High support need and minimally verbal children with autism are a heterogeneous group. They are also less studied than their higher-functioning counterparts. Observing children as individuals may reveal capacities previously unseen in children’s performance. This study’s results indicate that it is plausible to design a research methodology that acknowledges the specific challenges of high support need and minimally verbal children.
HIGH SUPPORT NEED AND MINIMALLY VERBAL CHILDREN WITH AUTISM -

EXPLORATION OF TECHNOLOGY-BASED RESEARCH METHODOLOGY AND THE CASE OF ATTENDING TO EYES
Vesa Korhonen

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Publications of the University of Eastern Finland
Dissertations in Education, Humanities, and Theology
No 94

University of Eastern Finland
Joensuu
2017
Korhonen, Vesa
High support need and minimally verbal children with autism - exploration of technology-based research methodology and the case of attending to eyes
Itä-Suomen yliopisto, 2017, 63 pages
Publications of the University of Eastern Finland
Dissertations in Education, Humanities, and Theology; 94
ISBN: 978-952-61-2376-9 (PDF)
ISSNL: 1798-5625
ISSN: 1798-5625
ISSN: 1798-5633 (PDF)

ABSTRACT

High support need and minimally verbal individuals with autism spectrum disorder are a heterogeneous group. However, these children are often assessed and researched with the same instruments and methodologies, and are often grouped together by mental age and/or language age, regardless of their varying backgrounds and profiles. To date, most autism research has focused on the higher-functioning autism group. For this thesis, I explored research methodology for high support need and minimally verbal children with autism. First, I examined the research literature on joint attention (a skill requiring eye contact) to review previous research methods. Second, I developed a computerised game-like methodology to study attention to eyes. The computerised method was used because individuals with ASD like using computers and find them motivating.

After completing the literature review, I developed the computerised method in the form of a minimally verbal game. The new research platform was based on a previous game that provided positive user experience among high support need children with autism. The original game was a fun activity designed to take individual preferences into account. For my research purposes, I altered the game to include a virtual character. In the game, the children had to find what location the virtual character was looking at, using either the eyes or supporting arrows as cues. The player’s decisions and the location choice were recorded, and eye tracking was used to see how long the children were attending to the eyes when making correct decisions. The children’s performances were analysed on an individual level using case-control analyses for both the decision-making data and the eye-tracking data.

During the literature review, I discovered that most ASD studies used similar research methods to assess joint attention, and no study mentioned using children’s preferences in the assessment procedures or reported individual-level results. The subsequent designing of a computer game, being built on previous research results and game construction, for studying attention to eyes was a positive experience. In the game I constructed, the high support need and minimally verbal children with ASD were able to play the game at above chance level and use the eye cues without the support of arrow cues. Using the eye cues, one child out of four made more errors in choosing the location in comparison to the control group. Additional arrow cues, that were thought to help the game player, had a positive influence on the performance of the typically developing children, but not on the children with ASD. When making
correct decisions in the game, the dwell time on the eye area was shorter in one participant and equal in two, in comparison to the controls.

These results indicate that it is plausible to design a computer game for research purposes for high support need and minimally verbal children with ASD using pre-existing liked activities. I infer this as previous studies have shown the positive influence of technologies for individuals with ASD, based on the game playing in my study. The evidence also shows that in tandem with preference-based tasks, the individual-level skills analysis may be a useful addition to group level analysis when studying individuals with ASD.

