e.g., psychotropics, vitamins, special diets). Parents/carers with elevated stress were more likely to try both conventional and alternative approaches (e.g., speech and language therapy, occupational therapy, vitamins, special diets) in an attempt to try anything that might help their children. Parental stress might suggest the reason they report accessing several different autism specific support approaches (Wilson et al., 2018). Parent's/carer's beliefs about autism were also associated with a number of autism specific support. Some parents/carers of autistic children were more likely to access psychosocial support while parents/carers with a personal history of trauma who had autistic children were less likely to access behavioural approaches (Wilson et al., 2018). Finally, the review reported that parents'/carers' views on the genetic predisposition of autism predicted them using alternative approaches (e.g., vitamins, special diets) (Wilson et al., 2018).

The current study observed that autism specific support tends to decrease in autistic teenagers aged 13 – 18 years which aligns with the literature (Gibson, Kaplan, & Vardell, 2017). An online survey with 935 parents of autistic children aged 3 – 18 years (in North Carolina, US) has reported that there was less available information for older autistic children (aged 13+ years) from local services to support the transition to school and/or independent life including finding a job (Gibson, Kaplan, & Vardell, 2017). It requires further investigation to explore if autism specific support decreases because autistic children are more capable over time or there is inadequate support for autistic adolescents or a combination of both. Nonetheless, in our study, after speech and language therapy and occupational therapy, social communication support for autistic children (e.g., social stories, social skills training) was reported by parents/carers being the most popular one across all age groups which is indicative of the ongoing needs of autistic people.

Parents/carers in the current study appeared to be keen to explore technology-based support while 49% of autistic children had mostly access to tablets. These findings might indicate that parents'/carer's attitudes related to technology-based support is likely to be shaped by their child's use of technology at home or in school. However, previous work has reported parents'/carer's concerns about increased screen time in autistic children as well as that their autistic children were not sharing what they do with the tablet (Laurie et al., 2019). Nonetheless, in our study, the use of a tablet was reported to be the most preferred technology device across all age groups due to convenience. Technologies such as a robot or

a virtual reality headset raised concerns in parents/carers of autistic children with their design and appearance and their special characteristics (e.g., claustrophobic). Although, parents/carers were keen to explore technology-based support, tablets were accessible in 49% of households and the mostly preferred technology-based support in this study. Prior research with parents has also emphasised their concerns over screen time (Laurie et al., 2019). However, it is apparent from our study that autistic children had accessed other conventional devices such as a computer/laptop or gaming platforms not as a support tool but rather as entertainment which is increasing the duration of screen time compared to be children engage in other play activities (e.g., walk, running, drawing).

The study took place during the first national lockdown in England necessitated by the coronavirus pandemic. Overall, parents/carers described in the free-text area that autistic children had a positive experience of using technology during the coronavirus pandemic. Technology accommodated homeschooling, supported maintaining their routine (e.g., virtual therapy) and helped children to become relaxed and more independent via playing their usual games online and/or experimenting with new online activities. This in combination with the positive perspective of parents/carers considering technology-based support in autism, suggests that technology-based support was not driven as an alternative to the coronavirus pandemic. The prominence of using multiple autism specific support simultaneously suggest that lack of the available autism specific support remains a significant problem and a key drive to accessing more and more new approaches.

5.4.1 Strengths and limitations

Parent's/carer's preferences about technology-based support in autism is scarcely, if ever, reported in the literature. This study allowed us to get a better understanding of parents'/carer's knowledge and preferences about technology-based support in autism and the decision-making factors when they seek autism specific support. The study has some clear limitations. The study aimed to investigate the knowledge and preference of parents/carers of autistic children about the use of technology-based support as gatekeepers of access to technology. However, it may have been useful to also understand than children's preferences and attitudes to technology. In addition, the survey did not collect data on whether parents/carers identified as autistic. This may have been useful to know as it may have influenced their views on the different technologies. Parents/carers may have reported more

broadly on their child's use of technology (including entertainment for example) rather than focusing on their view as an autism specific support. It is also likely that parental biases may be present in the data particularly around the use of virtual reality and robots which have been a debatable topic in literature. Virtual reality and robots are fairly new technology-based support and parents/carers might not be fully informed of their use and the potential benefits in autism. These data should, therefore, be interpreted with caution. The sampling strategy might have also introduced a bias in the response rates from different nations/countries and to those parents/carers with access to technology. The link was posted online on support groups and mostly UK (and one US) autism-related websites. This could be viewed as a convenient sampling strategy that might affect the results due to self-selection and access to technology. The sample size limits the ability to generalise the study findings to the autism population. There were scarce responses from parents/carers from the remaining three nations of the UK sample. Participants were also predominantly mothers and of a White ethnic group. These data are hard to interpret without a deeper analysis of parent and child factors including cross-cultural differences in employment and socioeconomic status, age, gender, additional needs that a recent systematic review identified as factors related to autism specific support decision-making for autistic children (Wilson et al., 2018). The lack of fitting a regression model due to limited sample size per technology-based approach restricts our understanding of the relationship between parents'/carer's preference and technology-based support.

5.4.2 Implication and suggestions for future research

Exploring parents'/carers' knowledge and use of technology-based support in autism can inform professionals of routine practices. By gaining a more comprehensive understanding of parents'/carers' preferences around technology-based support, professionals would be in an advanced position to work with families and identify which approach may accommodate the support needs of autistic children following diagnosis. In addition, learning more about parents'/carers' decision-making processes in autism specific support might benefit professionals who need to propose and explain new and complex approaches to families via information materials and decision-making support tools during a consultation. These documents would be informed by the literature, designed, and reviewed by autistic individuals and professionals to be accessible to all while including the right content. Finally,

raising awareness of the extent of parental knowledge about technology-based support in autism may guide future research and clinical priorities and/or identify engaging ways to increase the visibility and promote the dissemination of research findings to the public. It is critical to explore the issue further to ensure that parents/carers receive the guidance and support they find most helpful to choose an autism specific support for their autistic child.

The study findings of the most preferred technology to use in a session with autistic children has a number of implications for the design of technology-based support and future research. New technology-based support for autistic children needs to be accessible to parents/carers and competitive to current technologies that autistic children use. The results of the study also have implications for the most popular technology-based support to parents/carers of autistic children. Lack of knowledge was reported to be the reason that respondents did not choose non-conventional technology-based support such as virtual reality and robots against more conventional ones including tablets. Future research should focus on developing an evidence-based on the way technology-based support is being used in a session and monitor their availability to autistic children as technology evolves and change over time. Finally, it is important to systematically examine the preferences of autistic children for different types of technology, the focus and format of autism specific support and the specific support needs of autistic teenagers as there is some evidence that access to autism specific support is decreasing as children get older (Gibson, Kaplan, & Vardell, 2017).

This study also reported that 49% of autistic children had mostly access to tablets which might be indicative that parents'/carers' attitudes related to mostly preferred technology-based support were likely to be shaped by their child's use of technology at home and/or in school. However, the analysis of qualitative data revealed that parents/carers were concerned about their children's dependency on technology, online safety and the obstacle of online communication which might exacerbate misinterpretation during online communication. Previous work has reported parents'/carers' concerns about increased screen time in autistic individuals aged 0 – 26 years as well as that autistic children and young people were not sharing what they were doing with the tablet (Laurie et al., 2019). Qualitative research could explore if parent's/carer's attitudes to technology-based support are indeed shaped by their child's use of technology at home and/or in school.

5.5 Conclusion

This study revealed that although tablets were the most preferred technology-based support to use in a session with an autistic child, parents/carers were open minded to the introduction of technology-based support. Parents/carers described being influenced by professionals, the autistic community, and media to select a technology-based support for their autistic child. Such findings might suggest the necessity to collaborate more closely with the autistic community and publicise research on diverse media (e.g., blogs, social media, online newspapers, radio) with the aim to disseminate the progress of research and the potential benefits of technology in autism with the wider society. Available evidence generally suggests that early autism specific support is imperative making this a promising area for ongoing research regarding parent's/carer's technology wariness and openness of using technology devices as an autism specific support from an early stage. The increased number of children aged 6 – 12 years and teenagers aged 13 – 18 years who had access to technology, notably tablets, compared to young children aged 2 – 5 years might suggest the popularity of technology is increasing as children get older. Equally, it might indicate the readiness of autistic children using technology as they grow older or might indicate parent's/carer's attitudes about (controlled and limited) access to and use of technology with young children aged 2 – 5 years. It is encouraging that technology-based support has attracted the attention of parents/carers and professionals who might suggest using them more as a support medium for learning rather than simply for fun and entertainment. However, research findings should be interpreted cautiously because there is limited research on the topic and the study was unable to describe the predictors which directed parents'/carers' choices. To increase our understanding of technology-based support in autistic children, there is a need for more research with the autistic community allowing the inclusion of autistic and adults to share their preferences and views about technology-based support in studies.

Chapter 6: Exploring parents' perspectives on the use of humanoid robots with autistic children: A qualitative study

6.1 Introduction

The aim of this chapter is to explore parents' perspectives on the use of robots with autistic children. Parents' views in the robot and autism literature are scarce and almost overlooked. Although there is much to be learned from small scale and exploratory studies about the feasibility and acceptability of robots in autism, their integration as a technology-based support necessitates in-depth understanding of the views and perspectives from all parties involved in the session. Some robots might require a moderator that is usually an adult figure (e.g., therapist, teacher, parent) who controls the robot. Understanding their perceptions is a prerequisite to establish a smooth transition to robot-mediated support with autistic children. Parents, as gatekeepers and responsible decision-makers for their child's development, are essential collaborators with whom technology-based support can be explored and introduced to autistic children in a timely manner.

Very few studies have sought parents' views about the use of robots with autistic children (Huijnen et al., 2017; Lin et al., 2021; Tolksdorf & Rohlfig, 2020). Huijnen and colleagues (2017) interviewed autism stakeholders including professionals (e.g., teachers, speech therapists, psychologists, occupational therapists), autistic adults, and parents of autistic children in the Netherlands mapping out the role of a humanoid robot, called Kaspar, as a mediator in a triadic interactive session among the child, the robot, and the therapist/adult play partner. Among the study findings, autism stakeholders outlined the significant contribution of the therapist/adult play partner in the session as *"a huge determiner of the success of the interaction and thereby of the intervention"* (Huijnen et al., 2017). Lin and colleagues (2021) explored the acceptance of 18 parents after using storytelling robots with their children. The study reported that predictors of acceptability comprised of the context of using the robot as a storytelling agent (e.g., compared to not involving the parent), the role of the robot in the task (e.g., a mediator) and the sophisticated operation of robots that might resemble human – human interaction (Lin et al., 2021). Similarly, Tolksdorf & Rohlfig (2020) asked parents to respond to a questionnaire about the use of the humanoid robot, called NAO, in a language learning task with young autistic children following four sessions. Parents

recognised that language learning through NAO was a playful approach, but NAO would be more beneficial if it could adapt its speech style to each situation rather than following a restricted script (Tolksdorf & Rohlfig, 2020). In summary, these studies indicated that parents seemed to be broadly receptive, albeit cautious, toward the introduction of robots with autistic children (Huijnen et al., 2017; Lin et al., 2021; Tolksdorf & Rohlfig, 2020).

Parents' interviews provide a valuable starting point to understand whether and how robots might be introduced into the lives of autistic children, the way to integrate robots into different settings (e.g., home, school, clinics) and how to upskill different stakeholders (e.g., parents, peers, teachers, therapists) to control robots as a new technology-based support. In chapter 4, parents/carers were in principle receptive of exploring technology-based support. Although, the administration of tablets was reported to be the most preferred technology device across all age groups due to its convenience, very few parents/carers had heard of robots as a technology-based support. This might be the reason robots were reported by parents/carers of autistic children as being a less preferred technology-based support (chapter 4). The fact that parents/carers described robots as being "*scary*", "*cold*", "*unnatural*" and "*unknown territory*" clearly indicated the lack of their knowledge on the way robots can facilitate a robot-mediated session with an autistic child and their mechanisms for potential gains across different domains of a child's development (chapter 4).

Current studies have focused on professionals including teachers working with autistic children to explore the acceptability and feasibility of deploying robots in an educational setting (Alcorn et al., 2019; Fridin & Belokopytov, 2014; Huijnen et al., 2017; Serholt et al., 2017; Westlund et al., 2016). Teachers acknowledged the benefits of using robots with autistic children in class including their engaging nature and predictability acting as motivators for learning and good exemplars of inclusivity in class (Alcorn et al., 2019; Huijnen et al., 2017; Serholt et al., 2017; Westlund et al., 2016). They also critiqued that the presence of robots might prevent autistic children from interacting with peers (Westlund et al., 2016). In addition, they shared that introducing robots in class requires additional input and consideration from teachers to identify the target group of autistic children, prepare activities related to the curriculum and ensure activities within the class and the child's home are consistent to facilitate the transition of any gains across environments (Alcorn et al., 2019; Huijnen et al., 2017; Serholt et al., 2017; Westlund et al., 2016).

Exploring parents' understanding and engagement in autism research is considered an effective way to acknowledge the real needs of autistic children. Parents' views on robots as a technology-based support is lacking in the current autism literature. Parents, as previously indicated, are key stakeholders heavily involved in their child's development whose parenting role is evolving depending on the child's needs. As such, the perspectives of parents are important as they *"are the representatives of children and experience the effects of robot tutoring first-hand"* (Konijn, Smakman, & van den Berghe, 2020, p. 9). Meanwhile professionals including clinicians and educators have predominantly been interviewed so far. This is contradictory since, on the one hand, clinicians and educators usually deliver a support session but at the same time, it is recognised that parents, as gatekeepers and key carers, need to be informed of new technologies and trained as users to further practise and generalise learned skills, if agreed, to take on this role.

6.1.1 Study objectives

This research project aimed to conduct individual interviews and/or focus groups to elicit the views of parents of autistic children about the future role of robots in a session to support autistic children in the domains of social and communication. Parent's views about the use of robots in autism have been scarcely reported in the literature. The topic guide was semi-structured, so the researcher was able to respond and react to the responses of parents who represented their autistic children. The study objectives were as follows:

1. To understand parents' views about the potential benefits of a robot-mediated session in the social and communication skills of autistic children
2. To elaborate on the social and communication skills that should be targeted in a robot-mediated session with an autistic child
3. To comprehend parents' views about the structure of a robot-mediated session with an autistic child targeting social and communication skills

6.2 Methods

The COnsolidated criteria for REporting Qualitative research (COREQ; Tong, Sainsbury, & Craig, 2007) checklist [Appendix D: COnsolidated criteria for REporting Qualitative research (COREQ) Checklist] was used to facilitate the reporting of this qualitative research. The COREQ checklist has been developed to enhance the quality, establish transparency of study procedures, and guide the reporting of qualitative research among researchers.

6.2.1 Design

A descriptive qualitative approach was chosen to allow for a deep level of exploration of parents' views on the use of robots with autistic children. In psychology research, qualitative research is considered as a way of understanding people's opinions, behaviours, attitudes, and reflection of their experiences (Percy, Kostere, & Kostere, 2015). Individual interviews, focus groups and observations are among the most common forms of data collection in qualitative research (Percy, Kostere, & Kostere, 2015). Online individual interviews and/or focus groups were, therefore, selected to facilitate the discussion of the topic (see Procedure for details).

6.2.2 Participants

Parents were included in the study if they: 1. had completed the online survey (see chapter 4); 2. had an autistic child; 3. had capacity to consent; 4. were able to take part in a conversation in English and 5. were above 18 years of age. Exclusion criteria were: 1. lack of mental capacity to consent to research and 2. insufficient fluency in English as it would not allow participation in an individual interview and/or a focus group conversation.

In total, 69 parents who took part in the online survey reported in chapter 4 had expressed an interest to be contacted about a new study in the future (see Recruitment procedure). Of those, 19 parents responded to the PhD candidate's email initiating parents to take part in a new study. In the end, only 16 parents participated in the study. The remaining three parents were unable to join remotely on the scheduled interview date. They were contacted to reschedule a virtual meeting at another time but due to ongoing cancellations and lack of availability to organise another meeting remotely, they were not followed-up more than three times.

All parents provided reasons for cancelling the remote invitation to take part in the interview. Two parents were based in the United States and the time difference was an additional factor for ongoing cancellations alongside other commitments. The other parent was highly upset with the implications of the COVID-19 outbreak and could not identify a convenient time to meet. Twelve individual interviews and one focus group with four parents of autistic children were conducted. All parents were living in England. Participant characteristics are presented in Table 6. 1 and 6. 2.

Table 6. 1 *Demographic characteristics of parents*

| Parents N = 16 | | |
|---------------------------|------------------------------------|-----------------------|
| Age (years) | Mean age in years (range) | 43.68 (5.77; 33 – 56) |
| Gender | Male | 2 |
| | Female | 14 |
| Ethnicity | White British | 7 |
| | White Other | 6 |
| | Mixed | 1 |
| | Asian or Asian British - Pakistani | 1 |
| | Black or Black British | 1 |
| Employment | Employed full-time | 7 |
| | Employed part-time | 2 |
| | Full-time carer | 7 |
| Relationship to the child | Mother | 14 |
| | Father | 2 |

Table 6. 2 *Demographic characteristics of children*

| Children N = 16 | | |
|--------------------------|------------------------------------|----------------------|
| Current age (years) | Mean age in years (SD; range) | 10.25 (3.47; 5 – 16) |
| Age of diagnosis (years) | Mean age in years (SD; range) | 5.5 (3.65; 1 – 13) |
| Gender | Male | 12 |
| | Female | 4 |
| Ethnicity | White British | 13 |
| | Mixed | 1 |
| | Asian or Asian British - Pakistani | 1 |
| | Black or Black British | 1 |

| | | |
|---------------------------|------------------------------------|---|
| Type of school attendance | Mainstream school | 8 |
| | Special school | 8 |
| Additional diagnosis | None | 9 |
| | Intellectual (learning) disability | 3 |
| | ADHD | 2 |
| | Epilepsy | 1 |
| | Co-occurring morbid conditions* | 5 |

*Co-occurring conditions include sensory processing disorder, hypermobility, hypersalivation, Raynaud's, behaviour that challenges, anxiety, arthritis, PIKA

6.2.3 Recruitment procedure

Participants were recruited through a list of parents of autistic children who had taken part in the online survey (chapter 5) and had agreed to be contacted about future research. Approximately a year after the survey launch (March 2021), the PhD candidate contacted all parents who agreed to be approached for further research via email providing a brief overview of the study. Once parents expressed an interest to be involved in the current study, the PhD candidate provided parents with a copy of the participant information sheet, a copy of the consent form, and shared a link to watch a video with the humanoid robot, Kaspar. This approach was adopted because these parents had reported in the online survey, they were largely unfamiliar with the use of robots in autism. The link with the robot Kaspar ([Autistic children can learn from this child-like robot how to put social skills into practice - YouTube](#)) was developed by researchers at the University of Hertfordshire, was provided to allow parents to develop a better understanding of a robot-mediated session with an autistic child.

6.2.4 Interview procedure

Semi-structured individual interviews and/or one focus group were conducted with parents remotely by a female trained researcher (e.g., PhD candidate). The PhD candidate had previous experience of conducting individual interviews and facilitating focus groups through her research role as a research assistant in the past and currently research fellow/trial manager. Her current role as a research fellow/trial manager includes developing a topic guide, interviewing participants (e.g., individual interviews and/or focus groups), coding and analysing data (e.g., thematic analysis and content analysis) and writing up findings.

The PhD candidate discussed with parents their preferred method of data collection (e.g., individual interview or focus group). Individual interviews have been the most widely used

data collection method in qualitative psychology research to understand people's experiences and perceptions (Kruger et al., 2019; Wilkinson, 1998, 2004). Focus groups, however, have attracted the attention of researchers because they support the generation of ideas within a group of people compared to individual interviews where sharing of thoughts is lacking (Coenen et al., 2012; Kruger et al., 2019; Wilkinson, 1998, 2004). In addition, focus groups can facilitate the exchange of perspectives within a group of people with similar experiences about a sensitive and personal experience (Coenen et al., 2012; Kruger et al., 2019; Wilkinson, 1998, 2004). Twelve online interviews and the one focus group took place using Zoom as the coronavirus health emergency had necessitated all in-person contact to cease. The growth of virtual platforms facilitated research during the pandemic via technological software (e.g., Zoom or Microsoft teams). Virtual communication still has the power of a synchronous social interaction where the researcher interacts with participants allowing to build rapport and develop a relationship with them.

The PhD candidate reviewed parents' understanding of the information sheet, gained informed consent, and explained the process of confidentiality, data protection, and their right to stop and/or pause the interview without any consequences. Following consent, parents completed a pre-interview questionnaire to collect demographic information about themselves and their child/children with a diagnosis of autism. All parents watched a video with Kaspar, prior to the interview or on the day of the interview, to get an insight of the operation and functions of a humanoid robot with an autistic child. Parents were informed this study was part of the candidate's PhD programme at the University of Hertfordshire and any questions could be directed to her via email. Data collection took place between April and June 2021 by the PhD candidate. The one focus group lasted 78 minutes while the 12 individual interviews lasted approximately 16 – 54 minutes (mean duration was 39 minutes).

6.2.5 Ethical considerations

Ethical permission from the Health, Science, Engineering and Technology Ethics committee with Delegated Authority (ECDA) from the University of Hertfordshire was granted prior to recruitment commencing (Protocol number: LMS/PGR/UH/04164 & LMS/SF/UH/04397) (Appendix E: University of Hertfordshire ethical approval for conducting interviews with parents of autistic children). Following University of Hertfordshire Institutional Review Board approval, the study started in April 2021.

The PhD candidate arranged two phone/video calls with potential participants to review and confirm their interest and understanding of the participant information sheet (including the study aim, timelines, process of data collection, confidentiality, analysis) before gaining informed consent. That time was also an opportunity for the PhD candidate and the future participants to get to know each other a bit better, learn about the background of the PhD candidate, her research interests and professional role at the time, the nature of the research study, and ask questions about the study as there was no face-to-face contact due to the COVID-19 public health emergency. Following these phone/video calls, another one was booked, if parents were happy to proceed, to arrange a convenient time to arrange the interview/focus group with no distractions to facilitate the discussion.

A copy of the informed consent was signed before the interview. Before starting the interviews/focus group, parents were informed that should there be any safeguarding concerns during the interview it is the responsibility of the PhD candidate to break the confidentiality agreement in place and inform the supervisory team of what was disclosed so that the necessary action could be implemented. It was, equally, important to remind those interested that their participation in this study was, in no way, connected to their (or their children) access to quality healthcare services in the NHS.

During the discussion, the PhD candidate ensured that parents were relaxed (i.e., were asked a few questions about themselves and their day, were sitting comfortably, were having a drink, stopped for a break, if needed, left early, if needed) and when in a focus group that everyone was welcomed to express their views without being interrupted and/or freely discuss topics they were comfortable to share with others. For example, the PhD candidate was asking at different time points if anyone would like to add something else, if there are any questions. The welfare of participants remained a priority from the outset of the study. The participant information sheet clarified the purpose and the reason(s) of the research. It also included information about support sites (e.g., organisations, charities) if parents were in need of additional support as a result of participating in the interview/focus group. The PhD candidate informed all interested participants before and during the interview/focus group about their right to stop and/or pause the discussion without any consequences, if they became distressed, including withdrawing from the study and request to deletion of their

data. There was no incidence of distress and/or withdrawal in this study. Nonetheless, parents were aware that they could re-arrange and/or discontinue the meeting, if needed.

The General Data Protection Regulation (GDPR) guidelines were followed in this study. Emphasis was given to their pseudonymisation ensuring that no real names/area of living/other identifiable information will ever be disclosed during the write up of the thesis. Participants were informed that anonymised parts of the the interview/focus group transcript would be discussed in meetings with the PhD supervisory team. The discussion was audio recorded only via a remote platform accessed through the university account of the PhD candidate and the transcript was provided through the same platform. All audio files and/or transcripts were saved on the personal password protected computer of the PhD candidate. No other member had access to these files and the anonymity of participants was always guaranteed.

At the end, the PhD candidate shared with all parents the next steps that included cleaning, reading, and analysing all data. It was repeated that only pseudonymised quotes from these meetings would be added in the thesis and/or any publication and/or report making sure that data are treated with respect and only those needed for the study are being collected. All parents had the phone number and the email address of the PhD candidate to review the study progress, ask questions and receive a copy of the preliminary findings, if requested.

The input of public and patient involvement (PPI) activities was important to ensure questions were focused and relevant (see section 6.2.6).

6.2.6 Topic guide

A semi-structured topic guide with prompts was developed by the PhD candidate with support from the supervisory team ensuring that the research questions and the concerns of parents of autistic children via the survey study (chapter 5) were explored through the topic guide. The topic guide was designed to explore the views of parents of autistic children about ways that robots might be helpful and/or unhelpful in a session with an autistic child and the support needs that can be accommodated. The topic guide was shared with two parents of autistic children to review and comment on its content before the interviews were conducted. As a result, two questions were reordered, one question was added and the wording in two items was adjusted. The conversation started by exemplifying the terms of “play-based

interventions” and “robot-mediated intervention”. To develop a shared language with parents, the PhD candidate asked them what terminology they use to describe their child's autism diagnosis prior to beginning the interview. Parents were asked to talk about topics including benefits of play-based activities, skills that should be prioritised in play-based sessions, the use of technology at home, the use of a robot as a mediator during a session, the structure and organisation of a robot-mediated session, and suggested activities/games that can be incorporated in a robot-mediated session with autistic children. Open-ended questions were used to encourage unanticipated statements and stories to emerge. Follow-up questions were used to gain greater clarity. The topic guide is available in Appendix F: Qualitative study with parents – interview topic guide.

6.2.7 Data Analysis

With consent from all parents, all interviews were audio recorded and transcribed verbatim. That meant that interviews and/or focus groups were transcribed word for word. Transcription was completed automatically via Zoom, a virtual platform, followed by the PhD candidate who carefully checked each transcript prior to analysis. Thematic analysis was selected as it offers a flexible and analytical method for complex accounts of data. This approach was appropriate in the current context in which the aim was to understand parents' views and perspectives of a robot-mediated session with autistic children.

In thematic analysis, there is a step-by-step process (Braun & Clarke, 2006, 2012). Braun and Clarke (2006; 2012) recommend researchers to be explicit about which theoretical approach is adopted in a study because thematic analysis can be used in both realist and constructionist paradigms. In this qualitative study, the analysis was conducted in a realist framework, that assumes experiences and meanings reflect participants' realities, and can be used to theorise motivations (Madill, Jordan, & Shirley, 2000; McEvoy & Richards, 2003). In addition, an inductive (bottom-up) approach to understand the data without following a pre-existing theory or coding framework was initially adopted in the current study (Braun & Clarke, 2006, 2012). This approach encourages iterative strategies of going back and forth between data and analysis ensuring that researchers continue to actively review their data before settling on an emergent theme (Braun & Clarke, 2006, 2012). On the other end, there is the deductive (top-down) approach which is driven by the researcher's interests or is based on a pre-existing hypothesis or theory which analysts then use for data interpretation. Braun and Clarke

acknowledge that inductive and deductive approaches can be combined within one analysis (Braun & Clarke, 2012). This was the case in the present study which was driven by the PhD candidate's analytical interest in the perceived usefulness and acceptability of robot-mediated support in autism whilst being concurrently data-led. A semantic approach was taken to identify, analyse and report the themes.

Data analysis was non-linear. The coding framework was elaborated and adapted through a cyclical process of reading, coding, and exploring the patterning of data. Anonymised transcripts were carefully checked alongside the audio file prior to analysis for accuracy. The PhD candidate familiarised herself with the data by re-reading the transcripts while making notes to assist the subsequent coding. A qualitative data management software system (NVivo version 12) was used to facilitate data analysis. The PhD candidate was a proficient user of NVivo. Anonymised transcripts were first read and descriptively openly coded (using the same language as participants, where possible) by the PhD candidate (i.e., initial coding). Emergent, recurring and/or salient themes in the data were grouped into broader categories (i.e., axial coding).

Following analysis of each transcript, a second stage analysis was conducted to compare and contrast findings across interviews/focus group. Focused coding is the process in which themes are collapsed and codes are finalised. The PhD candidate analysed all data. Approximately 25% (n = 3 out of 13) of the transcripts were independently open coded by a female MSc student as a validity check and on honing the coding framework. The two coders compared and discussed the coding framework until consensus was reached. The analysis stage involved discussions among the PhD candidate, the second coder and the supervisory team to further refine themes and to develop higher level themes that grouped open codes into meaningful conceptual categories. The final coding framework with example quotes was shared with two parents of autistic children to further support the interpretation of the study findings. This process allowed conclusions to be drawn about different aspects of the delivery of a session with a robot. This analytic process ensured themes did not have too much variety or too little data to support them and involved collapsing some themes that were conceptually similar. Figure 6. 1 detail the key phases of analysis performed in this study, including the three stages of coding: initial coding, axial coding, and focused coding. The analysis aimed to define key themes and points of consensus, disagreements, and

inconsistency within the interviews drawing on parents' perspectives and choice of language.

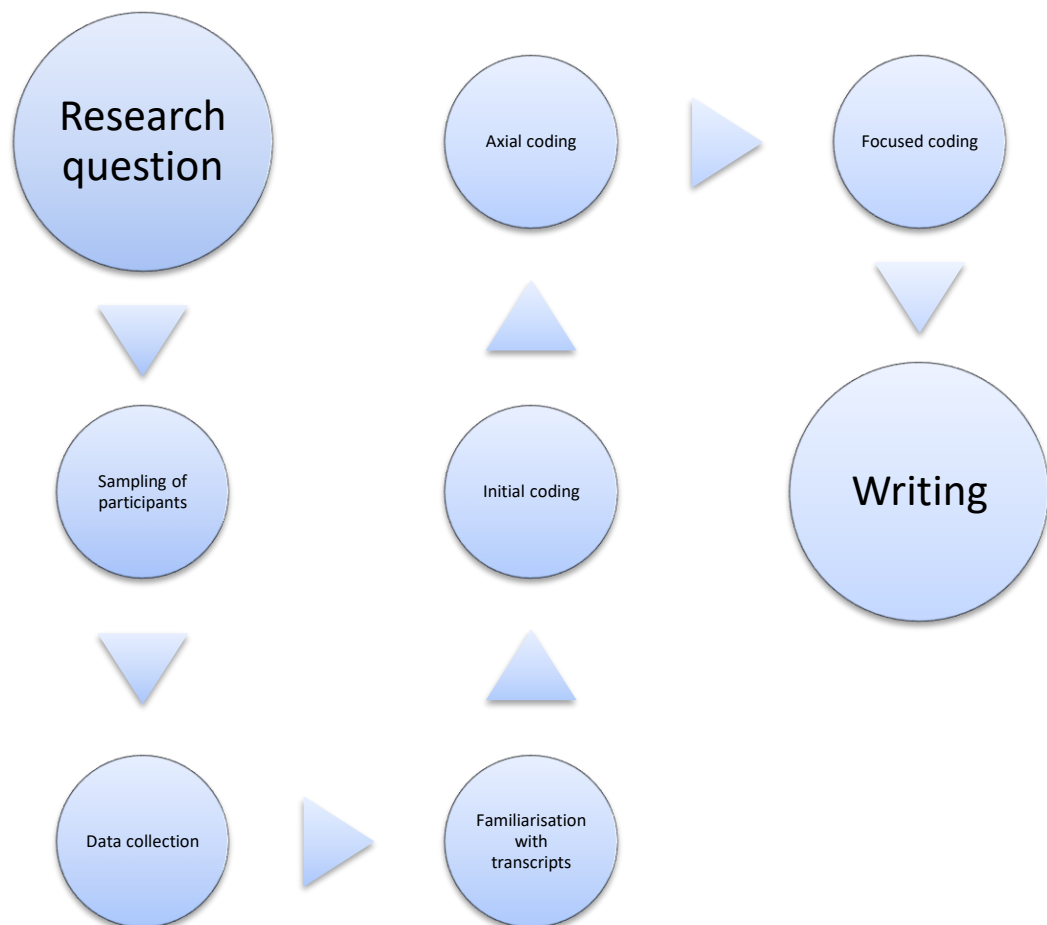


Figure 6. 1 A visual representation of data analysis

6.3 Results

6.3.1 Findings

A narrative overview of themes follows which includes illustrative quotes. Five main themes were identified which highlighted parents' views of the use of robots with autistic children in a session. The themes and associated sub-themes are presented in Figure 6. 2.

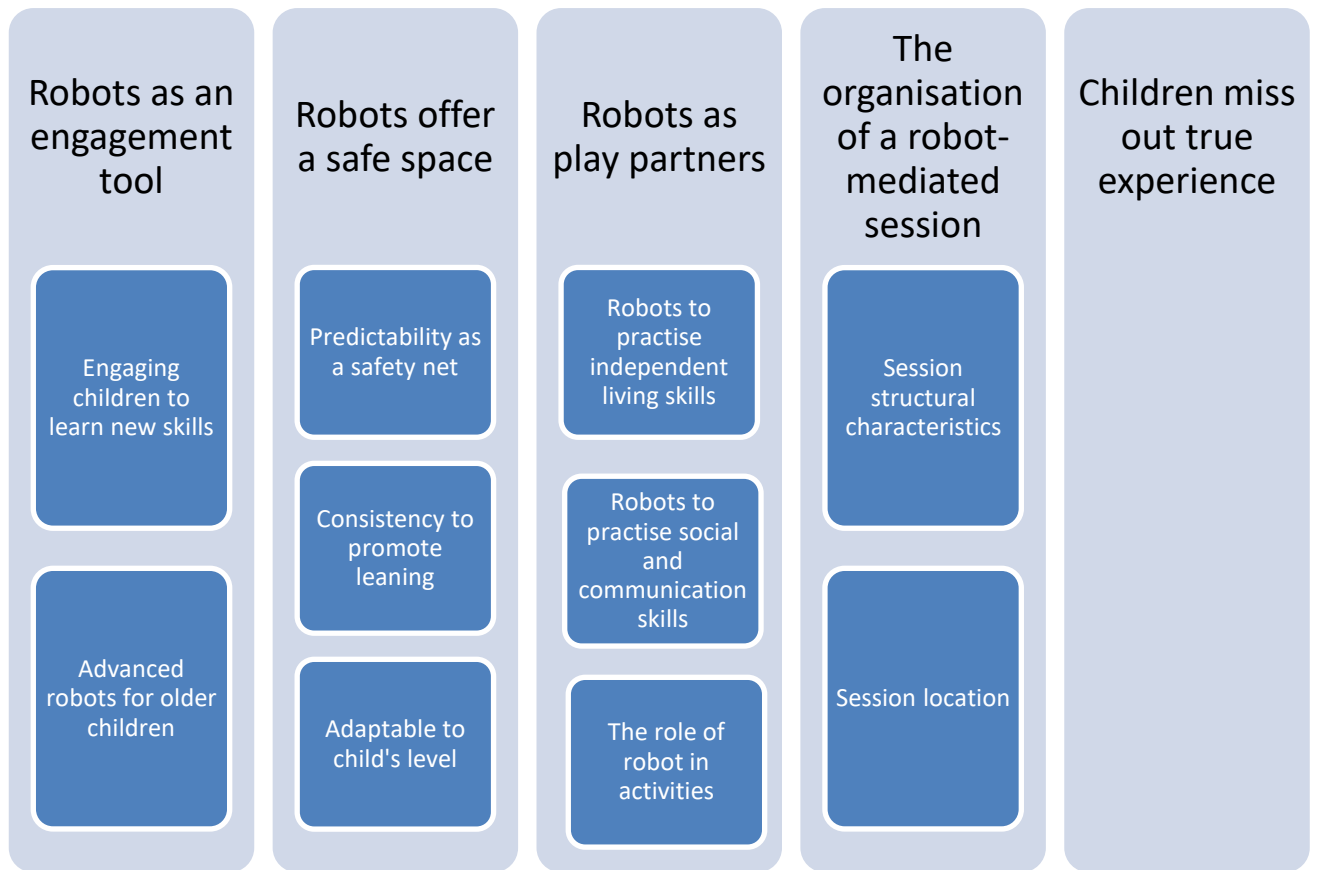


Figure 6. 2 Summary of themes and subthemes

Theme 1: Robots as an engagement tool

Twelve (75%) parents described robots as a potentially engaging approach for their children. Parents focused on different aspects of daily life that robots can potentially support their children. These are described below.

Subtheme 1.1: Engaging children to learn new skills

Parents of autistic children expressed positive views about robots potentially being a motivator for autistic children at different ages to facilitate learning. Parents highlighted that a robot might be a useful early autism specific support with young autistic children. Parents of autistic children also described that a robot could enhance autistic children’s levels of motivation for learning in a session due to their attractive appearance.

“I think it might be a really good way to engage them. I can imagine my boys who are nine and six being engaged with a robot and trying to learn a task with it.” (Parent 085958)

“I’m sure the robot is a good alternative to a playmate at the age of two.” (Parent 075634)

“The robot is more captivating than me. It is an animated toy. She would be excited to work with the robot much longer than usual. Robots are exciting.” (Parent 182851)

Parents of older autistic children considered the attraction of a robot in school might contribute to academically demanding courses/lessons including science acting as a motivator to learn more about technology.

“Maybe if it was introduced in the form of a science lesson, she might engage with it on an intellectual level.” (Parent 084053)

“I do believe that academically will help a lot. I think, six years above will be amazing.” (Parent 085726)

Subtheme 1.2: Advanced robots for older children

Parents also described that a robot need to be evolved and adapt to older autistic children with more advanced skills. Parents reported that these children were very likely to find the robot “boring” quickly.

“For children with more advanced skills they're going to say it's boring, there's nothing they can learn from it and it's too immature. My son would rather read about it and then listen to the robot.” (Parent 175741)

“It's potentially quite a good thing, especially for young children in early interventions in particular, to learn personal space but I don't see how older children can benefit from it.” (Parent 085726)

“My son is now nine now. After a certain age, I think that they don't even need a playmate, it could be a computer that's more age appropriate unless they (robots) can be more complex than that (Kaspar).” (Parent 075634)

Theme 2: Robots offer a safe space

Eight (50%) parents described robots might offer a safe space within which autistic children can potentially engage with it.

Subtheme 2.1: Predictability as a safety net

Parents of autistic children regarded robots could offer a predictable and secure environment to learn and practise skills. Parents shared their children could often become overwhelmed by the intensity of the human body language and verbal communication which often

comprises of hand gestures, hair movement, and variable intonation of the human voice. One parent made an analogy comparing the variability of human interaction with presenting a colour with different shades to another person.

“I mean imagine I show you the colour blue. You might see it as light blue somebody else might see it as dark blue. It’s similar to people’s voices. The human voice has different frequencies (e.g., bored, excited, heavy). I do believe that the sameness of the robot is key to autistic children.” (Parent 182851)

Parents also described that an autistic child often find social interaction with peers challenging due to being in a noisy environment, their own immature play preferences, or the unpredictable change of play activities in a group. Having a robot that responds similarly each time can be potentially beneficial for young autistic children. People and real life are unpredictable but with robots it is easier to predict what might happen in a session. That way, it can scaffold communication for the future.

“It is really interesting the robot can keep saying the same thing in a same tone. I can’t say the same thing over and over again. He might trust the robot more than me.” (Parent 182854)

“If you could get the robot to do something and then try to get my child to copy the robot and vice versa that may be good. She can relate happy with a smile or sad with try again.” (Parent 152306)

Subtheme 2.2: Consistency to promote learning

Parents of autistic children highlighted the possible benefits of robot’s consistency into following instructions and children’s learning. Parents described robots looking the same every time and responding in the same manner repeatedly compared to human beings’ variability of dressing, smelling, talking could potentially facilitate learning in autism.

“When robots do something and do it consistently, I think it would be quite engaging for my son. For him if there's something which always responds in whatever he says is quite an important thing. He can play on his terms, he can have control, so to speak. But I think this is very important with non-verbal children because their difficulty is that no one really understands them, and no one really responds to them appropriately.” (Parent 115224)

“The machine keeps saying the same thing in a same tone. My son won’t repeat what I say and won’t easily communicate with me. When I record myself on the phone, he repeats my words.” (Parent 152306)

“It looks sort of like an ABA approach. That constant repetition of something explicitly taught was effective with my son in the beginning to because they used to use the teach approach and he had that same repetition going on, but then what we found was that he outgrew that, and we needed to change it. A robot might be the next step to learn.” (Parent 085726)

Subtheme 2.3: Adaptable to child’s level

Parents of autistic children described robots being adaptable to the child’s level which is important not only to enhance learning opportunities and but also to eliminate any feelings of criticism that autistic children might be recipients of from human – human interaction. Autistic children are likely to feel intimidated at times by their peers and/or other adults.

“It [robot] probably allows them a safe space to communicate and watch expressions. My child often doesn’t have a two-way conversation. So, it could be a conversation between the robot and the child on their own terms.” (Parent 082720)

“Regarding emotional expression, a robot is definitely better because a lot of autistic children are more likely to express their emotions to someone who isn’t judgment. My child just wants to be the same as everybody else, so he would never tell his friend that he was upset and angry, had a meltdown and cried. But with the robot, he may be more likely to open up and say I was angry, because I couldn’t do whatever if he knows that robot isn’t human and won’t laugh at him.” (Parent 085958)

Robots are also likely to make the learning process more fun, easier, and interesting for autistic children compared to human interaction because of robot’s minimal facial expressions and limited body language movements that is often described as being overwhelming to autistic children.

“I think they [robots] could be helpful by taking away that threat by being non-judgmental because there’s no facial expressions there’s no gestures and that, I think, on the whole, in this day and age, I think they’re seen as fun.” (Parent 115224)

“The robot could interact on a sort of on the same level because with adults teaching children is that we're adults and children can't teach each other very well. So, I guess the thing about the robot is that it could teach the child on the child's intellectual level.” (Parent 085958)

Theme 3: Robots as play partners

All parents shared their views about the skills they perceived as important for their child to practise in a session with a robot.

Subtheme 3.1: Robots to practise independent living skills

Eight (50%) parents acknowledged the need for specific skills to be targeted in a session with a robot that are often get disregarded in sessions their children have accessed so far. Parents of autistic children expressed their concerns about their child's level of independent living skills. Personal hygiene of autistic children was a common concern among parents. Examples included brushing teeth, cleaning themselves (e.g., wiping mouth after eating or after visiting the toilet) and having a shower/bath which were reported by parents as highly problematic areas and important elements to accomplish throughout the child's life.