**Keywords:** autism, technology, high support need, minimally verbal, children, attending to eyes
Korhonen, Vesa
Vahvaa tukea tarvitsevat ja minimaalisesti verbaalit autismin kirjon lapset - teknologiapoljaisen tutkimusmenetelmän kokeilu silmiin katsomisen tutkimuksessa Itä-Suomen yliopisto, 2017, 63 sivua
Publications of the University of Eastern Finland
Dissertations in Education, Humanities, and Theology; 94
ISBN: 978-952-61-2376-9 (PDF)
ISSNL: 1798-5625
ISSN: 1798-5625
ISSN: 1798-5633 (PDF)

TIIVISTELMÄ

Vahvaa tukea tarvitsevat ja minimaalisesti verbaalit henkilöt ovat hyvin heterogeenni
nen ryhmä. Tästä huolimatta heitä arvioidaan yleisesti samalla tavalla arviointitapojilla ja
ryhmään kuuluminen määritellään usean aikaa, kyntä heidät lohkoisi perusteella. Tutkimuksessa on tähän saakka keskittyttä enemmän high
functioning -autismiin. Tässä väittöskirjassa keskityttiin vahvaa tukea tarvitseviin ja
minimaalisesti verbaaleihin lapsiin sekä siihen, kuinka heidät yleisestilta ottaan parem
min huomioon tutkimusmenetelminä valinnassa. Tutkimuksen ensimmäisessä osassa
keskityttiin jaettuun tarkkaavaisuuteen, jonka häiriö on yksi autismin tunnusmerk
kejä. Kirjallisuuskatsauksessa kartoitettiin viimeisen kymmenen vuoden aikana jul
kaistuista tutkimuksista jaetun tarkkaavaisuuden häiriön yleisyyttä sekä käytettyjä
arviointitapoja. Tutkimuksen toisessa osassa kehitettiin tietokonepelit lasten silmiin
katsomisen tutkimiseksi. Tietokoneistettu tutkimusmenetelmä valittiin siitä syystä,
eett autisman kirjon henkilöiden on tutkitusti havaittu pitävän tietokoneista ja tek
nologiasta.

Jaetun tarkkaavaisuuden kirjallisuuskatsaus suunniteltiin siten, että käytetty
arviointitapa sekä häiriön yleisyyttä voitiin arvioida systemaattisesti. Katsauksen
jälkeen silmiin katsomisen arviointitapa kehitettiin sellaisen aikaisemman pelin poh
jalle, pelin jolla oli havaittu positiivinen käyttäjäkokemus vahvaa tukea tarvitsevien
autismin kirjon lasten lapsilla. Näin pyrittiin lisäämään lasten motivointia ja keskitymistä
ite tehtävän suorittamiseen. Arviointia varten peliin lisättiin virtuaalinen hahmo,
jonka katseen perusteella lasten tuli löytää se laittiko, johon hahmo katsoi. Lasten
suoritumista pelissä ja heidän keskitymistään silmiin analysoitiin yksilötasella. Mit
tereina toimivat virheiden määrä ja silmänliikkeitä.

Tulokset osoittivat, että tutkimuksissa käytiin jaetun tarkkaavaisuuden arvi
oimiseen samoja tai samanlaisia arviointitapoja. Tutkimuksissa ei raportoitu huomi
oiduksi lasten kiinnostuksen kohteita eikä tuloksia raportoitu yksilötasolla. Tässä
tutkimuksessa käytetty peliä lapset pelasivat systemaattisesti eivätkä sattumanva
raisesti. Vain yksi autismin kirjon lapsi teki enemmän virheitä yrittäen löytää vir
tuaalihahmon katseen kohdetta. Kaksi autismin kirjon lasta keskittyi oikeita valintoja
tehdessään silmiin yhtä pitkään kuin verrokkiryhmän lapset. Yksi autismin kirjon
lapsista keskittyi vähemmän aikaa silmiin tehdessään oikeita valintoja ja yhden lapsen
silmänliikkeitä ei pystytty arvioimaan. Pelin perustuva metodologia ja yksilötasoinen
analyysi osoittivat, että osa autismin kirjon lapsista pystyi keskittymään silmiin, ja että
he keskittyivät silmiin yhtä kauan kuin verrokit. Tutkijan kokemus lapsille mieluisan pelin kehittämisestä arviointitarkoituksiin oli positiivinen.