“I think as a very young child on the autism spectrum almost like a baby animated robot could literally work for toilet training or personal hygiene.” (Parent 102747)

“He has some sensory issues. He doesn't have sensitivity around his mouth, and he can't tell when he's dirty. If the robot can teach them to be aware of it, because he just looks like he's messy. As he gets older that's going to be more noticeable to other people and other children don't really say anything to him, but I worry when he gets to secondary school whether he'll get teased for that, not so much in primary school because growing up he's been there since nursery so the children just accepted, but I do worry, so I wonder if it could be something like that the robot could interact with.” (Parent 115224)

Furthermore, fine motor daily tasks (e.g., use of cutlery, tie shoelaces, button themselves up), house chores (e.g., do the laundry, make own food/breakfast/dinner, shopping, make the bed), understanding the concept of time and time management, understanding of the concept of hot and cold water, independent travel to school, independent feeding were some of the domains referenced by parents as important to acknowledge in future robot-mediated sessions.

“Awareness of the road awareness of waiting for a bus what should you’d be looking out for. Those skills are really he’s probably quite behind compared to his peers.” (Parent 085726)

“If the robot could show how to do these buttons up and how to get dressed that would be useful” (Parent 152306)

“My youngest has no concept of hot water will burn you. I think it would be really important to kind of focus on that in a robot session, we have tried at home, and we’ve not got very far. He has no danger awareness of that. You know, hot water will burn cold water will shock you when you get in the shower. I still need to check everything. I have to put the blob of toothpaste on the toothbrush.” (Parent 082720)

One parent of a 13-year-old autistic boy expressed her concerns regarding radicalisation and the way social stories via a robot could potentially be a beneficial approach for her son. The parent explained that due to her son’s rigid thinking he tends to form extreme opinions and/or express strong views on a topic.

“I’m concerned about radicalization. When he gets something in his head it’s really hard to change his mind about it. With the feminism incident in class, he has to go to the extremes. But I always tell him, we have to find like a middle way to do things. But he’s always either black or white can never go in the grey area so that’s what I’m afraid. I guess social stories might be a good way. I mean via a robot.” (Parent 175741)

Subtheme 3.2: Robots to practise social and communication skills

Similarly, eight (50%) parents highlighted the need for their autistic children to practise social and communication skills with a robot.

“It (the robot) will be something positive. It might help him with meeting people and building up his confidence.” (Parent 085459)

Parents of autistic children aged 5+ years specifically referred to practicing social interaction skills using different life scenarios (e.g., make friends, approach a new child in class, ask for help) and turn-taking skills. Parents reported these skills are particularly important as children get older because it will be challenging to bridge the gap in social interaction with peers in the future.

“Let’s say I wanted him to play Lego with me and build different things he won’t wait for his turn.” (Parent 182851)

Additionally, parents reported staying on topic and maintaining a dialogue between speakers are challenging areas in autistic children. Autistic children demonstrated support needs in expressive language (e.g., rich vocabulary), information processing and interpretation during a conversation with peers and/or adults.

“Conversation can be very much one sided. They really need help in developing those skills. Especially staying on a topic and having that two-way conversation.” (Parent 085726)

Finally, parents expressed their concerns with lack of understanding of personal space by autistic children impact social integration with peers at school and/or the wider community.

“I suppose, for me, the important explicit teaching of conversation and personal space is important knowing how close down to get to someone.” (Parent 182851)

Subtheme 3.3: The role of robot in activities

Eight parents (50%) emphasised that the robot is important to stimulate the child to engage in activities. If robots can attract the attention of the child by looking like “*battle heroes*” or “*making sounds*” reacting to what they say, it is likely that autistic child remain in the activity longer.

“If Kaspar looked like a battle hero with lasers and rockets and stuff that might be more engaging for autistic children.” (Parent 075634)

“If the robot is like a puppet like a dummy, they (children) can role play. When you touch it (the robot), it can make sounds and can talk. You know it reacts in a way, so you can say that OK now go to copy it.” (Parent 175741)

Six parents (37.5%) suggested that a humanoid robot needs to be able to model a range of behaviours such as ball games and/or emotional recognition tasks. The robot would be teaching them how to behave within a social context while supporting them making sense of daily life.

“Activities like throwing the ball to each other and catching the ball and things that require so many other skills. I mean even to catch the ball the child needs to see the ball coming, throw the ball, evaluate how much strength is needed to throw it to the other person and so on.” (Parent 182851)

“If the robot’s face were coloured to distinguish emotional recognition such as green is okay, the conversation is going forward and yellow is a bit dangerous it’s an indication to train them because something needs to change. You have to train them as you do with a dog or a toddler. If the robot can show them what’s socially appropriate or not it might be easier for children to learn that via the robot and then apply these things in everyday life.” (Parent 075634)

Finally, three parents indicated that the robot can also be used as a medium which enables interaction with other children and/or adult play partners. They described a triadic relationship where the child, the robot and the adult play partner will pay attention, interact, and communicate with each other. For example, parents described activities such as card/letter matching games, chess, imitation games which require joint attention, memory, and turn-taking skills.

“Create a geometric pattern with different colours and the robot gives it to the child to copy the image. Those or problem-solving games and memory games might be games for the robot.” (Parent 085726)

Theme 4: The organisation of a robot-mediated session

Nine parents (60%) of autistic children reported their children had previously received autism support since diagnosis. Parents reported being familiar with the structure of a session. Therefore, they expressed their views on the structural characteristics (e.g., individual, group session) and the session location of a future robot-mediated session.

Subtheme 4.1: Session structural characteristics

Parents were split in half regarding their views of the structure of a robot-mediated session with an autistic child. Eight emphasised that individual sessions are preferable with the remaining eight parents highlighting the benefits of group sessions with a robot. All parents explained the structure of the session should depend on the targeted skills and level of functioning of each autistic individual. They acknowledged the role of a professional in the session with the robot as important not only to explain the activities to the child but also to act as a play partner. Parents considered class teachers knowledgeable to control a robot following a brief training which minimised the need for a healthcare professional /therapist.

“Ideally, I would imagine it would be better suited to one-to-one. It might be hard to have many children wanting to interact with this robot. My son will get very confused.” (Parent 085726)

“If the teacher is controlling the robot to play fun games or do learning activities via the robot that will potentially enhance the cognitive skills of all children not my son only. She (the teacher) is always there and is more helpful to get children together.” (Parent 075634)

Subtheme 4.2: Session location

Nine parents (60%) expressed a preference for the session to take place in school because it is a familiar place for their autistic children. Parents shared that the school remains an inclusive environment which might increase opportunities to involve peers in a session and enhance interactive opportunities compared to a clinic.

“If a child is in mainstream school, I think it should be done in class. If 29 of the children were joining in and giving a prod, he would probably be more likely to join the robot and give it a go rather than you take him and five friends who he knows are on the spectrum out of class. He would be questioning why him and the five the autistic children have been removed.” (Parent 082720)

Parents reported that children and teachers are both familiar with the school environment, emotionally connected to each other and knowledgeable of the school boundaries. Therefore, it was perceived by parents as less *“time consuming”* to start a session compared to a healthcare professional /therapist who requires time to conduct familiarisation visits with the child and adjust to a new environment.

“I think school will be better because it's familiar. He sees his teacher five days out of seven it's always the same teacher who's there so even if someone else comes into class he said she's familiar. Whereas let's just say you took them out in a group if he was uncomfortable. He would just sit there and not speak he wouldn't tell “I don't want to be here or don't want to do it. Whereas if there is someone familiar that he would more likely speak up.” (Parent 082720)

However, three parents (19%) argued that home, school, or a clinic are equally good alternative locations for a session with a robot. At home, parents will have opportunities to engage in their child's session compared to school that would be challenging to attend and/or observe the content of a session with a robot during school time.

“It's interesting, isn't it? If it happened in school, then I wouldn't be able to observe what they were learning, and I think I would quite like to observe what they were learning. And it would be an advantage happening at home but practically I'd be happy to take them to a clinic.... So, either of those would be fine.” (Parent 085958)

Finally, two parents (12.5%) only commented that the location of the session is not a concern to them as long as it takes place outside of the home which was regarded as an opportunity to travel and develop a new and fun routine.

“I think outside home is better for him because it's just like a trip, like an outing, like a new experience, and I think he likes that and then he gets used to go somewhere else as well to do something really fun. It's like his time.” (Parent 085459)

Theme 5: Children miss out the true experience

While all parents were positively inclined to the use of robots with autistic children, seven parents (44%) emphasised that human interaction should also be fostered in autism. Parents emphasised that too much predictability from robots might give autistic children a distorted view of real-life world.

Parents of autistic children expressed their concerns about robots. They discussed Kaspar's presentation and facial characteristics reporting that their children might get immersed into a robot neglecting real life.

“My first thought was his face was scary. His face doesn't change that could be potentially problematic because, as we know, one of the traits of autism, is that they can't read facial expressions so you're missing out on that real life.” (Parent 085726)

In addition, the robot's limited facial expressions are likely to impede on children's social understanding of peer interaction and communication because daily life is unpredictable.

“The facial expressions were not easy to interpret. Was it [the robot] sad or upset when it hid its his eyes? Can the robot smile? It was difficult to for me to guess from a short video how helpful that would be for a child, I suppose, it will be an extra problem to interact with people and read their emotions in real life.” (Parent 085958)

Another parent expressed her concern about the robot's subtle lip movement followed by unclear speech is potentially problematic for young children who are minimally-verbal. She

described children when learning to speak tend to observe the mouth of the speaker, but the robot was lacking that feature.

“Autistic children tend not to look you in the eye, but they look at your mouth. When you're speaking so it's very important to see the way your mouth moves which obviously you wouldn't get from Kaspar.” (Parent 085849)

Instead, parents suggested a balance between robot interaction and human interaction that will facilitate a transition from a safe and secure interaction to a realistic but still a safe one with neurotypical children/adults who can equally achieve the same goals as a robot.

“Those same things that they're working on with Kaspar could work with say another child who's neurotypical and probably find more effectiveness.” (Parent 085726)

6.4 Discussion

The aim of this study was to explore parents' views and perspectives of employing robots with autistic children in a robot-mediated session. The potential benefits, the targeted skills and organisation of future robot-mediated sessions were among the core study objectives to explore with parents of autistic children. Parents who had been approached to take part in the study were unfamiliar with the use of robots with autistic children, as reported in a previous study (chapter 5). As part of this study, parents were introduced to a humanoid robot called, Kaspar, to develop an understanding of how a humanoid robot might look like and its capacity and limitations in a robot-mediated session.

Parents were receptive, albeit critical, to the use of robots in sessions. Within this context, the study findings align with the current literature where parents raised concerns about robots' *“simplistic interactions”* (Kennedy et al., 2016) and *“being consistent”* (Diep et al., 2015). Parents acknowledged that robots are probably attractive to autistic children and children are likely to engage with them in a session which is consistent with previous literature (Alcorn et al., 2019). Moreover, parents described that the predictability and consistency of robots might facilitate learning in autistic children that, if scaffolded, might be an effective approach (Rudovic et al., 2017; van Straten et al., 2018). These two core features, as indicated by parents in the present study, are achievable because the robot can repeat certain actions repeatedly so that the child will learn a skill in a safe and secure environment.

Parents also shed light on diverse skills that future robot-mediated sessions should target to holistically support autistic children. Parents focused on a range of independent living skills followed by social and communication skills. Independent living skills are closely related to social and communication skills to allow autistic children to perform daily tasks at home, school, and other social environments. Although there is extensive literature about autism specific support targeting social and communication skills in autism, autism specific support targeting independent living skills are scarce in autism (Duncan et al., 2018; Wolstencroft et al., 2018). Similarly, the meta-analysis (chapter 3) highlighted a significant effect size for social and communication skills. It is worth mentioning the systematic literature review included three studies targeting motor skills which can be broadly considered as an aspect of independent living skills (So et al., 2018a, 2018b, 2019a, 2019b). These studies explored motor imitation of daily gestures such as wave, come, where, nodding yes/no as well as imitation of feelings and needs communicated via gestures including angry, annoyed, hungry, noisy in autistic children as a result of a robot-mediated session.

Indeed, the breadth of social and communication skills support needs might reflect the fact that social communication and interaction is one of the two core autistic characteristics (American Psychiatric Association, 2013; World Health Organization, 2018). In addition, social and communication development leads to greater independent living skills (Anderson, Liang, & Lord, 2014; Levy & Peery, 2011; Sasson et al., 2020). Such a significant gap in the literature and parents' need for independent living skills to be targeted in future robot-mediated sessions might equally indicate the need for more effective models of collaboration between autism researchers with key stakeholders in autism working together to progress autism research. Participatory research has been championed in autism over the years (Nicolaidis et al., 2019; Pellicano & Stears, 2011; Fletcher-Watson et al., 2019), but especially within technology-related autism research (Frauenberger et al., 2011; Porayska-Pomsta et al., 2012; Brosnan et al., 2016). Future work should enhance opportunities for better collaboration of researchers with all relevant key autism stakeholder members (e.g., parents, autistic children and adults, professionals) in the design and implementation process of new autism specific support. Such an initiative will give the opportunity to bridge the gap between research and clinical work by working together to design the study and the manual of a robot-mediated session based on evidence while taking into consideration the real needs of the population of

interest. Parents/carers and autistic children and/or adults working collaboratively with healthcare professionals and researchers will also ensure that new research work is sustainable to those in need and sufficiently tailored to the realities of their everyday life (Lloyd & White, 2011).

In the present study, parents described the role of the robot in a session with autistic children. Parents described that the robot needs to: 1. attract the attention of the autistic person; 2. be able to model different behaviour and 3. act as a mediator to facilitate human – human interaction. Previous literature predominantly with professionals (e.g., teachers, speech therapists, psychologists, occupational therapists), some autistic adults and a few parents of autistic children summarised the potential roles Kaspar, a humanoid robot, could take in a structured triadic robot-mediated session with autistic children (Huijnen et al., 2017). The role of a “provoker”, “trainer” and “mediator” appears to broadly align with our study findings (Huijnen et al., 2017). Based on Huijnen and colleague’s study (2017), the role of the robot that attracts the attention of children via its appearance in our study could be described as “provoker”. The role of a “trainer” might be related to the robot modelling a diverse range of skills including turn-taking, following instructions, problem-solving, responding to questions (Huijnen et al., 2017). Whereas a “mediator” could be defined as the robot that facilitates the interaction between two human parties (Huijnen et al., 2017). However, Huijnen and colleague’s (2017) study aimed to identify how to integrate Kaspar as a new autism specific support with autistic children while stakeholders (predominantly professionals) worked on a pre-specified session template. The current study was conducted with parents who had watched a 2-minute video with Kaspar only, were unfamiliar with the use of robots in autism and were brainstorming about their potential use in autism.

The current findings highlighted that a robot-mediated session needs to be flexible and adaptable to the child’s needs. The heterogeneity of specific autistic experiences and characteristics emphasises that there is no one-size fits all design for robots in autism. Nonetheless, the meta-analysis (chapter 4) indicated a large effect size of robot-mediated sessions for autistic children aged 4 – 7 years in comparison to children aged 8 – 12 years. Robots may be beneficial, if used in a certain way, and if certain measures are in place. That means that a therapist/adult play partner is important to guide session activities (Huijnen et al., 2017). In addition, the context within which robots will be introduced to autistic children

needs to be carefully acknowledged. Parents expressed that either individual or group sessions were preferable which aligns with previous literature specifically targeting the introduction of Kaspar in autistic children (Huijnen et al., 2017). In the present study, most parents also identified the delivery of a robot-mediated session in school as the most preferred option, if possible. A meta-analysis of 12 RCTs (chapter 4) summarised that an autism clinic/centre demonstrated improvements in the targeted skills of autistic children. Another study about the importance of context in autism specific support (in general) summarised autism sessions at home were most preferable among parents of autistic children (Guler et al., 2018). However, these studies are quite distinct from the current qualitative study which was based on parents' views and not evidence-based practice. However, the strength and needs of each autistic child should be prioritised before a decision on the type and location of a robot-mediated session.

Further, this qualitative study outlined parents' concerns of the importance of maintaining human – human interaction and balancing human and robot interaction for better outcomes in autism. The aim of robot-mediated sessions is not to replace human – human interaction. Instead, it aims to facilitate human interaction via a robot that is the mediator between a child and a therapist/adult play partner within a safe, engaging, and secure environment for those autistic children who find it challenging otherwise. Previous studies conducted with educators revealed that regardless of them being positive toward the future introduction of robot-mediated session in learning, they were equally cautious of the generalisability of skills and concerned of robots replacing human interaction (Alcorn et al., 2019; Coeckelbergh, 2016). On the other hand, parents of autistic children who were present in robot-mediated sessions delivered by a human therapist reported the session was “*satisfying*”, “*interesting*” and “*helpful*” (Amirova et al., 2022). Only two (out of 16) parents of autistic children described the robot as “*iron man*” or “*machine*” (Amirova et al., 2022). It is of interest that parents/carers in the online survey (see chapter 5) were not in favour of robots when asked to choose among a list of other technology types to support their autistic children. There is evidence of the importance of parental involvement in traditional autism specific support for autistic children with better engagement during the session, generalisability of gains and recognition of specific autistic experiences and characteristics (Burrell & Borrego, 2012; Kose, Fox, & Storch, 2018; Matson, Mahan, & LoVullo, 2009; Sofronoff, Attwood, & Hinton, 2005). Therefore,

future work should encourage the observation and/or presence of educators and/or parents/carers in a robot-mediated session with the autistic child. They can be observers and/or have a role in the session, if possible, with the support of a therapist/adult partner who would help them enhance their knowledge and understanding of a robot-mediated session in autism.

These conditions set the scene for the future evaluation of the effect of robot-mediated sessions and the outcomes of autistic children following exposure to robots. The short or long-term impact of robot use with autistic children remains unanswered. The current literature review (chapter 4) reported that studies usually examine improvements of a robot-mediated session at the end of a session. To understand retention of learned skills, and to set parent's expectations about autism specific support outcomes, longer-term data are essential. Robots might appear to facilitate learning (chapter 4) but there is no doubt that it needs to be ethically justifiable for the broader autistic community as a technology-based support.

6.4.1 Strengths and limitations

There were a number of strengths to this study. Firstly, the study included parents from White (82%) and multiple ethnic backgrounds (18%) which largely reflects the English population. Although, the survey was not intended to reflect the English population, according to the 2019 Office for National Statistics data, 85% of the population in England and Wales was White and 15% comprised of people from multiple ethnic backgrounds (Coates, 2021). There was also equal representation of autistic children in mainstream and special education. Although literature indicates that 71% of autistic children are in mainstream education, autistic children in special schools are less represented in research (Rowland, 2021). Secondly, this research adds to the existing literature suggesting skills to be targeted in a robot-mediated session as well as the session location, as indicated by parents. Much of the literature has focused on understanding professional's experiences such as therapists and/or teachers. Finally, the COREQ checklist improved the rigour and comprehensiveness of the reporting of data in qualitative research.

This study is not without limitations. First, given the convenience sampling of participants, the study findings should be interpreted with caution because it is unlikely to reflect the views of all parents of autistic children in England. Nevertheless, given the variable age ranges of

children and the school type they attended, parents are likely to have provided diverse views on the potential use of robot-mediated sessions with autistic children. A second key limitation is that although parents of autistic children reviewed and commented on the content of the topic, these were not autistic parents which might have commented on the topic guide from a different perspective. In addition, the topic guide was not piloted with parents to inform the methodological approach of this study and minimise biases. Parents had expressed an interest to be contacted about a new study via the online survey launched the first months (e.g., May 2020) of the coronavirus outbreak in the UK. Recruiting parents via the online survey might suggest that these participants were not only computer literate, but they were keen to engage in research as well. Parents, also, shared their perspective about robots having seen a familiarisation video of the humanoid robot, Kaspar, only, due to being largely unfamiliar with the use of robots in autism. It is likely parents may have expressed different views about other robot types (e.g., animaloid or industrial robots), if they were shown different videos or were already familiar with the use of robots in autism. That means that the consensus (by parents) about robots being engaging and motivating play partners might reflect humanoid robots or even Kaspar only. This is a biased methodology, that was adopted following request from participants as an aid to facilitate the discussion. The aim of observational studies is to capture a natural response without an external intervention (Sedgwick, 2012). However, the introduction of the video of Kaspar is viewed as an intervention that is likely to have influenced and minimised the generalisation of the study findings. It should also be emphasised that the introduction of Kaspar in this study might limit the promotion of diversity, and inclusivity in research. One critical consideration is its standardised design, which may not adequately represent or resonate with the diverse ethnic, gender, and disability-related backgrounds of autistic children it aims to support. For instance, Kaspar's appearance, programmed activities, and behavioural expressions are likely to be influenced by the Western culture suggesting that it is not attuned to cultural nuances and social norms pertinent to different ethnic groups. As a result, there are potentially limitations of its effectiveness in cross-cultural research. In addition, the design of Kaspar, although adaptable, does not reflect the gender diversity of today's society. Therefore, it is likely to reinforce gender biases and/or fail to address the individual needs of different genders in social interactions. Furthermore, while Kaspar is primarily designed to support autistic children, its application might not extend effectively to individuals with other types of

disabilities, thereby narrowing its scope and impact to establish meaningful and relevant results. These sociocultural and disability-related limitations underscore the necessity for a more inclusive approach in the design and deployment of robot support in future autism research. It is imperative to ensure that the diverse user experiences and support needs are comprehensively represented and addressed. In addition, if the focus of the topic guide was towards the ethics of using robots with autistic children, it is likely that parents may have projected more opposing views. Moreover, individual interviews were mixed with a focus group. That was a pragmatic choice from parents participating in the focus group who viewed it as an opportunity to exchange ideas with others on a topic none was largely familiar. There is evidence that individual interviews may offer the opportunity to share personal opinions and/or sensitive information more freely compared to a focus group discussion, but this is not set in stone (Guest et al., 2017). Finally, parents may have been positively inclined towards robots as a sign of social desirability which limited opportunities of constructive criticism on the study.

6.5 Conclusions

This study demonstrated that parents/carers recognised and understood the promising avenues of robots in autism and shed light on the skills that a robot-mediated session could potentially target. Equally, the study presented parents'/carers' concerns of the importance of maintaining human – human interaction and balancing both types of interaction for better outcomes in autism. The context of a robot-mediated session was summarised with either individual and/or group sessions with a robot preferably taking place in a school setting. As new specific support approaches emerge in autism, it will be important to promote the presence of educators and/or parents/carers in a robot-mediated session for the benefit of all autism stakeholders. Further, it is equally imperative to actively promote better collaboration between researchers with key autism stakeholders in future studies to acknowledge the real needs of autistic children and their parents and identify ways to maximise the effect of robots as a technology-based support.

Chapter 7: Joint attention skills in autistic children interacting with a human therapist alone or a humanoid robot along with a human therapist

7.1 Introduction

Autistic children have been described having increased levels of interest in technology which in turn can be leveraged to promote social interaction and communication in a session (Fletcher-Watson, 2014; Hourcade et al., 2013). In chapter 4, the findings of the systematic review and the meta-analysis guided the analysis of the current research study. According to the systematic literature review, humanoid robots had been widely applied in sessions to address the social and communication support needs of autistic children (see Table 4. 4). In addition, the review reported that where such robots had been used, autistic children had on average received eight sessions (see Table 4. 6). When all sets of outcomes (e.g., social and communication, emotional development, and motor skills) from the randomised controlled trials (RCTs) were combined, the meta-analysis showed that having sessions with a robot was marginally more effective than having a session with a human therapist alone (see Figure 4. 2). For social and communication skills, the effect size was significant with low heterogeneity in robot-mediated sessions indicating improvements in the social and communication skills of autistic children compared to the human therapist group. It is also worth mentioning that younger autistic children aged 4 – 7 years appeared to demonstrate greater improvements in a robot-mediated session compared to older children aged 8 – 12 years (see Figure 4. 4). Finally, it was observed that the delivery of sessions took place in a clinic room in the vast majority of studies (see Table 4. 5). These findings suggest that humanoid robots are an “optimal” medium which encourages the development of social and communication skills for some autistic children. Nonetheless, the benefits of robots depend on the age of the autistic child and the session location.

In the survey, most parents/carers reported robots were the least preferred technology-based support due to considered being “*impersonal*”, “*cold*” and “*scary*” (see chapter 5). Despite this, in interviews with parents of autistic children who were largely unfamiliar with the use of robots in autism, they expressed positive views towards humanoid robots in autism and shared examples of how humanoid robots can target different behaviours with autistic

children (see chapter 6). Parents also expressed their children had a particular interest in technology which is likely to positively mediate an interaction with a humanoid robot (see chapter 6). However, parents commented that the potential limited playing capacity of robots in a robot-mediated session is a risk factor of disengagement with it (see chapter 6). Therefore, parents' insights into humanoid robots in autism emphasised that children's interests, but also scaffolding interaction in a stimulating way for the child, are imperative features to be taken into consideration when introducing technology-based support. In summary, humanoid robots could promote social and communication skills in autistic children following careful design and development of engaging and age-appropriate activities. Engagement in social and communication skills though requires two individuals to process the information that they attend to a person, an object or an event and this process is common to both parties – that is called joint attention (Mundy & Newell, 2007).

7.1.1 Joint attention in autism

Joint attention refers to the behaviour of an individual including initiations or responses to shared attention bids with others (Bottema-Beutel, 2016; Locke et al., 2010). Autistic children appear to develop joint attention skills differently compared to neurotypical children (Adamson et al., 2008). In neurotypical infants, the ability to engage in joint attention usually develops within the first year of life (e.g., child's use of gestures or eye-contact with another person to direct attention to an object, person or event) whereas more enhanced skills of joint attention (e.g., follow the direction of eye-contact or gestures of another person to respond to bids of interaction, share an object or engage in reciprocal game) are frequently developed between two and three years of life (Mundy & Newell, 2007).

Autistic children or suspected autistic children appear to present with reduced frequency of joint attention behaviours such as fewer responses to people's bids of shared attention, fewer responses to their name, and rare initiations to attract the attention of others either with pointing or showing objects to other people (Dawson et al., 2004). Researchers suggest that autistic children may need support in initiating joint attention than responding to joint attention bids from others, but autistic children engage in joint attention behaviours including initiating social (verbal or non-verbal) interactions when they are in interesting and motivating environments for them (Jaswal & Akhtar, 2019; Meindl & Cannella-Malone, 2011; Mundy & Newell, 2007; Mundy et al., 2007; Murray, Lesser, & Lawson, 2005).

Joint attention is thought to be the cornerstone for further social and communication skill development in autistic children (Charman, 2003). Therefore, psychosocial support in autism commonly targets joint attention (Bottema-Beutel, 2016; Warreyn, van der Paelt, & Roeyers, 2014). There is evidence from longitudinal studies that responsiveness to others' joint attention bids in early childhood is associated with a range of cognitive and social outcomes such as quality of social play in later life (Bruinsma, Koegel, & Koegel, 2004; Jones & Carr, 2016), peer relationships at school (Freeman et al., 2015), expressive and receptive language in adolescent life (McGovern & Sigman, 2005), and improved social functioning in adult life (Gillespie-Lynch et al., 2012).

7.1.2 Robots and joint attention in autism

As Charman described (2003), joint attention is a pivotal skill in autism. Nonetheless, little is known about the way robots might support the development of joint attention skills in autistic children. Literature suggested that autistic children may be highly engaged during robot interactions (Robins, Dautenhahn, & Dubowski, 2006; van Straten et al., 2018), and may show spontaneous joint attention (Anzalone et al., 2019; Warren et al., 2015). The humanoid robot, Kaspar, in particular, has been researched as an autism specific support predominantly in pilot studies with autistic children to encourage social communication and emotional understanding (e.g., turn-taking, emotional recognition) since 2007 (Robins, Dautenhahn, & Dickerson, 2009; Robins et al., 2007, 2008, 2010). Kaspar has been upgraded five times since its development in 2005 which indicates that Kaspar has been adapted to the variable needs of autistic children over the years (Wood et al., 2021). The humanoid robot, Kaspar, has been also used to facilitate collaborative behaviour in autistic children while playing a video game either with a neurotypical adult play partner or with the robot as a play partner in a dyadic interaction (Wainer et al., 2014). Autistic children looked at Kaspar more frequently compared to the adult play partner, but they collaborated better with the adult play partner in the video game (Wainer et al., 2014). Although this was pilot study with a single session, such a finding provides additional evidence of the potential benefit of using Kaspar with autistic children.

There is growing evidence that robot-mediated sessions are a potentially valuable approach to support the development of joint attention skills in autistic children (Kumazaki et al., 2018; Pennisi et al., 2016; Scassellati et al., 2018; So et al., 2020a, 2020b; Warren et al., 2015; Zheng et al., 2016, 2017). However, a recent systematic review of 13 peer-reviewed studies about

the clinical effect of robots in autistic children's joint attention skills reported inconclusive outcomes (Sani-Bozkurt & Bozkus-Genc, 2021). Likewise, the systematic review and meta-analysis in chapter 3 aligns with the current literature about the effect of robots in autistic children being uncertain. However, these findings can mainly be attributed to methodological weaknesses such as the small sample size, the brief session protocols, and a lack of generalisability of autism specific support gains. So, while there is inconclusive evidence to support the effect of robot-mediated sessions in autistic children, robots might still offer an alternative intervention support approach where some autistic children may find it a motivating and encouraging environment to practise and enhance joint attention skills.

7.1.3 Study objectives

The current study aimed to explore the effect of a triadic robot-mediated session with a human therapist along with a humanoid robot, Kaspar, compared to a dyadic interaction with a human therapist alone on the development of autistic children's joint attention skills. This chapter addresses the following research questions:

1. Are there greater improvements in the joint attention skills of autistic children receiving a session from a human therapist along with Kaspar compared to those receiving the same session with a human therapist alone?
2. Is there an improvement within the Kaspar or the human therapist group in the joint attention skills of autistic children from the first to the last session?

7.2 Methods

This chapter presents data that have been collected as part of a National Institute for Health Research (NIHR; award ID: PB-PG-0215-36122) funded feasibility RCT conducted in 2016 – 2019 (the Kaspar study) for which the Principal PhD supervisor (Dr Shivani Sharma) was the academic lead (Appendix G: University of Hertfordshire ethical approval to analyse the video recordings from the Kaspar feasibility trial). The RCT aimed to explore the feasibility of using a humanoid robot, Kaspar, to support the development of social and communication skills of autistic children (Mengoni et al., 2017). Video recordings were collected as part of the feasibility trial while the PhD candidate was employed as a research assistant. These are original, unanalysed, and unpublished data from sessions of autistic children that took place in a clinic room in a local NHS setting. This chapter presents a secondary analysis of existing

video recording data. The PhD candidate managed, cleaned, and analysed the data but did not contribute to the original study design, inclusion of study participants and selection of activities and data collection of video recordings.

7.2.1 Participants

The total sample size of the feasibility RCT was 38 autistic children who were recruited via an autism diagnostic clinic in Hertfordshire Community NHS Trust. The Communication Disorders Assessment Clinic (CDAC) in Watford offered assessment and support to autistic children who had been referred to the CDAC from the catchment area. The CDAC team screened recently diagnosed (within 12 months in 2017 – 2018) autistic children from their existing records and identified eligible autistic children who were referred to the research study team at the time.

Autistic children were eligible to be referred to the study if they: 1. were aged 5 – 10 years; 2. had a confirmed autism diagnosis via the Autism Diagnostic Observation Schedule (ADOS) and/or the Autism Diagnostic Interview – Revised (ADI-R); 3. were diagnosed at least within the last 12 months; 4. had a borderline or above cognitive capacity (intelligent quotient; IQ above 70); and 5. were able to understand and/or communicate in English. Autistic children were excluded if: 1. they were receiving social and communication support privately; 2. they were non-verbal, unable to understand or speak English; and 3. the parent/carer was unable to understand and/or communicate in English during the completion of study measures (e.g., questionnaires, interviews).

In the current study, the video recordings of 10 autistic children were selected to be coded and analysed based on the following criteria: 1. all six sessions had been completed; 2. the face of the child and the therapist was visible throughout the session; and 3. there was a video recording from the first session and the last session. Out the 38 recruited children, 13 children/therapists were not captured in the camera in the first or the last session, five children withdrew, five children attended five sessions only, Kaspar broke down in the first session of two children, two children were playing with the blocks available in the room rather than with Kaspar and one child refused to be video recorded.

The profile of these 10 included autistic children per session group is summarised in Table 7. 1. The participant characteristics of this pilot study resemble the profile of the 38 autistic children who participated in the feasibility RCT. There was no significant difference between

the two session groups on any participant characteristic (see Table 7. 1 and section 7.2.5 Data analysis). Autistic children had a mean age of 7 years 3 months and diagnosis had happened approximately over the past 2 years (mean time 1 year 8 months). Most autistic children in the study were boys (n = 9; 90%) and were predominantly from a White ethnic background (n = 9; 90%). Three children had received additional diagnoses including attention deficit hyperactivity disorder (ADHD), joint hypermobility, and asthma. ADHD and joint hypermobility had been diagnosed by a paediatrician whereas asthma has been diagnosed by a GP. ADHD had been diagnosed two years prior to an autism diagnosis. Joint hypermobility and asthma were diagnosed the same year as autism. Half of children had received no autism specific support. Three autistic (30%) children had accessed speech and language therapy. All children were living with both parents and had at least one (male or female equally) sibling whose mean age was 6 years 7 months. Two autistic children were twins, but one sibling had taken part in the study. Half of autistic (n = 5, 50%) children were living with another autistic child of which one sibling had a global developmental delay while another one showed traits of a specific learning disability (e.g., dyslexia).

Table 7. 1 *Demographic characteristics of autistic children per allocation group*

| | Kaspar group n = 5 | Human therapist group n = 5 | Full sample n = 10 | p-value |
|--|--------------------------|-----------------------------------|--------------------------|---------|
| Mean age in years (SD); range | 6.5 (0.84) 5.3 – 7.4 | 8.1 (1.98) 5.3 – 10.1 | 7.3 (1.67) 5.3 – 10.1 | .127 |
| Mean time since autism diagnosis in months (SD); range | 22 (8.68) 6 – 27 | 18 (14.15) 4 – 36 | 20 (11.23) 4 – 36 | .635 |
| | n (%) | n (%) | n (%) | |
| Gender | | | | .292 |
| Male | 4 (80) | 5 (100) | 9 (90) | |
| Female | 1 (20) | - | 1 (10) | |
| Ethnicity | | | | .292 |
| White | 4 (80) | 5 (100) | 9 (90) | |
| Pakistani | 1 (20) | - | 1 (10) | |

| | Kaspar group n = 5 | Human therapist group n = 5 | Full sample n = 10 | p-value |
|--|--------------------------|-----------------------------------|--------------------------|---------|
| Additional diagnosis | | | | .490 |
| Yes | 1 (10) | 2 (40) | 3 (30) | |
| No | 4 (90) | 3 (60) | 7 (70) | |
| Support received | | | | .469 |
| None | 2 (40) | 3 (60) | 5 (50) | |
| Speech & Language Therapy (SLT) | 1 (20) | 2 (40) | 3 (30) | |
| PECS* | 1 (20) | - | 1 (10) | |
| Social Skills Training | 1 (20) | - | 1 (10) | |
| Living conditions | | | | 1.000 |
| Both parents | 5 (100) | 5 (100) | 10 (100) | |
| Mean number of siblings (SD); range | 1.4 (0.89) 1 – 3 | 1.2 (1.09) 0 – 3 | 1.3 (0.95) 0 – 3 | .760 |
| Living with autistic sibling | | | | N/A |
| Yes | 2 (40) | 3 (60) | 5 (50) | |
| No | 3 (60) | 2 (40) | 5 (50) | |

*PECS: picture exchange communication system; ** N/A: not applicable; Mann-Whitney test

7.2.2 Robot

A humanoid robot, called Kaspar, has been used in the study. Kaspar has been developed by researchers in the School of Computer Science within the Adaptive Systems Research Group at the University of Hertfordshire. Kaspar was employed in this study to explore the effect of robot-mediated session in the development of joint attention skills in young autistic children. As described in chapter 2, humanoid robots resemble the characteristics of the human body. Kaspar is a child-sized 60cm tall robot (Figure 7. 1) with a silicone face that has subtle but distinct facial features (e.g., eyes, nose, mouth) and is minimally expressive. Kaspar has a head, two arms, a torso which can move and two legs. Kaspar cannot stand, run, or walk. Instead, Kaspar is in seated position usually on a steady surface such as a table. Kaspar has

sensors on its body (e.g., tummy, feet, hands). Kaspar is described by the researchers in the School of Computer Science within the Adaptive Systems Research Group as a semi-autonomous robot because it can react to tactile interaction. At the time of the session, Kaspar was wearing a brown wig, a blue hat, a blue checked shirt, blue trousers, and grey socks.



Figure 7. 1 *Picture of Kaspar*

7.2.3 Procedure

This section describes the procedures of the overall feasibility RCT that led to the collection of video recordings.

7.2.3.1 Participant consent

Parents/carers provided written informed consent. Written assent was also gathered from autistic children, where appropriate. A copy of the participant information sheet was shared and discussed with parents/carers and children during a home visit once an expression of interest form had been completed via the paediatrician. In the home visit, the PhD candidate explained the study to the parent/carer and the child and gave them time to ask questions. Parents/carers and children were informed that each session was video recorded but explained the video data were accessed by the research team only.

7.2.3.2 Assessment

A paper case report form was developed and completed by all study participants as part of the NIHR funded feasibility RCT to record their demographic information and complete all study measures (e.g., questionnaires). In the current study, the demographic information section from the case report form was extracted to describe the participating sample.

7.2.3.3 Structure of the session

Children were randomly allocated to two groups: a human therapist alone group and the Kaspar group. The human therapist alone group included the child and the therapist (i.e., a dyadic interaction). The Kaspar group included the therapist, the robot, and the autistic child (i.e., a triadic interaction). Randomisation was performed online via Qualtrics. Different (female) healthcare professionals including a research nurse, a speech and language therapist, and an occupational therapist were appointed in the role of the therapist. All therapists were already employed within the local NHS Trust and had prior experience of working with autistic children. Therapists received training and a copy of the manual on how to operate and set-up Kaspar. They all practised the delivery of the session and the standard activities with and without Kaspar twice supervised by the research team.

All sessions took place in an NHS clinic room in Watford, Hertfordshire, over a period of 14 months starting in June 2017 until August 2018. Adjacent to the clinic room that sessions were conducted in, there was another room that was utilised by parents/carers to observe the session via a one-sided glass wall. Parents/carers were able to watch only but not hear the content of the session via this room. Autistic children had weekly meetings with the same human therapist, along with or without Kaspar, for the Kaspar group and the human therapist alone group, respectively, for eight weeks. Sessions lasted 20 minutes. Parents/carers were offered the opportunity to replace up to two sessions that might have been cancelled/missed in a 10-week window. Of the eight sessions, the first two were brief (up to 10 minutes) familiarisation sessions with the robot, the therapist, and the location.

During the familiarisation sessions, the autistic child was meeting with the human therapist or the human therapist along with Kaspar in the clinic room. Parents/carers and/or other familiar escorts (e.g., sibling, grandparent) were allowed in the session room, if it was deemed necessary for the child (e.g., in the first two meetings). In the first two familiarisation sessions, the child was free to explore the room. In addition, the therapist showed to the child that the parent/carer was watching them via the mirror wall. The child met with the therapist (and Kaspar, if appropriate) and played structured games that were part of the session in the first two brief meetings. The familiarisation sessions were also an opportunity for the therapists to discuss with parents/carers the child's interests and preferred activity as well as their mood on the day so that they were more informed on how to approach and accommodate the

individual. Following completion of the two familiarisation sessions, autistic children received six sessions for 20 minutes.

The clinic room had a table with two child chairs (one for each person). Those children allocated in the robot-mediated group had Kaspar sitting on the table facing the child. There were two cameras in the room. One was a static close-up camera that was placed behind Kaspar but within the child's eyesight. The other was a wall mounted camera that was placed on the top left corner of the ceiling out of the child's way. In the Kaspar group, a laptop was connected to the robot via tapping a white plastic card and the therapist was controlling the activities with Kaspar via a remote control (see Figure 7. 2).

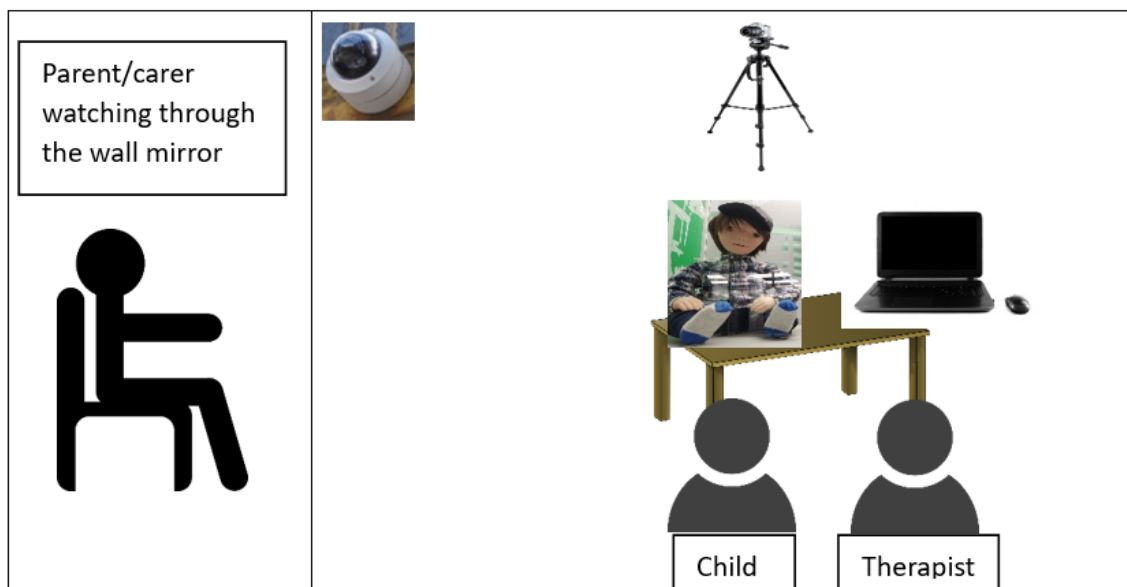


Figure 7. 2 Session room layout

7.2.3.4 Activities

Both session groups (Kaspar and human therapist) of autistic children played the same activities during all sessions regardless of group allocation. All activities had purposefully been selected and designed to include elements of social and communication skills such as joint attention, turn-taking, and imitation. The therapist was able to select activities based on the child's preferences and responses in the session. For example, Kaspar was able to sing nursery rhymes including "if you're happy and you know it", "Incy Wincy" and "old McDonald", play drums and play follow me (copy) games. In addition, there were some standard activities that Kaspar could do such as wave, say hello, raise one/both hands.