Tämän tutkimusten perusteella voidaan päätellä, että lasten kiinnostuksen kohteet sekä tietokoneistetut tai peleihin perustuvat metodologiat ovat mahdollisia tapoja tutkia vahvaa tukea tarvitsevia ja minimaalisesti verbaalisia lapsia. Hyödyntämällä jo valmiiksi mieluisia ympäristöjä on mahdollista saada kattavampi käsitys lasten osaamisesta. Tutkimuksen perusteella voidaan myös todeta, että yksilötasoiset analyysimallit ovat hyvä lisä ryhmätutkimuksen rinnalla tutkittaessa autismia.

Avainsanat: autismi, teknologia, vahva tukea tarvitsevat, minimaalisesti verbaalit, lastet, silmiin katsominen
ACKNOWLEDGEMENTS

It has been a long process to get to this final stage of my doctoral thesis. This thesis would not have been possible without the support of a great number of people. First and foremost, I would like to express my gratitude to my supervisors Professors Eija Kärnä and Hannu Räty for providing me with constant encouragement and guidance at every step of the way. Their knowledge and expertise coupled with positive thinking got me to this point.

I would like to thank the CASCATE-project staff (Eija Kärnä, Marjo Virnes, Katja Tuononen and Virpi Vellonen) for their collegial help, support and expertise, and for their valuable feedback during the planning and on the progress of this thesis. I am very grateful to Katja Tuononen for assisting me with the data collection and giving invaluable insights. I would also like to thank Anton Lin for the programming of the game used in this thesis, and everyone who worked with me during my thesis. Thanks also to my fellow PhD students and friends at the University of Eastern Finland.

My special thanks go to the schools in which I conducted the research and I am especially very grateful to the children and families who participated in the research. Another special thank you goes to Professor Eija Kärnä who hired me to work on her project funded by the Academy of Finland. Eija had enough courage and trust to hire someone she knew very little about. Eija’s encouragement to learn new skills during my thesis work led me to develop specific and transferable skills that I have found useful both within and outside academia. An enormous thank you to Professor Hannu Räty whose calm, relaxed but firm guidance was a lifesaver in those moments when I felt my motivation flagging.

I would also like to thank the National Doctoral Programme of Psychology (DOPSY) that was a major support during these last four years. Their affiliate position provided opportunities and funding to educate myself over this period, and opened up avenues to network with other PhD students in psychology, as friends but also as colleagues and fellow professionals. I hope this network will continue its valuable work in the future. The doctoral school at the University of Eastern Finland, Life Course in Context, has also provided valuable seminars and contacts that have made the experience and my time at University of Eastern Finland fuller and richer. I would also like to thank the University of Eastern Finland’s Ethics Board for the chance to work with them and learn about issues one rarely encounters during doctoral work; although there is still plenty to learn, this work experience has advanced my critical and ethical thinking in my thesis work.

Last, but not least, my thanks to my family and friends who have indirectly been part of the thesis work. Finally, I would like to express that I have had the pleasure to work with extremely professional individuals, an opportunity for which one should be very grateful.

Helsinki, December 2016

Vesa Korhonen


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1 This thesis utilises text from the published articles in their current form, especially in the method and results sections.
# TABLE OF CONTENTS

**ABSTRACT** ........................................................................................................... 5

**TIIVISTELMÄ** ........................................................................................................ 7

**ACKNOWLEDGEMENTS** ......................................................................................... 9

**ORIGINAL PUBLICATIONS** .................................................................................... 10

1 **INTRODUCTION** ................................................................................................ 13

2 **PURPOSE OF THE STUDY** ............................................................................... 14

3 **LITERATURE** ....................................................................................................... 16
   3.1 Autism Spectrum Disorder ................................................................................. 16
   3.2 High support need and minimally verbal individuals with Autism Spectrum Disorder ........................................................................................................... 19
      3.2.1 High Support Need Individuals with ASD .................................................. 19
      3.2.2 Minimally verbal individuals with ASD ....................................................... 20
   3.3 Individual variation ............................................................................................ 21
   3.4 Benefits of using technologies in autism spectrum disorder research ............. 23
   3.5 Attention to eyes in autism ............................................................................... 25
      3.5.1 Attention to eyes .......................................................................................... 25
      3.5.2 Attention to eyes in autism .......................................................................... 26
   3.6 Attention to eyes in the present study ................................................................. 28