7.2.4 Secondary data collection and coding

The video recordings of autistic children who had attended the first and the last session were selected from the total video footage collected in the feasibility RCT. Following review of the first and the last video recording, the PhD candidate was reviewing the inclusion criteria for analysis and was proceeding to the next participant presenting in ascending order. A small sample of the total video recordings was eligible to conduct this pilot study and explore the feasibility of analysing the footage from the feasibility RCT.

Prior to the first session, all autistic children had met with the human therapist or the human therapist along with Kaspar two times (once per week) in two brief (10 minute long) familiarisation sessions. Each session was lasting 20 minutes. Therefore, autistic children had two weeks to adapt to the new environment (e.g., room, therapist, robot) before the session used to code their behaviours took place. Five-minute footage from the first and last session was extracted for coding of pre-specified behaviours (Baranek, 1999; Colgan et al., 2006; LaGasse, 2014; McGarry, Vernon, & Baktha, 2020). The clip was selected starting at 10 minutes after the start of the video recording of each session (first & last) to maximise the chances that autistic children were relaxed during play to display a range of behaviours. Previous studies have adopted this approach in analysis of video recordings (Baranek, 1999; Colgan et al., 2006; LaGasse, 2014; McGarry, Vernon, & Baktha, 2020). The total footage analysed was 20 video clips each lasting five minutes which yielded 100 minutes (1.6 hours) of video footage. The management and coding of video data was conducted manually by the PhD candidate.

A coding scheme was developed using the SCERTS model. The SCERTS acronym derives from Social Communication, Emotional Regulation, and Transactional Support. The SCERTS model is a multidisciplinary approach that aims to enhance communication and socioemotional interaction of autistic individuals via everyday activities and across different partners to facilitate long-term effects on child's development (Prizant et al., 2006). Each domain of the SCERTS model is divided into two components. For example, social communication includes joint attention and symbol use. Emotional regulation includes mutual regulation and self-regulation while interpersonal support and learning support defines transactional support. In this pilot study, children's social play with the human therapist or Kaspar were rated using 10 pre-selected components of joint attention skills within the SCERTS social communication

domain. The amended version of behaviours rated in this study is listed in Table 7. 2. A study-specific coding scheme was developed taking into consideration the samples' communication stage (e.g., verbal versus minimally verbal), the nature of activities during sessions, and the length of observation to capture a range of behaviours across a short period of time.

Table 7. 2 *SCERTS coding scheme and definitions for each behaviour*

| Behaviour | Description |
|--|--|
| Look towards people | Directs gaze spontaneously toward another person's face. |
| Requests help or other actions | Direct verbal or non-verbal signals to get another person to provide help or assistance in carrying out something they cannot do or other actions (e.g., patting chair to get them to sit down) |
| Initiates bids for interaction | The child initiates a bid for interaction through verbal or nonverbal means. The behaviour must be directed towards another person by proximity (moving toward or away from another person), physical contact (touching another person with a gesture or an action) or gaze. |
| Engages in brief reciprocal interaction | The child initiates and responds to bids for interaction for at least two consecutive exchanges* *an exchange consist of a turn from the child and a turn from the partner. At least one of the exchanges must be initiated by the child. |
| Engages in extended reciprocal interaction | The child initiates and responds to bids for interaction for at least four consecutive exchanges* *an exchange consist of a turn from the child and a turn from the partner. At least one of the exchanges must be initiated by the child. |
| Requests social game | Verbal or non-verbal signals to direct another person to begin or continue in a game-like social interaction |
| Takes turns | Directs verbal or non-verbal signals as a turn filler to keep a cooperative social exchange going at least two times |
| Calls | Direct verbal or non-verbal signals to gain the attention of another person, followed by an additional communicative signal (e.g., touching arm followed by a reach to request, vocalising followed by a point to comment) |
| Comments on action or event | Directs verbal or non-verbal signals to get another person to notice or look at an action or event (e.g., reaching toward and looking at partner when |

| Behaviour | Description |
|---|--|
| | bubbles pop or tower of blocks fall over; pulling a partner to a preferred TV programme to point out a character) |
| Shares positive emotion using facial expressions or vocalisations | Displays positive emotion and shares it with another person by looking at, approaching, gesturing toward or touching the person immediately before, during or after the emotion is displayed |

7.2.5 Secondary data analysis

Data were manually extracted by the PhD candidate in Excel and were transferred to SPSS. Frequency counts, *n*, were used to calculate the total number of observations within 5 minutes of each observed behaviour. Descriptive statistics were used to describe the demographic characteristics of the two session groups (i.e., Kaspar and human therapist). A non-parametric test (e.g., Mann-Whitney test) was conducted to compare the means of the two session groups (i.e., Kaspar and human therapist) in the first session and identified no differences in the sample of participants due to skewed data (see Table 7. 1). An analysis of covariance (ANCOVA) with allocation group as a fixed factor (i.e., independent variable), data from the first session as a covariate and data from the last session as a dependent variable was implemented to control for error variance. The dependent variable (i.e., data from the last session) was normally distributed. The ANCOVA shows the effect of the independent variable after the effect of covariates have been controlled. ANCOVA was chosen instead of a non-parametric independent t-test (e.g., Mann-Whitney test) which is traditionally used to examine between group differences because it is superior to a non-parametric independent t-test in skewed RCT data (Blackford, 2006; Vickers, 2005). A Wilcoxon signed rank test was used to identify the within group difference in means from the first to the last session (Rosner, Glynn, & Lee, 2006). Significance ($p \leq .05$) and effect sizes (i.e., partial eta squared) were calculated to indicate the magnitude of the difference found. Statistical analysis was performed using IBM Statistical Package for Social Sciences (IBM SPSS. version 27.0).

7.3 Results

7.3.1 Are there greater improvements in joint attention skills of autistic children receiving a session from a human therapist along with Kaspar compared to those receiving the same session with a human therapist alone?

Table 7. 3 presents the mean and standard deviation (SD) of all ten joint attention behaviour scores for both session groups separately and for the whole sample of participants in the first session and the last session. A non-parametric Mann-Whitney test explored differences between the two session groups in the first session to ensure both groups displayed similar levels of joint attention. There was no statistically significant difference between groups in any of the observed behaviours other than positive emotions which were significantly higher in the human therapist group compared to the Kaspar group in the first session ($U = 2, p = .032$). The one-way ANCOVA was conducted to compare the effectiveness of allocation group whilst controlling for the first session (i.e., covariate). Homogeneity assumptions using the Levene's test were carried out and assumptions met for all behaviours. There was not a statistically significant effect of session group in any joint attention behaviour in the last session when controlling for the scores in the first session (see Table 7. 3).

7.3.2 Is there an improvement within the Kaspar or the human therapist group in the joint attention skills of autistic children from the first to the last session?

A Wilcoxon signed rank test was used to identify the within group difference in means from the first session to the last session. Table 7. 3 shows the raw scores (e.g., means and SD) of each session group at different time points (e.g., first and last session). There was no statistically significant difference in any joint attention behaviour in the two session groups apart from number of times autistic children requested a social game in the human therapist group ($Z = 1.070, p = .038$).

Table 7. 3 Description and relationship of joint attention skills in autistic children per session group

| Outcome | First session | | Last session | | Between group difference | | | | Within group difference | | | |
|-------------------------|---------------------------------|--------------------------------|------------------------------|-----------------------------|--------------------------------|-------------|------------------|----------|-------------------------|-------------|-------------|---------|
| | Kaspar n = 5 Mean (SD) | Human n = 5 Mean (SD) | Kaspar n = 5 Mean (SD) | Human n = 5 Mean (SD) | Interaction group*behaviour | P- value | Min-max score | η^2 | Kaspar group | | Human group | |
| | | | | | | | | | Z* | P- value | Z* | P-value |
| Gaze | 7.4 (3.43) | 20.4 (16.53) | 9.2 (6.79) | 20.4 (13.35) | $F(1,7) = 0.323$ | .588 | -18.45- 11.31 | .044 | 1.095 | .273 | .405 | .686 |
| Request help | 2.8 (1.30) | 1.8 (1.09) | 3.2 (1.64) | 1.8 (1.78) | $F(1,7) = 0.721$ | .424 | -1.88- 3.99 | .093 | .477 | .655 | .505 | .786 |
| Initiations | 6 (6.96) | 6.2 (1.09) | 7.4 (5.22) | 6.8 (0.83) | $F(1,7) = 0.939$ | .365 | -1.07- 2.55 | .118 | 1.289 | .197 | 1.134 | .257 |
| Brief interaction | 4.4 (4.03) | 4.2 (2.70) | 6.2 (5.21) | 6 (2.34) | $F(1,7) = 0.033$ | .862 | -2.41- 2.81 | .005 | 1.841 | .066 | 1.633 | .102 |
| Extended interaction | 2.2 (2.16) | 3.2 (2.38) | 3.0 (2.34) | 4.4 (2.96) | $F(1,7) = 0.189$ | .677 | -2.11- 1.45 | .026 | 1.633 | .102 | 1.604 | .109 |
| Request social game | 5.8 (4.02) | 5.4 (1.30) | 6.0 (3.93) | 7.2 (1.30) | $F(1,7) = 0.750$ | .415 | -4.47- 2.07 | .097 | .365 | .715 | 1.070 | .038** |
| Turn-taking | 6.4 (3.36) | 11 (4.31) | 7.4 (4.72) | 13 (2.12) | $F(1,7) = 1.581$ | .249 | -8.66- 2.64 | .184 | .552 | .581 | 1.236 | .216 |
| Calls | 4 (4.30) | 3.8 (1.09) | 6.0 (4.80) | 4.8 (0.84) | $F(1,7) = 0.737$ | .419 | -1.76- 3.77 | .095 | .477 | .655 | .505 | .786 |
| Comments | 2.4 (1.51) | 4.6 (2.07) | 5.0 (4.2) | 5.6 (1.51) | $F(1,7) = 1.305$ | .291 | -2.23- 6.39 | .157 | 1.841 | .066 | 1.890 | .069 |
| Positive emotions | 3.4 (1.34) | 6.0 (1.24) | 5.0 (2.12) | 5.2 (1.78) | $F(1,7) = 0.770$ | .409 | -2.66- 5.81 | .099 | 1.511 | .131 | 1.069 | .285 |

*Z; Wilcoxon signed rank test **p < .05

7.4 Discussion

In this chapter, ten joint attention behaviours have been explored using the SCERTS framework for improving social and communication skills and emotional skills in autistic children engaging in a dyadic social interaction with a human therapist alone compared to a triadic social interaction with a human therapist along with the humanoid robot, Kaspar. This pilot study provides valuable insights into the effect of robot-mediated sessions for autistic children. A five-minute video recording was coded for each child during the two different time points.

The main finding is that there were minimal significant differences between the two groups. Autistic children increased the number of requests for a social game from the first to the last session in the human therapist group. The current literature about robot-mediated versus human therapist alone sessions in autism has targeted eye gaze and initiations to evaluate social engagement. These studies have reported the positive effect of robot-mediated sessions in autistic children (Aryania et al., 2020; Cao et al., 2019; Chung, 2021; DeKorte et al., 2020; Simut et al., 2016; Yoshikawa et al., 2019; Yun et al., 2017). In the current study, the lack of statistical significance between the two groups may be attributed to the small sample size (five children per group) compared to the abovementioned studies (15 – 30 children per group).

Joint attention was slightly improved (see mean scores in Table 7. 3) in a psychosocial support delivered either via a human therapist or a human therapist along with a humanoid robot (i.e., Kaspar). But there was not a statistically significant difference between groups in the last session and within groups from the first to the last session. Regardless of the lack of statistical significance, autistic children expressed a true interest towards Kaspar and showed signs of enjoying the session. For example, autistic children made initiations and calls more often in the Kaspar group compared to the human therapist group in the last session. The increased number of initiations in a robot-mediated session aligns with the current literature (DeKorte et al., 2020; Scassellati et al., 2018). Autistic children increased the number of gaze and requests for help in the Kaspar group compared to the human therapist group whose number of occurrences remained stable from the first to the last session. The benefits of robot-mediated sessions in eye-contact and gaze over human therapists have been reported

in the literature over the years (Chung, 2021; Simut et al., 2016; Yoshikawa et al., 2019; Yun et al., 2017). Similarly, the observed frequency of turn-taking skills in the Kaspar group compared to the human therapist were greater (but not statistically significant) in the Kaspar group in the last session which aligns with the literature (David et al., 2020). In addition, autistic children showed more positive emotions (e.g., laughed, smiled) (but not statistically significant) in the Kaspar group from the first to the last session compared to the human therapist group where children demonstrated fewer positive emotions from the first to the last session. Differences in the frequency of joint attention behaviours observed in autistic children aligns with the current literature about the promising effect of robots in autism (Dickstein-Fischer et al., 2018).

Taken together, the current study identified very few statistically significant findings. Although the only significant finding was that autistic children increased the number of requests for a social game from the first to the last session in the human therapist group, the observation of marginally “better” mean scores (though not statistically significant) in children’s performance in robot-mediated sessions across a range of joint attention behaviours may be justified by the inherent interest of autistic children in technology and robots specifically which may be related to increased levels of motivation (Kostrubiec & Kruck 2020; Taher et al., 2019). Motivation has been described as a pivotal area in sessions (Koegel, Koegel, & McNERney, 2001). Therefore, it is equally important to look beyond robots and identify the child and contextual factors which might all interact and lead to specific moments of meaningful and child-led interactions.

It would be imperative to further explore in a larger scale study if these aspects of joint attention behaviours remain greater in the robot-mediated group and to use these gains, if possible, in sessions for autistic children. Analysing more behaviours (e.g., response to intonation cues, re-engagement in activity after recovery from dysregulation, regulation of emotions in new situations) including from video recordings of autistic children would also complement researchers’ understanding of how to best personalise and tailor sessions in clinical practice.

In addition, the effect of any autism specific support might also be analysed considering the number and duration of sessions offered to autistic children. Research indicates that time to complete a session is influenced by the number of cancellations and length of time to complete a session especially in families from low socioeconomic status who are usually underrepresented in autism studies (Carr & Lord, 2016). Explicit reporting of incentives (e.g., no waitlist to enter an autism specific support, free cancellation policy) and/or adjustments to facilitate access to autism specific support (e.g., location of session, age group of children, confirmed diagnosis of autism) not only increases the inclusion of families of autistic children in autism research and access to specific support, but it also informs autism researchers on effective ways to design their own research programmes. Finally, the overarching aim of any autism specific support including robot-mediated sessions remain to investigate whether autistic children apply new learning from Kaspar in future interactions with other people spontaneously. Achieving transfer and generalisation of learned skills remains a challenge when working with autistic children.

7.4.1 Strengths and limitations

With respect to methodological considerations, this is a pilot study with a small number of autistic children whose analysed video recordings derived from a single site. Out of 38 participants, the video recordings of only 10 participants were included in the analysis due to missing sessions and/or recordings and withdrawal of participants emphasizing the need for a careful review and consideration of future study procedures. In addition, such a small sample size limits the opportunity to analyse data in depth and generalise the study findings to the wider study population. Although therapists received training on how to operate and set-up the robot and practised the delivery of the session including standard activities with and without Kaspar, information about treatment fidelity is lacking in this pilot study. Video recordings were mainly targeting the autistic child rather than the therapist and therefore no one coded therapists' response to children in the robot-mediated or human therapist alone group to monitor the quality of autism specific support delivery across therapists. The lack of statistically significant difference may also be attributed to the lack of parental/carer involvement, not only at the early phases of the development

and/or selection of activities, but also throughout the sessions to accommodate the session delivery and engagement of the child. Parents/carers were present in the first two familiarisation sessions only. In this pilot study, the frequency of occurrence of ten different joint attention behaviours for 5 minutes from the first to the last session was coded. It is likely that by snipping 5 minutes from a 20-minute video footage might introduce a degree of bias in the subsequent analysis because the PhD candidate tried to analyse a segment of the session that was mostly relevant to the study. However, the order of activities was different at different time intervals which means that not the same games were always analysed in the first and the last session. It is likely that the beginning and the end of each session might have provided important information such the robot, laptop or keypad not working, or the child being upset, tired, excited, reluctant to finish the session. This is likely to have impacted the results because some activities might have provided more opportunities for certain behaviours. For example, singing a song in the first session with Kaspar and a human therapist was very likely to offer fewer opportunities for eye contact with a human therapist compared to a blinking task with a human therapist alone in the last session. The lack of statistically significant difference may also be attributed to Kaspar. There is no one size fits all model meaning that another humanoid robot or a different robot type may have triggered another reaction to some autistic children. Children react differently in new toys/activities because of ageing, new technologies, and different functions of the robot. There was also no second coder to apply the suggested coding scheme in the data, reflect on its applicability and enhance the interpretation of data. Therefore, the rigor could be extended in the future but here was within the resources available for the research. Finally, it should be acknowledged that these are secondary data which means that the PhD candidate was limited to analyse social and communication skills (e.g., joint attention) in the behaviours that could have been analysed and that was directed by the aims of the previously funded research project. It may be that both the support sessions and skills therefore coded in the future could be further modified with stakeholder input to be more sensitive to change aligned to the use of SARs.

7.5 Conclusions

This study identified there was no statistically significant difference in the joint attention skills of autistic children regardless of receipt of a psychosocial support. In addition, this study found that autistic children increased the number of requests for a social game from the first to the last session in the human therapist group but not in the Kaspar group. Although there was lack of evidence to claim the effect of robot-mediated session, observation of the mean scores between the two groups indicates that increased levels of motivation about the robot might likely shape autistic children's social interactions during interaction in a robot-mediated session with a humanoid robot and a human therapist. This pilot study, also, identified, but without reaching a statistically significant difference, that autistic children in the robot-mediated group engaged with the human therapist when they needed help, wanted to make a comment, or celebrated a fun activity. This is an indicator that robots can scaffold social interaction in autistic children if robots are also among the interests (i.e., motivators) of the child. Therefore, the interaction style of autistic children within a socially engaging environment might create unique opportunities for joint attention and social engagement between a human therapist, a robot, and the child. Future studies could explore the effect of variable robot types in the social and communication skills of autistic children.

Chapter 8: Discussion

The aim of this thesis was to summarise evidence on the use of robots in autistic children and to further identify ways in which the use of SARs in autism might be enabled focusing on parent perspectives. In doing so, the thesis also sought to demonstrate, based on secondary data analysis, some of the ways in which SARs may or may not support young autistic children. This body of work adopted a mixed methods approach, which allows exploring patterns, evaluating people's experiences in-depth and validating findings across studies. Four studies including a systematic literature review and a meta-analysis, a cross-sectional online survey, individual interviews and one focus group, and video recordings yielded qualitative and quantitative data to facilitate an in-depth investigation of the research questions. These research studies gathered primary data from parents/carers of autistic children plus a secondary analysis of video recordings from autistic children aiming to develop our knowledge and understanding of the future use of robots in autism. This thesis adopted a person-centred approach exploring parents'/carers' preferences around technology-based support, the organisation and structure of a robot-mediated session and the effect of a robot-mediated compared to a human therapist alone session to enhance autistic children's joint attention skills. Such an approach aimed to produce outcomes that have direct impact in research and in the long-term clinical practice.

8.1 Summary of findings

The two introductory chapters outlined the context of autism and the rationale for exploring the use of robots with autistic children. Autism is a heterogeneous neurodevelopmental condition that is characterised by social and communication support needs and specialised, focused, or intense interests (American Psychiatric Association, 2013; World Health Organization, 2018). Chapter 1 suggested that as the number of people diagnosed with autism has increased over time, it is imperative to offer early recognition and specific support and/or services for autistic children across childhood and to support their parents/carers to be able to identify evidence-based support taking into consideration the specific autistic experiences and characteristics of their children (World Health Organization, 2014; NICE, 2017). Chapter 2 outlined that autistic children often demonstrate an affinity towards technology including

smartphones, tablets, computers, robots (Clark & Adams, 2020; Grynszpan et al., 2013). Technology features such as less distractions, repetition, time to think and structure are considered attractive characteristics to autistic children when used in autism specific support (Sabayleh & Alramamneh, 2020). Research about the potential role of robots in autism specific support is slowly progressing from case studies to robust research methodologies. Despite the potential of Socially Assistive Robots (SARs) in autism specific support, significant gaps exist in the literature relating to robot-mediated sessions. Chapter 3 outlined the research methodology of this programme of work to address its aims.

The fourth chapter presented an up-to-date synthesis of the evidence base regarding the use of SARs with autistic children and summarised the reported effects of robot-mediated sessions in autistic children setting the scene that SARs could be useful for some autistic children. Although there are a number of reviews in the literature, the main strength of this study was that this was the first PROSPERO preregistered systematic literature review and the first meta-analysis published internationally about the effects of robot-mediated sessions in autistic children. The meta-analysis found that age was a significant moderator with effect sizes being significantly larger in younger samples aged 4 – 7 years which supports research highlighting the importance of early specific support with autistic children (Landa, 2018). The systematic literature review findings highlighted an ongoing need for more research evidence drawn from experimental designs with transparent reporting on sample selection, characteristics, and adverse events, as well as assessment of session gains beyond the immediate study period. Transparency and examination of long-term effects of a robot-mediated session will benefit the evaluation of the clinical effectiveness of robots in autism in the future.

Chapter five presents original data from a cross-sectional online survey that aimed to identify parents'/carers' current knowledge of the use of technology-based support in autism, their preferences among different technology-based support (i.e., smartphone, iPod, tablet, virtual reality, robot, other) and the reasons behind their choice. It was important to explore the reasons that may or may not facilitate some of the benefits yielded in the meta-analysis may be widely applicable. The online survey

revealed that tablets were the most preferred technology-based support compared to smartphones, iPods, virtual reality headsets, robots and other (e.g., computers, laptops) to use in a session with an autistic child, while the least preferred was a virtual reality headset followed by robots. This study showed that there is scope to extend robots in the autism community. Among the strengths of this study was that the survey link was shared in national and international parenting online groups and was promoted via a United States-based research centre. It was encouraging that technology-based support had attracted the attention of parents/carers of autistic children at a global level indicating that professionals might suggest using technology devices more as a medium for learning rather than simply for fun and entertainment in the future. However, research findings should be interpreted cautiously because there is limited research on the topic and the study was unable to describe the predictors that directed parents'/carers' most preferred choices. To increase our understanding of technology-based support in autistic children, there is a need for more research with the autistic community facilitating the inclusion of autistic children and young and/or older adults to share their preferences and views about technology-based support in studies. The cross-sectional online survey indicated lack of knowledge about robot-mediated sessions with autistic children describing them as an *"unknown territory"* and hesitation from parents/carers (and potentially autistic children) because robots may be considered as were *"scary"*, *"cold"*, *"unnatural"*.

The findings from chapter six contain original qualitative data about parents' (recruited via the online survey) perspectives on the use of robots with autistic children which is scant in the current literature. The main contribution of this study in the literature includes parents'/carers' acknowledgement of the potentially promising contribution and the risks of robot-mediated sessions with autistic children. In addition, this study included an equal number of parents with autistic children in mainstream and special schools. The perspectives of parents of autistic children in special schools are less represented in the autism literature (Rowland, 2021). This study also highlighted the gap in the current literature of autism specific support targeting independent living skills in autism. Therefore, future autism specific support studies should facilitate a collaborative research culture between autism researchers

and key autism stakeholders to acknowledge the real needs of autistic children and their parents and identify ways to maximise the effect of robots as a technology-based support.

The final research study in chapter seven was a secondary analysis of previously collected data. This study aimed to explore the effect of a triadic robot-mediated session with a human therapist along with Kaspar compared to a dyadic interaction with a human therapist alone on the development of autistic children's joint attention skills. This study showed there was no statistically significant difference in the joint attention skills of autistic children receiving an autism specific support session by a human therapist compared to a robot-mediated one. This pilot study indicates, but without reaching a statistically significant difference, that robots may scaffold social interaction in autistic children if robots are among the child's interests (i.e., motivators) (Koegel, Koegel, & McNeerney, 2001; Kostrubiec & Kruck, 2020; Taher et al., 2019). Therefore, the motivating factors of the autistic children within a socially engaging environment might create unique opportunities for joint attention and subsequent social engagement between a therapist/adult play partner, a robot, and the child. Finally, there was not a statistically significant difference in the joint attention skills of autistic children from the first to the last session in either group. The only variable that demonstrated a statistically significant difference was the requests for social games which enhanced from the first to the last session in the human therapist group. The overall analysis of video recordings indicates that reported benefits, if any, are not always easily captured and/or maybe tuned to the way a session is organised. Future studies could explore the effect of different robot types in the social and communication skills of autistic children.

In summary, the overall findings from this research programme contribute to a better knowledge and understanding of the use and the effect of robots in autism research and clinical practice. The research programme synthesises a mixed method design which provides stronger evidence in the study findings balancing out the strengths and limitations of quantitative and qualitative research methodologies. The studies highlight that there is a context within which a robot-mediated session is more effective (e.g., autism clinics/centres) but that parents thought additional and more

inclusive environments (e.g., school) might foster social and communication opportunities with peers in a class environment via an individual and/or group activity (i.e., session). This indicates that the use of robots across variable settings while taking into consideration the strengths and the specific support needs of each autistic child might facilitate collaboration, promote social and communication skills, and increase the motivation of autistic children to engage with peers. The limited knowledge of parents/carers of autistic children about the range of technology-based support available for autistic children might suggest that professionals, the autistic community, and media appear to be less informed and/or sceptical about the potential use of robots in autism. In conclusion, it is important to emphasise the dynamic relationship of robots, autistic children, and therapists/adult play partners. Robots might indeed motivate social interaction and communication in autistic children, but so do the interaction style and preferences of autistic children and the readiness of therapists/adult play partners to introduce technology-based support within a suitable context. Robots, as a potential autism specific support, need to scaffold interaction because children get older while therapists/adult play partners need to be appropriately trained to facilitate an individual and/or group robot-mediated session in a safe and inclusive environment for autistic children. The overall emerging themes from this research programme relate to trial design and collaborative research (see Future directions).

8.2 Implementation framework

The findings from this thesis can be helpfully brought together in a framework that synthesises the four studies of this research programme. Such a framework would provide guidance about the implementation and translation of research findings into practice (Creswell & Clark, 2011; Grol et al., 2007; Michie, 2008; Sinclair, 2007).

There is currently no evidence of a framework that can help understand ways in which future research can support better the translation of robot-mediated sessions with autistic children into practice. There is, however, comprehensive guidance from the Medical Research Council (MRC) framework to facilitate the development and evaluation of complex interventions (Campbell et al., 2000; Craig et al., 2008; Moore et al., 2019; Skivington et al., 2021). The proposed framework here (see Figure 8. 1) is

informed by research conducted as part of this research programme with parents of autistic children and autistic children themselves taking into consideration the complex interplay of variable components and their impact on robot-mediated support for autistic children (Kessler & Glasgow, 2011; Rutter et al., 2017). Its aim is to ensure that robot-mediated support is acceptable, implementable, scalable, and transferable to multiple contexts and adaptable to the needs of autistic children and their family/carers. The framework advanced common areas of interest in complex support in healthcare including the following domains: 1. Population; 2. Context; 3. Delivery; 4. Effectiveness⁴; and Research (Grant et al., 2013).

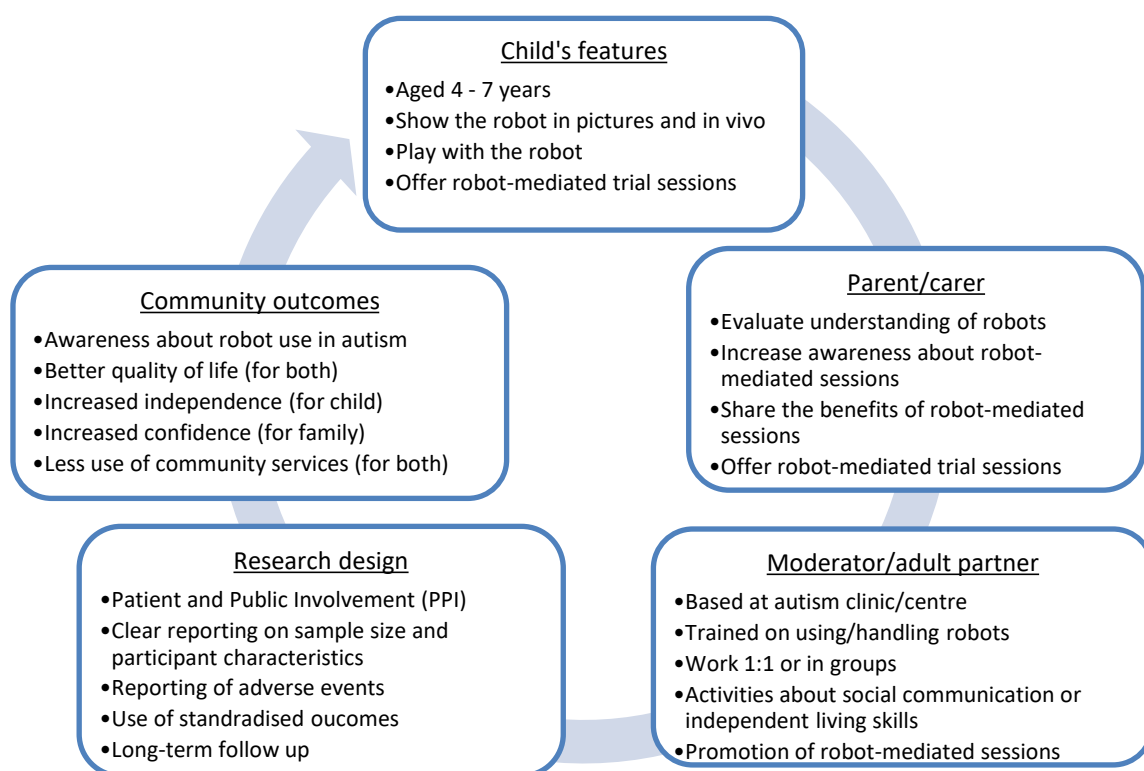


Figure 8. 1 *Implementation framework in robot-mediated sessions*

The framework can be visualised as a series of interrelated steps. The child (aged 4 – 7 years) needs to familiarise him/herself with the robot via showing the child the robot and allowing them to play with it. Following familiarisation with the robot, the child would be benefited by attending a robot-mediated trial session. Parents/carers also need to undergo stages of awareness, information sharing, and trial the robot-

mediated session which is initially influenced by the child. In parallel, the moderator/adult partner ideally based at an autism clinic/centre needs to be a confident user of the robot and able to handle risks associated with its operation. The moderator/adult partner will be already qualified to deliver individual or group sessions with autistic children targeting social and communication and/or independent living skills. The moderator/adult partner should facilitate the promotion of robot-mediated sessions for autistic child among their networks and the wider community. Finally, research studies should follow high quality standards seeking and endorsing the ongoing guidance of the autistic community at every stage of a research study (e.g., conceptualisation of an idea, study design, operation, selection of activities and/or staff, public facing study documents, data analysis and interpretation, write up) while ensuring the transparent reporting of participant characteristics and sample size of those approached, declined, participated in researched, adverse events, use of standardised outcome measures and long-term follow up data to monitor sustainability of benefits, if any, and enhance the generalisability of study findings.

The combination of the child attending robot-mediated sessions, the parents/carers and the moderator's/adult partner's actions along with quality research standards will potentially lead to a series of outcomes with benefits for the community. The parent/carer and the child would experience better quality of life, the child would be more independent while the parent/carer may be more confident to enjoy quality time with their child and handle behaviour that challenges, if needed. Consequently, there may be a decreased number of referrals to community services for both the parent/carer and the child for either physical and/or mental health checks. Overall, the wider community would become more aware of the benefits of robot-mediated sessions which may influence other families to explore the benefits of robot-mediated sessions and maximise the effect(s) for the community. It is important to emphasise that the proposed framework requires validation by key stakeholders (e.g., autistic children, adults, parents, clinicians, school staff, and researchers). The validation process of the framework will lead to its refinement by adding more components that might influence the implementation of a robot-mediated session with autistic children. In addition, it may lead to a more transparent framework containing in

depth information about the content and the structure of robot-mediated sessions with autistic children.

8.3 Thesis implications

This thesis brings together two distinct research fields – developmental psychology and human – robot interaction. This thesis provides information that could guide clinicians, researchers and inform the autistic community. The core message from the first study in this thesis is that humanoid robots appear to be engaging tools that could enhance the social and communication skills of autistic children most likely in a clinic setting (see Figure 4. 2). Throughout this thesis, studies have emphasised that parents/carers of autistic children were open to technology-based support (see Table 5. 11 and Figure 5. 3), but their views are likely to be shaped by the adaptability of technology-based support to accommodate the strengths and the specific support needs of autistic children (chapter 6). For instance, parents talked about the ability of humanoid robots to attract older autistic children aged 11 years and above as well as autistic children with more advanced needs (chapter 6). A person-centred interpretation of the findings in this thesis also emphasised that leveraging robots in educational settings might enhance opportunities for learning in autistic children (chapter 6). For instance, the statistically significant difference in favour of the human therapist group in the number of requests of social games during a session might indicate the need to enhance the humanoid robot, Kaspar, to elicit more social requests for social games (e.g., verbal, or non-verbal signals to begin or continue an activity) (chapter 7). Overall, the key message from this thesis entails that any concerns about robot-mediated sessions should be addressed by designing robots and autism specific support programmes alongside parents/carers and autistic children and/or adults.

8.3.1 Bridge the gap from research to practice

A key priority of autism specific support research is to evaluate whether programmes are effective and applicable into day-to-day practice (e.g., clinical, educational) to support autistic children (Dingfelder & Mandell, 2011). Bridging the gap between research to practice in autism specific support and robots remains unresolved regardless of the acknowledgement that researchers should translate their research

findings to inform clinical practice (Curtis et al., 2017). In the literature, it has been documented that among the barriers of technology use and implementation (i.e., of smartphone, virtual reality, tablet, robots) among autism stakeholders (e.g., parents/carers of autistic children, young people, educators, clinicians) includes lack of knowledge, limited research followed by inconsistent findings to make an informed decision as well as external factors including the cost of technology device (for organisations as well), limited time to reflect on practices (for professionals only), lack of engagement (e.g., from parents/carers who forget to bring a tablet in sessions), and dependence on technical support (Ghanouni et al., 2020). It is important to emphasise that parents of autistic children reported that they would be willing to cover the cost of the technology device if there is evidence of its effectiveness (Ghanouni et al., 2020).

These obstacles align with the thesis findings. The systematic literature review and meta-analysis reported a small number of RCTs (12 out of 18) of which seven RCTs reported that a significant effect size with low heterogeneity for social and communication skills. In addition, there is an increase in the number of robot studies published over the past nine years compared to before 2012 that suggests that the popularity of robots is increasing. It is encouraging that robot-mediated sessions have attracted the attention of professionals and funding bodies. However, research findings were often tentative and should be interpreted cautiously because of a lack of high-quality evidence from randomised study designs. Similarly, the international cross-sectional survey completed by 267 participants reported that 61% of parents/carers only knew about the use of tablets as a technology-based support followed by 34% of parents/carers who reported none of the listed technology devices (e.g., smartphone, iPod, virtual reality, robot) were known to them as a technology-based support for autistic children. Interestingly, the cost of a technology-based support (e.g., virtual reality, robots) was referenced by a small number of parents/carers ($n = 3$ and $n = 5$, respectively) as a barrier for least preferring virtual reality and robots.

Although the appeal of robots was recognised as being motivating, engaging, predictable, and consistent, professionals have called for clear protocols on how and

why robots should be used to ensure effective learning support (Alcorn et al., 2019). In chapter 4, the systematic literature review and meta-analysis suggested the use of robot-mediated session as a relatively brief form of therapy for an average of 8 sessions each lasting approximately 30 minutes contributed to the development of social and communication skills at least in the immediate post session period. Taken with the findings of the meta-regression that showed an overall non-significant effect of autism specific support based in the school environment, this suggests that future research should focus far more on clarifying the theory of change underpinning the use of robots in therapy, optimising session protocols and their practicability within school environments as well as effective training and ongoing support for professionals implementing them.

Another conflicting issue in autism specific support research, technology and robots are the gap between evidence-based research and availability of technology devices for autistic children, parents/carers, educators, and clinicians (Kim et al., 2018; Laurie et al., 2019; Parsons et al., 2017, 2019). In addition, improving the evidence-base in autism specific support, technology and robots is a challenging research topic not only because of the heterogeneity of specific autistic experiences and characteristics but also due to the rapid explosion of technology and the need for ongoing adaptation (Zervogianni et al., 2020). The results of the cross-sectional survey with parents/carers of autistic children revealed that tablets were the most preferred technology-based support for their children (see Table 5. 11 and Figure 5. 3). In particular, the correlation analysis reported that older parents/carers and older autistic children were more likely to mostly prefer a tablet among the rest of the shown technology-based support (e.g., smartphone, iPod, virtual reality, robots, other). Similarly, the older the age the child was diagnosed with autism, parents/carers were more likely to mostly prefer a tablet. The characteristics, cost, physical appearance, and lack of knowledge were among the reasons parents/carers did not choose non-conventional technology-based support such as virtual reality and robots against more conventional ones including tablets. The only technology that cost was mentioned as a barrier of consideration was virtual reality and robots. In any autism specific support, there is little expectation from parents/carers to pay to access a device and/or a toy at home.

Therefore, this study revealed that new technology-based support for autistic children need to be accessible to parents/carers and competitive to current technologies that autistic children use. In addition, gaining a more comprehensive understanding of parents'/carers' preferences around technology-based support would allow professionals to inform, partner and negotiate with families about variable autism specific support. Further, learning more about parents'/carers' decision-making process in autism specific support might benefit professionals who need to propose and explain new autism specific support via information materials and decision-making aids designed and reviewed by autistic individuals.

8.3.2 Collaborative research culture

Another priority in autism research is to identify effective ways to create alliances with the autism research community and key autism stakeholders (e.g., children, young people, parents/carers, educators, clinicians, policy makers) (Fletcher-Watson et al., 2019; Stahmer et al., 2017). These are often expensive and difficult to achieve due to financial incentives to parents/carers or autistic adults, disengagement from them due to other commitments followed by the need to identify new members, conflicting demands between researchers and autism stakeholders on the focus of topics being researched (Fletcher-Watson et al., 2019; Pellicano, Dinsmore, & Charman, 2018). Nonetheless, the presence of community engagement in autism research has increased over the years (den Houting et al., 2021).

It is important to think of collaborative and non-hypercritical ways of shared power with autism researchers and autism stakeholders working together to progress autism research which is now endorsed by funding bodies (Fletcher-Watson et al., 2019; Stahmer et al., 2017). It appears that better collaboration between autism researchers and autism stakeholders is required to shape the research question of a study, adapt the methodology of a study, consult on the evaluation, implementation, and dissemination of a research project to facilitate the translation of research into day-to-day practice (Fletcher-Watson et al., 2019; Stahmer et al., 2017). The outdated model of a researcher collecting and presenting data within their networks and then clinicians trying to impose protocols developed by researchers with no community involvement is inefficient these days.

As illustrated in chapters 5 and 6, parents of autistic children alongside the Public Involvement in Research Group (PIRG) at the University of Hertfordshire were invaluable in shaping the survey before the launch to the public and commenting on the qualitative results and sharing their insights about the presentation of the findings in these research studies. That is an attempt of collaborative research in some parts of the research programme (for pragmatic reasons; lack of collaboration with an organisation, lack of a consistent group of experts by experience, lack of funding to compensate public and patient involvement (PPI) activities) with benefits for future clinical practice and the autistic community. It is fair to admit that PPI activities are important to be structured and organised from the outset of a research programme. PPI activities should be actively promoted in all stages of research. Therefore, alliances between parents/carers and researchers could pave the way for ensuring research is accessible and impactful to autism stakeholders such as clinicians, parents/carers, autistic people, and policy makers. It is important to also address that the parents of autistic children shared their views on the skills a robot-mediated session should target referring to independent living skills as well as social and communication. Although there is extensive literature about specific support targeting social and communication skills in autism, support targeting independent living skills are scarce in autism (Duncan et al., 2018; Wolstencroft et al., 2018). However, the breadth of social and communication skills support might reflect the fact that social communication and interaction is one of the two core features of autism (American Psychiatric Association, 2013; World Health Organization, 2018). In addition, social and communication development leads to greater independent living skills (Anderson, Liang, & Lord, 2014; Levy & Peery, 2011; Sasson et al., 2020). Such a significant gap between what is being researched and what parents/carers want to see targeted in future robot-mediated sessions indicates that collaborative research with key autism stakeholders is not only imperative, but it also requires shared understanding of theory to keep autism stakeholders engaged, work towards a shared goal and co-create new knowledge (Fletcher-Watson et al., 2019).

8.3.3 Affinity for robots

The empathising – systemising theory (Baron-Cohen, 2009) might explain the affinity of autistic children to robots. The empathising – systemising theory describes that autistic children like to systemise making no or one change at a time which makes the environment more predictable (Baron-Cohen, 2009). This description resembles robots which are programmable to perform one task at a time. Since the use of robots might increase in the coming years (e.g., Aerobot and FRAnny as assistants at Istanbul and Frankfurt airport, respectively) (Aerobot, Your Friendly Airport Digital Assistant, n.d.; Symonds, 2019), it might help us conduct more research which might lead to develop new theories about human – robot interaction and the reasons that autistic children demonstrate an affinity about robots. The findings from chapter 7 indicated without reaching statistical significance that autistic children in the robot group engaged with the human therapist when they needed help, wanted to make a comment, or celebrated a fun activity. This is an indicator though that a robot can scaffold social interaction in autistic children. Session gains might also improve if robots are among the interests (i.e., motivators) of the child (Koegel, Koegel, & McNerney, 2001; Kostrubiec & Kruck 2020; Taher et al., 2019). Therefore, the motivating factors of autistic children within a socially engaging environment might create unique opportunities for joint attention and subsequent social engagement between a therapist/adult play partner, a robot, and the child due to increased levels of motivation which requires further investigation. For example, robots might provide a safe, predictable, and engaging environment within which autistic children may feel more confident to express themselves (Diehl et al., 2012; Robins, Dautenhahn, & Dubowski, 2006; Syriopoulou-Deli & Gkiolnta, 2020). This thesis provides preliminary evidence that with support from a therapist/adult play partner and via robots, autistic children may be supported to practise and develop social and communication skills (see chapter 7).

8.4 Future directions

8.4.1 Transparent reporting of procedures in autism specific support studies

The systematic literature review focused on reporting the structural characteristics (e.g., number, frequency, context) of robot-mediated sessions in autistic children.

When the systematic literature review was conceptualised, the aim was to report on adverse events following sessions, but that was not possible as this data was poorly reported in studies. Better reporting on session characteristics and adverse events, as well as increased use of standardised outcome measures is needed to enable researchers, clinicians, educators, parents/carers, autistic adults, policy makers to better understand robot-mediated sessions and make informed decisions about its suitability in the future. A recent study on adverse events reporting in autism specific support research with children presented that only 7% of studies (11 out of 150) reported adverse events (Bottema-Beutel et al., 2021). Adverse events reporting in autism research is imperative to consider the advantages of an autism specific support compared to its disadvantages. Transparent reporting would also allow professionals and guide researchers to critically evaluate the strengths and limitations of a robot-mediated session leading to scientifically robust evidence base about the future use of robots in autism.

The effect of any autism specific support might also be analysed in light of the number and duration of sessions offered to autistic children and the additional work required from parents/carers at home taking into consideration families from all socioeconomic backgrounds. Research indicates that time to complete a session is influenced by the number of cancellations and length of time to complete an autism specific support programme especially in families from low socioeconomic status who are usually underrepresented in autism specific support studies (Carr & Lord, 2016). Explicit reporting of incentives (e.g., no waitlist to enter an autism specific support programme, free cancellation policy) and/or adjustments to facilitate access to autism specific support (e.g., location of session, age group of children, confirmed diagnosis of autism) not only increases the inclusion of families of autistic children in autism research and access to autism specific support, but it also informs autism researchers on effective ways to design their own research programmes. The overarching aim of robot-mediated support remains to investigate whether autistic children apply new learning via robots in future interactions with other people spontaneously. Achieving transfer and/or generalisation of learned skills is still not greatly reported in the literature which indicates more longitudinal research programmes are needed in

autism. Finally, the variability of implementation of robot-mediated support across settings per research team that creates their own robot for different purposes and absence of standardised evaluation of immediate and sustained treatment gains undermines the clinical utility of robot-mediated support over the years.

8.4.2 From small to larger sample sizes

On the systematic literature review and meta-analysis, the average sample size of autistic children across 44 studies were 10 ranging from 1 to 30 participants. Small sample sizes with fewer than 10 participants were noted in more than 50% of the included studies in the review. In addition, the marginally “better” mean scores, though not statistically significant, in children’s joint attention skills in robot-mediated support in video recordings may be related to the inherent interest of autistic children in technology including robots and consequently their increased levels of motivation (Kostrubiec & Kruck, 2020; Taher et al., 2019). Although there is much to be learned from small scale and exploratory studies about the feasibility and acceptability of robots in autism, findings from small sample sizes undermine the clinical effectiveness of a research programme. Therefore, future research studies should rely on sample size calculations to allow to examine the effect size of robots in autistic children (Hemming et al., 2020).

8.4.3 Better link of research findings with clinical practice

In chapter 4, the meta-analysis revealed that autism clinics/centres appeared to be the most beneficial session location. One of the considerations for implementing any specific support is its cost-effectiveness alongside clinical effectiveness (Skivington et al., 2021). It is though unclear if a robot-mediated support is cost-effective due to the absence of a health economic evaluation in the literature to help support this assertion. Everyday settings (e.g., home, schools) may be more feasible routes to embed a robot-mediated support and may indeed also be more cost-effective. For evidence-based autism specific support to reach the autistic community at the most developmentally appropriate time, school environments offer a mechanism for more children to benefit if therapists/adult play partners are technology literate (Cremin et al., 2021; Wood et al., 2015).

Chapter 5 reported that parents/carers are influenced by healthcare professionals, the autistic community, and media when considering a technology-based support for their autistic child which aligns with the literature (Carlton et al., 2013, 2014; Gibson, Kaplan & Vardell, 2017; Grant et al., 2015; Hartley & Schultz, 2015; Hebert, 2014; Miller et al., 2012; Twombly, Holtz, & Daub-Sychra, 2011). This is an important finding which emphasises the importance of healthcare professionals being in close contact with the autistic community (e.g., support groups, member of an autism charity), media (e.g., TV, talks on the radio, online article writing), and researchers to support parents/carers of autistic children identify evidence-based autism specific support. Further, gaining a more comprehensive understanding of parents'/carers' preferences around technology-based support means that healthcare professionals would be in an advanced position to partner and negotiate with families of autistic children to identify a suitable autism specific support for all. In addition, raising awareness of the extent of parental/carer knowledge and their preferences will support the future work of researchers and/or clinicians about technology-based support in autism.

8.4.4 Parents' preferences and the autistic community

In this thesis, the characteristics, physical appearance, lack of knowledge, and cost was reported to be some of the reasons that parents/carers did not choose non-conventional technology-based support such as virtual reality and robots against more conventional ones including tablets. It is critical to explore the issue further to ensure that parents are provided with the guidance and support they find most helpful to consider autism specific support plans for their autistic child based on their accessibility and availability to technology-based support. Similarly, the study findings of the most preferred technology (i.e., tablets) to use in an autism specific support with autistic children has a number of implications for the design of technology-based support and future research. New technology-based support for autistic children needs to be accessible to parents/carers of autistic children to use. Future research should focus on developing an evidence-base for the way technology-based support is being used as an autism specific support and monitor their availability to autistic children as technology evolves and change over time. It is important to systematically examine the preferences of autistic children for different types of technology, the

focus and format of sessions and the support needs of autistic teenagers as there is some evidence that access to autism specific support is decreasing as children get older (Gibson, Kaplan, & Vardell, 2017). Equally, it is important to explore if parent's attitudes to technology-based support are shaped by their child's use of technology at home and/or in school.

8.4.5 Autistic children and (young and older) adults in research

This thesis has been built on the perspectives of parents/carers of autistic children rather than the perspectives of autistic children. Although, parent's/carers' preferences about technology-based support in autism are scarcely, if ever, reported in the literature, autistic children's preferences on the topic are equally lacking. Autism research is predominantly based on parent/carer or professional-reported outcomes without giving autistic children, young adults and/or older adults the opportunity to report their own views and/or rate their own progress. Although there has been an increase in researching older autistic adults over the past decade, autistic children still dominate the autism literature leaving professionals, researchers, the autistic community with less knowledge on the needs of older autistic adults (Mason et al., 2022). Even though the studies conducted with parents in this thesis were exploratory, they paved the way to further explore the mechanisms behind parents'/carers' attitudes toward technology-based support. Further, it allows other researchers to explore children's preferences about technology-based support and to gather their views about the potential use of robots in autism specific support in the future. National and international autism specific charities/parenting support groups/research centres facilitated recruitment of parents/carers of autistic children across the globe. Active and ongoing promotion of autism research studies within these networks could promote information sharing about autism research. It is, equally, important to be mindful of the inclusion of autistic people's expertise because the vast variety of autism research and practice is coming from non-autistic people. As Donna Williams, an autistic person, said: *"Right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced."* (Williams, D., 1996, p.14).

8.4.6 Exploring motivation and/or interest in robots

This thesis summarised that parents/carers think that robots might attract the attention of autistic children which in turn can provide greater opportunities for practicing and/or learning a new skill. Following from this point, it is important to measure whether the motivation and/or interest about robots predicts learning in autistic children. It is likely that autistic children with a particular interest in robots and other characteristics (e.g., advanced reading and/or speaking skills) could demonstrate greater improvements following a robot-mediated session compared to autistic children who are less interested in robots and have less advanced reading and/or speaking skills. Developing better knowledge and understanding of the association of child factors such as age, IQ, reading, language, and motivation and/or interest about robots might support the development of new theories which could then provide opportunities for enhancing the use of robots with autistic children.

8.5 Personal reflections

Before I started this PhD, I was working as an assistant psychologist in the NHS with psychiatrists, neurologists, paediatricians, and clinical psychologists for about three years (2014 – 2017). As a research assistant and a fellow later, I was working with clinical academics in psychiatry and a few in psychology. Working as a research fellow while doing a PhD was a journey of discovery for me towards shaping my research identity. I noticed when revising my thesis that although I was trying to avoid using language with a negative connotation such as therapy, disorder, aggression, ASD, and I was replacing these with intervention, condition, challenging behaviour and so on that is also potentially offensive language. This language has been commonly used in peer-reviewed research papers, in meetings with researchers and with members of the public and patient involvement (PPI) group. As a research assistant, I had minimal interaction with the PPI group. Since 2019, as a research fellow, I was responsible for leading PPI meetings. However, having worked with four different PPI groups (mainly family carers of autistic children and/or children/adults with intellectual disability and a few adults with intellectual disability), very little attention had been paid by them at that point of time into language use in meetings and study documents.

During my research journey, it has become clear to me that I value the principles of the neurodiversity paradigm and I align with the social model of disability. The neurodiversity paradigm empowers the voices of all autistic individuals and their carers while it shifts the attitudes of those outside of autism who may (e.g., clinicians, researchers, teachers etc.) or may not (e.g., general public) be linked with them to better understand autism. It should be admitted though that the voices of autistic individuals with less support needs are often more present in advocacy compared to the voices of autistic individuals with high support needs. One explanation for their underrepresentation may be that they have less opportunities to become advocates due to the fact that the wider autism advocacy team feel they are not able to handle the demands of such a role. The social model of disability focuses on the barriers the society imposes on people with specific support needs (Anastasiou & Kauffman, 2013; Union of the Physically Impaired Against Segregation, 1976) which is predominantly designed to meet the needs of those who fall within the typical range of neurodevelopment while failing to acknowledge the needs of neurodivergent people. Neurodiversity looks beyond neurobiology. Autism advocates (Kapp, 2020; Pripas-Kapit, 2020; Sinclair, 1993) have shaped the work and approach of autism research (Baron-Cohen, 2000b; Gernsbacher, 2007; Happé & Frith, 2020; Monk, Whitehouse & Waddington, 2022; Nicolaidis, 2012; Pellicano & den Houting, 2022) suggesting that autistic people and their surrounding environment need better access to support and/or services. For example, the social model has shifted our attention from viewing certain autistic characteristics such as echolalia as a negative behaviour. There is evidence that echolalia is a way of self-regulation and communication of their needs in autistic people (Prucoli et al., 2021; Ryan, Roberts, & Beamish, 2022).

However, while writing up my thesis, designing and preparing my studies in chapters 5 and 6, it is evident my theoretical positioning was unclear. After all these years of interaction with (possibly neurotypical) medical doctors and researchers and my studies in psychology and mental health, I was trained to follow science and diagnostic manuals that present autism as a disorder, impairment, and abnormal brain development. Although I was aware of the damage of the medical model in our society, policymaking and research directions for many years, I was unconsciously

using offensive language favouring the medical model (Llewellyn & Hogan, 2000; Marks, 1997). The medical model views the person with specific support needs, namely autistic, as a problem whose disruptive behaviour and/or presentation needs to be treated to abide by the rules of our society. For years autism has associated with vaccines (Silverman 2012). Since the emergence of autism, being autistic has been described as an impairment, deficit, difficulty, problem, challenge or delay in social and communication skills and restricted interests and repetitive behaviours. For years, autism research funding was allocated to identifying the root cause(s) of being autistic and understanding its biology indicating the overarching aim was to cure autistic people. In line with this, there is extensive literature indicating that Applied Behaviour Analysis and similar approaches (see chapter 1.3) is considered gold standard support for autistic children disregarding the techniques and the theory behind behaviourism.

My research work so far is directed to improving support and/or services (e.g., clinical or educational) for autistic people and/or people with intellectual disability to facilitate inclusion, visibility, equality and acceptability. In my personal research experience, I found that quality research involves a researcher that is actively reflective of their work and open to criticism to develop better research in the future. These are qualities I would like to embrace in any future work. Over the years, there has been notable advances in raising awareness, producing knowledge, and reducing the stigma surrounding autism from autism advocates. Nonetheless, the inclusion of neurodivergent individuals in all aspects of daily life remains questionable at a national and international level. My personal reflection as a non-autistic researcher with no autistic family member or an autistic friend is that I need to be consciously aware that science progresses. A decade ago, Professor Michael Rutter said: *“It seems decidedly odd that after more than half a century of both research and clinical experience with Autism Spectrum Disorders, there continue to be arguments on the nature of autism”* (2014). Therefore, we need to ask better questions and apply more nuanced statistical techniques when conducting research about the use of robots with autistic people.

8.6 Conclusions

This thesis gathered evidence from the literature, parents/carers of autistic children and video recordings of autistic children concluding that robots could potentially be an engaging approach to facilitate social and communication skills in autistic children (e.g., joint attention). This research programme explored the role and the structure of a robot-mediated session with autistic children, its effect on joint attention along with parents'/carers' preferences about technology-based support and their perspectives on the future of robot-mediated support. This research programme contributes to the current literature which has outlined that robots appear to be an engaging mediator to support social and communication in autistic children (Diehl et al., 2012; Ghiglino et al., 2021; Korneder et al., 2021; Scassellati et al., 2018; Silva et al., 20219; van den Berk-Smeekens et al., 2021). These four research studies also provide novel insights into the way robots could promote social and communication opportunities in a clinic setting. In the future, the effect of robots for autistic children and new theories about human – robot interaction could be explored. Finally, this work paves the way for more inclusive approaches to learning through the use of robots.

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Appendices

Appendix A: Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

| Table. Checklist for Reporting Results of Internet E-Surveys (CHERRIES). | | |
|---|--|--------------------|
| <i>Checklist Item</i> | <i>Explanation</i> | <i>Page Number</i> |
| Describe survey design | Describe target population, sample frame. Is the sample a convenience sample? (In “open” surveys this is most likely.) | 88 |
| IRB (Institutional Review Board) approval and informed consent process | Mention whether the study has been approved by an IRB. | 90 |
| Informed consent | Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study? | 88 & 287 |
| Data protection | If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access. | 91 & 286 |
| Development and testing | State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire. | 88 – 90 |
| Open survey versus closed survey | An “open survey” is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey). | 91 |
| Contact mode | Indicate whether or not the initial contact with the potential participants was made on the Internet. (Investigators may also send out questionnaires by mail and allow for Web-based data entry.) | 88 – 91 |

| | | |
|------------------------|---|---------|
| Advertising the survey | How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. Ideally the survey announcement should be published as an appendix. | 88 – 91 |
| Web/E-mail | State the type of e-survey (eg, one posted on a Web site, or one sent out through email). If it is an e-mail survey, were the responses entered manually into a database, or was there an automatic method for capturing responses? | 88 – 91 |
| Context | Describe the Web site (for mailing list/newsgroup) in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a autoimmunization Web site will have different results from a Web survey conducted on a government Web site | 88 – 91 |
| Mandatory/voluntary | Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey? | 91 |
| Incentives | Were any incentives offered (e.g., monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)? | 91 |
| Time/Date | In what timeframe were the data collected? | 91 |

| | | |
|--|---|-----|
| Randomization of items or questionnaires | To prevent biases items can be randomized or alternated. | N/A |
| Adaptive questioning | Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions. | N/A |
| Number of Items | What was the number of questionnaire items per page? The number of items is an important factor for the completion rate. | 89 |
| Number of screens (pages) | Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate. | 89 |
| Completeness check | It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if “yes”, how (usually JAVAScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as “not applicable” or “rather not say”, and selection of one response option should be enforced. | N/A |
| Review step | State whether respondents were able to review and change their answers (eg, through a Back button or a Review step which displays a summary of the responses and asks the respondents if they are correct). | 89 |
| Unique site visitor | If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both. | N/A |
| View rate (Ratio of unique survey visitors/unique site visitors) | Requires counting unique visitors to the first page of the survey, divided | N/A |

| | | |
|---|--|-----|
| | by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary. | |
| Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors) | Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called “recruitment” rate. | N/A |
| Completion rate (Ratio of users who finished the survey/users who agreed to participate) | The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). This is only relevant if there is a separate “informed consent” page or if the survey goes over several pages. This is a measure for attrition. Note that “completion” can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. (If you need a measure for this, use the word “completeness rate”.) | N/A |
| Cookies used | Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (eg, the first entry or the most recent)? | N/A |
| IP check | Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (eg, 24 hours). Were duplicate entries | 91 |

| | | |
|---|---|-----|
| | avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (e.g., the first entry or the most recent)? | |
| Log file analysis | Indicate whether other techniques to analyse the log file for identification of multiple entries were used. If so, please describe. | N/A |
| Registration | In “closed” (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, which entries were kept for analysis (e.g., the first entry or the most recent)? | N/A |
| Handling of incomplete questionnaires | Were only completed questionnaires analysed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analysed? | 88 |
| Questionnaires submitted with an atypical timestamp | Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point and describe how this point was determined. | N/A |
| Statistical correction | Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; if so, please describe the methods. | N/A |

Appendix B: Copy of the Parents, Autism, TecHnology (PATH) participant information sheet , consent form and survey

Information sheet

Preferences about Technology based interventions for Children and Young People (CYP) with Autism Spectrum Disorders (ASD)

We would like to invite you to participate in a study. Before you decide to take part in this study it is important that you understand the study that is being undertaken and what your involvement will include. Please take time to read the following information sheet carefully and feel free to email the researcher (Nancy Kouroupa - ak18adj@herts.ac.uk) should you need more information about the study. Please do take your time to decide whether or not you wish to take part.

What is the purpose of the study?

This study aims to explore parents' knowledge and preferences in relation to the use of technology based interventions for children and young people (up to 18 years old) with a diagnosis of ASD. There are different types of interventions that aim to support individuals with developing a range of skills. Technology is a specific avenue that has been explored. In this study we want to understand parent's definitions of "technology", which you have engaged with, and what you feel may be useful in the future. Even if your child has not used any technology based intervention to date, we welcome parents to take part in the survey and record your views on the topic.

Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you decide to take part you will read this information sheet and be asked to click continue to review the consent form. You will then be asked to create a personalised User ID. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw without giving a reason. To withdraw from the study, just close the browser window without submitting your responses. Once you submit your answers you can still withdraw your responses. Email the researcher on ak18adj@herts.ac.uk sharing your User ID to delete your responses from the dataset.

What are the criteria to take part?

You must be at least 18 years old and be a parent/carer of a child/young person aged 0-18 years with Autism Spectrum Disorder (diagnosed, in the process of diagnosis or suspected

autism). You also need to feel confident to express yourself in English to complete the survey because there will be a few sections where you will be asked to express your views.

How long will my part in the study take?

If you decide to take part in this survey, it will take around 15-20 minutes to complete.

What will happen to me if I take part?

If you decide to take part, you will be directed through the study online which includes a mix of tick box and open ended answers. We will collect some basic information about you and your child and ask you specific questions about your knowledge and use of technology based interventions as well as your thoughts about future use.

What are the possible advantages and disadvantages of taking part?

There are no direct benefits or risks of taking part in this study. We anticipate that you may find the study interesting and feel good about contributing to research that further elucidates the potential scope of technology based interventions to support children and young people with ASD.

How will my taking part in this study be kept confidential?

We will treat personal information with respect and confidentiality. If you decide to take part in the study, you will be allocated a Participant Identifiable (PID) number automatically. All of the information from the study will be stored by PIDs. If you provide your email address, we will store personal information separately from your responses and delete any identifiable information from the main dataset. Only the research team at the University of Hertfordshire will have access to the data. Anonymised data will be stored as password protected files on password protected computers. The online account where the study is hosted is also the researcher's personal account allocated by the University of Hertfordshire which is secure.

What will happen with the data collected within the study?

All data will be anonymised and stored electronically as password protected files on password protected computers for the duration up to 5 years after the completion of the study. The results of the study will form part of the researcher's PhD thesis and will be presented at conferences and/or submitted for publication in academic journals. The findings of the study will be shared with participants, if requested. All outputs will protect participant anonymity.

Who has reviewed this study?

The study has been reviewed by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. The UH protocol number is

LMS/PGR/UH/04164.

Who can I contact if I have any questions?

If you have any concerns about this study, please contact the main researcher, Nancy Kouroupa, who can be contacted at ak18adj@herts.ac.uk.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address: Secretary and Registrar University of Hertfordshire College Lane Hatfield Herts AL10 9AB. Thank you very much for reading this information sheet and considering taking part in this study.

Consent form

I confirm that I have understood the information sheet for the "Preferences about technology based interventions for Children and Young People (CYP) with Autism Spectrum Disorders (ASD)".

I understand that my participation is voluntary and I can withdraw at any time by closing the browser.

I understand that all information will be kept confidential.

I understand that any personal details provided will be stored separately from the main dataset.

I agree to take part in the above study.

Yes (1)

No (2)

Skip To: End of Survey If QID1 = 2

End of Block: Introduction

Start of Block: User ID

User ID (e.g., nk20, 111, 0123456).

Please avoid using your name or any other identifiable information to ensure your anonymity.

End of Block: User ID

Start of Block: Parents/Carers

About you: Parent/Carer

How old are you?

What is your relationship to the child?

Mother (1)

Father (2)

Other, please specify (3) _____

Prefer not to say (4)

This question is about your self-identified gender (how you feel internally). A person's self-identified gender may differ from the sex assigned to them at birth and it may be different to what is shown on official documents (e.g. birth certificate).

Please select the option that best describes your gender.

Male (1)

Female (2)

Gender diverse/ non-binary/ X gender (3)

Other, please specify (4) _____

Prefer not to say (5)

Please indicate which of the following best represents your ethnic origin?

- White - English/Welsh/Scottish/Northern Irish/British (1)
- White - Irish (2)
- Any other White Background - Please specify (3)
-
- Mixed/Multiple Ethnic Groups - White and Black Caribbean (4)
- Mixed/Multiple Ethnic Groups - White and Black African (5)
- Mixed/Multiple Ethnic Groups - White and Asian (6)
- Any other Mixed/Multiple Ethnic Group - Please specify (7)
-
- Black/African/Black British - African (8)
- Black/African/Black British - Caribbean (9)
- Any other Black/African Background - Please specify (10)
-
- Asian/Asian British - Indian (11)
- Asian/Asian British - Pakistani (12)
- Asian/Asian British - Bangladeshi (13)
- Asian/Asian British - Chinese (14)
- Any other Asian Background - Please specify (15)

Other Ethnic Group - Arab (16)

Other Ethnic Group - Please specify (17)

Where do you live?

City/Town/Village (e.g. Birmingham, Driffield, Fulbourn in Cambridgeshire) (1)

Country (e.g. England, Ireland, France) (2)

What is your highest qualification?

GCSEs (1)

GCE or International Baccalaureate (2)

Higher National Certificate / Diploma (HNC/D) (3)

Diploma in Higher Education (4)

Foundation degree (5)

Undergraduate degree (6)

Postgraduate degree (7)

Ph.D/ Doctorate (8)

Other, please specify (9) _____

Prefer not to say (10)

Please tell us about your current employment?

Employed full time (1)

Employed part time (2)

Unemployed looking for work (3)

Unemployed not looking for work (4)

Retired (5)

Student (6)

Career break (7)

Other, please specify (8) _____

Prefer not to say (9)

What is your total household income? If you need to convert your income to british pound, please use the following link: <https://www.xe.com/currencyconverter/>

▼ up to £20,000 (1) ... Prefer not to say (7)

How many children do you have in total?

▼ 1 (1) ... 8 (8)

How many of your children have a diagnosis of ASD?

▼ 1 (1) ... 4 (4)

End of Block: Parents/Carers

Start of Block: Children and Young People

If you have previously reported you have more than one child with ASD, please complete the questionnaire taking into consideration the youngest individual with ASD first. Then, respond to the same set of questions taking into consideration the other(s) individual(s) with ASD. If you only want to report on one child, you can click back to the Question "How many of your children have a diagnosis of ASD" and select 1 to respond to the questions once.

What is the child's gender?

Male (1)

Female (2)

Other, please specify (3) _____

Prefer not to say (4)

What is the exact age of the child (e.g. 4 years 2 months)?

Has your child been diagnosed with ASD by a health professional (e.g. pediatrician)?

Yes (1)

No, awaiting diagnosis (2)

No, ASD suspected (3)

Other, please specify (4) _____

Skip To: QID46 If QID10 = 1

Display This Question:

If QID10 = 1

At what age was your child diagnosed (e.g. 5 years 5 months)?

Does your child have additional support needs confirmed by a health professional? For example, learning disability, anxiety, sleep problems, epilepsy, genetic condition (syndrome) or other?

Yes, please specify (1) _____

Maybe, please specify (2) _____

No (4)

Prefer not to say (5)

What is your child's spoken language? (select more than one option)

- Babbling (1)
 - Word approximation (e.g. Ma for Mummy) (2)
 - Single words (e.g. banana) (3)
 - Two words (e.g. want banana) (4)
 - Short phrases (e.g. I want a banana) (5)
 - Multi-part sentences (e.g. When I finish, I want a banana) (6)
 - "Wh" questions (e.g. Who is bringing the bananas?, Where does the banana come from?, Why do not we have any bananas?) (7)
 - Complex sentences (e.g. I am not sure. I might be hungry after school) (8)
 - Using pronouns appropriately (e.g. he, she, I, you , me) (9)
 - Fluent (10)
 - Other, please specify (11)
-
- Prefer not to say (12)
-

How would you describe your child's reading skills? (select more than one option)

- Respond to a storybook by making sounds (1)
- Look at pictures and name familiar items (e.g. dog, cup, chair) (2)
- Know the correct way to hold a book (3)
- Understand that words are read from left to right and pages are read from top to bottom (4)
- Recognise letters of the alphabet (5)
- Retell a story using words or pictures (6)
- Start reading (7)
- Read at a slower pace compared to peers (8)
- Describe (either verbally or in pictures) the setting, characters and the plot of a story (9)
- Identify themes and summarise the sequence of events in a story (10)
- Read fluently (11)
- Other, please specify (12)

- Prefer not to say (13)

End of Block: Children and Young People

Start of Block: ASD intervention

About ASD Intervention

If you have previously reported you have more than one child with ASD, please complete the questionnaire taking into consideration the youngest individual with ASD first. Then, respond to the same set of questions taking into consideration the other(s) individual(s) with ASD. If you only want to report on one child, you can click back to the Question "How many children with ASD do you have" and select 1 to respond to the questions once.

Is your child currently/over the past 6 months in receipt of any intervention to support their needs for ASD? (select more than one option)

Yes (1)

On a waiting list, please specify (2)

Other, please specify (3)

No (4)

Since diagnosis (or suspected ASD), has your child ever received an intervention to support their needs for ASD?

Yes (1)

No (2)

Where is/has your child receiving/ed the intervention? (select more than one option)

- At home (1)
 - In school or other educational setting (i.e., preschool) (2)
 - Private setting (3)
 - National Health Service (NHS) (4)
 - Other, please specify (5)
-
- Not applicable - My child hasn't started therapeutic work yet (7)

Which of the following interventions have you accessed for your child with ASD? (select more than one option)

- Applied Behavior Analysis (ABA) (1)
- Discrete Trial Training (DTT)/"Lovaas therapy" (2)
- Functional Communication Training (FCT) (3)
- Pivotal Response Training (PRT) (4)
- Sensory Integration (SI) (5)
- Lego therapy (6)
- Occupational Therapy (OT) (7)
- Speech and Language Therapy (SLT) (8)
- Floortime (9)
- Picture Exchange Communication System (PECS) (10)
- Social Stories (11)
- Sign Language Training (12)
- Social Skills Training (13)
- Cognitive-Behavioral Therapy (CBT) (14)
- Auditory integration training (AIT) (15)
- Nutritional Supplements (16)

Gluten- and Casein-Free Diet (17)

Other, please specify (18)

None (19)

How many professionals related to ASD have you consulted to decide your child's treatment plan?

1-3 (1)

4-6 (2)

7-9 (3)

10+ (4)

None (5)

End of Block: ASD intervention

Start of Block: Technology in ASD

About Technology based interventions

Technology based interventions are gaining attention in the field of autism. This section is interested in what you understand by "technology" in this context, any interventions that you have or are using, and your thoughts about the future of interventions in such modalities.

If you have previously reported you have more than one child with ASD, please complete the questionnaire taking into consideration the youngest individual with ASD first. Then, respond to the same set of questions taking into consideration the other(s) individual(s) with ASD. If you only want to report on one child, you can click back to the Question "How many children with ASD do you have" and select 1 to respond to the questions once.

Please select the relevant option. You can select more than one option.

| | Smartphone (1) | iPod (2) | Tablet/iPad (3) | Virtual Reality headset (4) | Robot (5) | None (6) | Other (7) |
|---|--------------------------|--------------------------|--------------------------|--------------------------------------|--------------------------|--------------------------|--------------------------|
| Which technology based intervention have you heard about for children with ASD? (1) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Has your child engaged with an intervention for ASD that uses any of the listed technologies? (2) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Display This Question:

If QID20 = 7

If Other, please specify

If you were seeking an intervention for your child, would you consider a technology based session?

Yes (1)

Maybe (2)

No (4)

Skip To: QID52 If QID19 = 1

Skip To: QID52 If QID19 = 2

Which of the following technology based devices, if any, you are most interested in using with your child with ASD? (select more than one option)

- Smartphone (1)
 - iPods (2)
 - Tablets/iPads (3)
 - Virtual Reality headset (4)
 - Robot (5)
 - Other, please specify (6)
-
- None (7)

Please choose from the following technology based alternatives. Only one option is available.

| | Smartphone (1) | iPod (2) | Tablet/iPad (3) | Virtual Reality headset (4) | Robot (5) | None (6) | Other (7) |
|---|-------------------|----------|--------------------|--------------------------------------|--------------|-------------|--------------|
| Which alternative would you MOST like your child to take part in? (1) | | | | | | | |

Skip To: QID23 If QID22 = 1

Skip To: QID26 If QID22 = 2

Skip To: QID47 If QID22 = 3

Skip To: QID27 If QID22 = 4

Skip To: QID28 If QID22 = 5

Skip To: QID44 If QID22 = 7

Skip To: QID48 If QID22 = 6

Why would you most like your child to take part in a session with a smartphone?

Skip To: QID30 If Condition: Why you would most like you... Is Displayed. Skip To: Please choose from the following tech...

Why would you most like your child to take part in a session with an iPod?

Skip To: QID30 If Condition: Why you would most like you... Is Displayed. Skip To: Please choose from the following tech...

Why would you most like your child to take part in a session with a Tablet/iPad?

Skip To: QID30 If Condition: Why would you like your chi... Is Displayed. Skip To: Please choose from the following tech...

Why would you most like your child to take part in a session with a virtual reality headset?

Skip To: QID30 If Condition: Why would you most like you... Is Displayed. Skip To: Please choose from the following tech...

Why would you most like your child to take part in a session with a robot?

Skip To: QID30 If Condition: Why would you most like you... Is Displayed. Skip To: Please choose from the following tech...

Display This Question:

If QID22 = 6

If none, please specify

Display This Question:

If QID22 = 7

If other, please specify

Please choose from the following technology based alternatives. Only one option is available.

| | Smartphone (1) | iPod (2) | Tablet/iPad (3) | Virtual Reality headset (4) | Robot (5) | None (6) | Other (7) |
|--|-------------------|----------|--------------------|--------------------------------------|--------------|-------------|--------------|
| Which alternative would you LEAST like your child to take part in? (1) | | | | | | | |

Skip To: QID24 If QID30 = 1

Skip To: QID49 If QID30 = 2

Skip To: QID31 If QID30 = 3

Skip To: QID32 If QID30 = 4

Skip To: QID33 If QID30 = 5

Skip To: QID50 If QID30 = 6

Skip To: QID51 If QID30 = 7

Display This Question:

If QID30 = 1

Why would you least like your child to take part in a session with a smartphone?

Display This Question:

If QID30 = 2

Why would you least like your child to take part in a session with an iPod?

Display This Question:

If QID30 = 3

Why would you least like your child to take part in a session with a Tablet/iPad?

Display This Question:

If QID30 = 4

Why would you least like your child to take part in a session with a Virtual Reality headset?

Display This Question:

If QID30 = 5

Why would you least like your child to take part in a session with a robot?

Display This Question:

If QID30 = 6

If none, please specify

Display This Question:

If QID30 = 7

If other, please specify

Which factors influence your decision to access technology based interventions for your child's treatment choice for ASD (select more than one option)?

- Books (4)
 - Health professionals (e.g. paediatrician, psychologist, speech therapist, occupational therapist) (5)
 - Recommendations by other parents (6)
 - Workshop/Training at a conference (7)
 - Workshop/Training at an agency/charity (8)
 - Child's school (9)
 - Media (e.g. TV, shows, movies dedicated to autism) (10)
 - Other, please specify (11) _____
 - None (12)
-

Which technology devices does your child with ASD have access to (e.g. smartphone, tablet, Wii, playstation, nintendo, Xbox)?

- Smartphone (4)
 - Tablet/iPad (5)
 - Wii (6)
 - Playstation (7)
 - Xbox (8)
 - Nintendo (9)
 - Other, please specify (10) _____
-

What are your concerns, if any, of using technology based support with children with ASD?



How, if at all, has COVID-19 influenced your opinion about the use of technology with children and young people with ASD?



Page Break



Start of Block: End

Is there anything else you would like to tell us?

Yes, please specify (1) _____
No (2)

If you would like to have a copy of the study findings, please enter your email address.
This project forms part of the researcher's PhD that is aimed to be completed in 2021-2022.

Email address (1) _____

If you would like to be contacted to take part in a short interview about the use of robots
with children and young people with ASD at a later date, please enter your email address. If
you agree now, you can still change your mind later.

Email address (1) _____

Thank you for taking the time to complete this survey.

Click the continue button to submit your responses.

If you have any questions or concerns, please email Nancy Kouroupa at
ak18adj@herts.ac.uk.

Below you will find a list of links that you might find useful:

<https://www.autism.org.uk/services.aspx>

<https://www.ambitiousaboutautism.org.uk/>

<https://www.nhs.uk/service-search/other-services/>

Appendix C: University of Hertfordshire ethical approval for conducting a survey



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA
ETHICS APPROVAL NOTIFICATION

TO Athanasia (Nancy) Kouroupa
CC Dr Shivani Sharma, Dr Karen Irvine, Dr Silvana, Mengoni
FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair
DATE 19/05/2020

Protocol number: LMS/PGR/UH/04164

Title of study: Parent preferences about technology based interventions for children and young people with autism spectrum disorders

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 19/05/2020

To: 31/12/2020

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.

Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix D: COnsolidated criteria for REporting Qualitative research
(COREQ) Checklist

**COnsolidated criteria for REporting Qualitative research (COREQ)
Checklist**

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|--|----------|--|----------------------|
| Domain 1: Research team and reflexivity | | | |
| <i>Personal characteristics</i> | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | 147 |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | 147 |
| Occupation | 3 | What was their occupation at the time of the study? | 147 |
| Gender | 4 | Was the researcher male or female? | 147 |
| Experience and training | 5 | What experience or training did the researcher have? | 147 |
| <i>Relationship with participants</i> | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | 147 - 148 |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 147 -148 |
| Interviewer characteristics | 8 | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 147 -148 |
| Domain 2: Study design | | | |
| <i>Theoretical framework</i> | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 149-151 |

| | | | |
|--|----|--|-----------|
| <i>Participant selection</i> | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 145 |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | 145 |
| Sample size | 12 | How many participants were in the study? | 145–146 |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | 145 |
| <i>Setting</i> | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | 148 |
| Presence of non-participants | 15 | Was anyone else present besides the participants and researchers? | 148 |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | 145–146 |
| <i>Data collection</i> | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 150 & 315 |
| Repeat interviews | 18 | Were repeat inter views carried out? If yes, how many? | N/A |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | 150 |
| Field notes | 20 | Were field notes made during and/or after the interview or focus group? | N/A |
| Duration | 21 | What was the duration of the inter views or focus group? | 148 |
| Data saturation | 22 | Was data saturation discussed? | N/A |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | N/A |
| Domain 3: analysis and findings | | | |
| <i>Data analysis</i> | | | |
| Number of data coders | 24 | How many data coders coded the data? | 151 |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | 153 |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | 151–153 |

| | | | |
|------------------------------|----|---|---------|
| Software | 27 | What software, if applicable, was used to manage the data? | 152 |
| Participant checking | 28 | Did participants provide feedback on the findings? | N/A |
| <i>Reporting</i> | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | 154–164 |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | 154–164 |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | 154–164 |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | 154–164 |

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix E: University of Hertfordshire ethical approval for conducting interviews with parents of autistic children



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA
ETHICS APPROVAL NOTIFICATION

TO Dr Karen Irvine
FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair
DATE 14/12/2020

Protocol number: LMS/SF/UH/04397
Title of study: Improving the inclusivity of robot-mediated play for children with Autism Spectrum Disorder (ASD)

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Silvana Mengoni – 750250
Shivani Sharma – 730164
Athanasia Kouroupa – 755149

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 14/12/2020

To: 30/04/2020

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.

Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix F: Qualitative study with parents – interview topic guide

1. Introduction & Setting Ground Rules (3 mins)

Welcome and thank the participant for their availability, introduce yourself and explain:

- Nature and focus of research
- Agree on preferred language to describe children (with autism or autistic)
- Confidentiality: The names of all participants will only be known to the researcher only
- The session will be audio-recorded. The researcher will analyse the transcript
- The participants will be identified by an ID and all potentially identifying information will be removed from the written notes

Ground Rules

- You do not have to share any information that you do not want to.
- There are no right or wrong answers.
- We are looking for the widest possible range of views.
- The conversation is confidential.
- Mobile phones should be off or on silent-vibrate, if possible.
- Any questions?
- Start recording.

2. Background (2 mins)

Aim: Icebreaker

- Ask the participant(s) to introduce themselves:
 - Previous experience of/participation in a research study

3. Discussing Intervention Delivery for ASD (20-30 mins)

Play-based interventions are suggested for children with autism/autistic using a range of strategies such as floortime, family work, school-based intervention to motivate and engage the child.

Item 1: What do you think are the benefits of play-based interventions?

Item 2: What skills should be prioritised in play-based sessions with children?

Item 3: Which technology, if any, does your child regularly access?/ What do they like about technology?

Item 4: Have you ever seen or heard about interventions in autism facilitated by robots?

Note 1: Robots have been increasingly used with children as a play partner. I'd like to show you a picture of one robot known as Kaspar. Kaspar can sing songs, say hello, introduce itself, wave goodbye, express emotions (sad, happy).

Prompts: What are your immediate thoughts?/ How would you expect the child to respond to the robot?/ What you think of its appearance?

Item 5: How do you feel about using robots with children?

Item 6: In what way, if any, you think robots are likely to be helpful for children?

Item 7: What are your concerns, if any, of using robots with children (with autism or autistic)?

Item 8: How you would like a session with a robot to be delivered?

Prompts: Which skills should a session target?/ What would you like to happen during a sessions?, What should the therapist/professional do?, Where you would like the session to take place?, Would you play similar activities elsewhere (at home/in school)?

Item 9: What activities/games you would suggest that robots can play with children?

4. Conclusion / Debrief (5 mins)

- Thinking about the conversation we have had today, how did you like/dislike talking about the use of robots in relation to autism?
- Is there anything important to you we have not mentioned?

Thank participant(s) for his/her/their contribution

Remind participant(s) that all information is confidential

Information on study timescale (data analysis and write up of findings)

Role, age, gender, ethnicity, job role, number of children with autism/autistic, age of children with autism/autistic, age of child's diagnosis and other diagnoses.

Appendix G: University of Hertfordshire ethical approval to analyse the video recordings from the Kaspar feasibility trial



East of England - Cambridge South Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

16 August 2018

Ms Nancy Kouroupa
University of Hertfordshire
College Lane Campus
Hatfield
AL10 9AB

Dear Ms Kouroupa,

| | |
|-------------------|--|
| Study title: | Feasibility study of an RCT to investigate the effectiveness of a humanoid robot to support social skills development in children with an Autism Spectrum Disorder |
| REC reference: | 16/EE/0387 |
| Amendment number: | SA05 |
| Amendment date: | 22 June 2018 |
| IRAS project ID: | 206323 |

The above amendment was reviewed on 10 August 2018 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The members of the Sub-Committee were in agreement that the Substantial Amendment did not raise any material ethical issues.

Approved documents

The documents reviewed and approved at the meeting were:

| Document | Version | Date |
|---------------------------------|---------|------|
| Covering letter on headed paper | | |

| | | |
|--|------|--------------|
| Notice of Substantial Amendment (non-CTIMP) | SA05 | 22 June 2018 |
| Other [IRAS form resubmitted for SA05] | | 26 July 2018 |
| Other [Telephone interview schedule] | 1.0 | 18 May 2018 |
| Other [Write-draw-tell document for KG] | 1.0 | 18 May 2018 |
| Other [Write-draw-tell document for TOG] | 1.0 | 18 May 2018 |
| Other [CRF_KASPAR] | 3.0 | 21 May 2018 |
| Participant consent form [consent to telephone interview_KASPAR] | 1.0 | 18 May 2018 |
| Participant information sheet (PIS) [Parent info sheet for interview_KASPAR] | 5.0 | 18 May 2018 |
| Participant information sheet (PIS) [Parent info sheet for telephone interview_KASPAR] | 1.0 | 18 May 2018 |
| Research protocol or project proposal [protocol_KASPAR] | 7.0 | 18 May 2018 |
| Summary CV for student [CV Nancy Kouroupa] | | |
| Summary CV for supervisor (student research) [Shivani Sharma CV] | | |

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

| | |
|-------------|--|
| 16/EE/0387: | Please quote this number on all correspondence |
|-------------|--|

Yours sincerely,



Dr Leslie Gelling
Chair

E-mail: nrescommittee.eastofengland-cambridgesouth@nhs.net

Enclosures: List of names and professions of members who took part in the review

*Copy to: Ms Sally Anne Doyle-Caddick, Hertfordshire Community NHS Trust
Ms Nancy Kouroupa*

East of England - Cambridge South Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 10 August 2018

Committee Members:

| <i>Name</i> | <i>Profession</i> | <i>Present</i> | <i>Notes</i> |
|----------------------|---------------------------|----------------|--------------|
| Dr Leslie Gelling | Reader in Research Ethics | Yes | |
| Mrs Nikki Phillimore | Locum Pharmacist | Yes | |

Also in attendance:

| <i>Name</i> | <i>Position (or reason for attending)</i> |
|-------------|---|
| Kate Loven | REC Assistant |