4 **RESEARCH QUESTIONS** ...................................................................................... 31

5 **METHOD** ............................................................................................................. 32
   5.1 Study 1: Review ............................................................................................... 32
   5.2 Studies 2 & 3: Game(s) .................................................................................... 32
   5.3 Studies 4 & 5 ..................................................................................................... 33
      5.3.1 Participants .................................................................................................. 34
      5.3.2 Game apparatus ......................................................................................... 35
      5.3.3 The task ...................................................................................................... 35
      5.3.4 Study 4: data collection by decisions ......................................................... 36
      5.3.5 Study 4: Design ........................................................................................ 36
      5.3.6 Study 5: Data collection by eye-tracking apparatus ................................... 37
      5.3.7 Study 5: Design ........................................................................................ 37

6 **OVERVIEW OF THE ORIGINAL STUDIES** ...................................................... 38
   6.1 Study 1 ............................................................................................................. 38
   6.2 Study 2 ............................................................................................................. 39
   6.3 Study 3 ............................................................................................................. 39
   6.4 Study 4 ............................................................................................................. 40
   6.5 Study 5 ............................................................................................................. 41

7 **DISCUSSION** ....................................................................................................... 43
   7.1 Main findings .................................................................................................... 43
   7.2 Evaluation of Results ....................................................................................... 44
1 INTRODUCTION

Heterogeneity within autism spectrum disorder (ASD) is widely recognised. In education and rehabilitation, individualised plans are commonplace and the person’s skills, abilities, weaknesses and strengths are mapped to provide the best possible service. In research, it is also common to map certain abilities, on top of diagnoses, to make comparisons between mental age, language age and chronological age. Standardised tests are used for these purposes. The test results allow us to rule out those factors that may influence the participant’s performance.

When an autism population has a variety of symptoms and comorbid characteristics, it becomes difficult to infer which parts of behaviour or features are due to autism and which are due to their differing symptoms. Due to the nature of autism, children and the task, it can be difficult to engage the child in a standardised manner; for example, the child may not understand the task, or the environment may present distractions or feel unfamiliar to him/her, or the child may have had bad experiences with previous tests and assessments.

Can we therefore make inferences and conclusions from a study that categorises individuals based on such tests or could we develop different methods, at least for the high support need and minimally verbal children with autism, who have the most individualised strengths, weaknesses and preferences? Is there a way of treating these individuals as a group or should we try to look at them as individuals?

When we have a heterogeneous group of people who have difficulties with language, social situations, and possibly, who have had bad experiences within those contexts and with research or testing, is it sensible to research these individuals using tasks based on group averages? Could we instead develop research methodology to account for the individual’s preferences and contexts, with tasks that are not designed solely for attentive and verbally typical individuals, who not only comprehend but also have no difficulty following all the instructions? If the research context and task are both difficult to concentrate on and to comprehend, are we perhaps expecting too much from the individual participating in research and making conclusions based on skewed data?

My thesis explores these aspects of individuals with high support needs by using a technology-based environment, which is known to be beneficial to individuals with autism. This exploration is attempted by using a game that has already been found to have a positive impact on children with ASD, to create a situation in which the individual is able to concentrate on the task. On top of this, I am concentrating on individual-level performance to address the question of heterogeneity that is emphasised by the high support need and minimally verbal children with autism.

In this thesis, in the interest of brevity, autism or ASD is used instead of ‘autism spectrum disorder’. Typically developed (adult) individuals and typically developing (children) individuals, usually the comparison group in research, are referred to by the acronym TDI.
2 PURPOSE OF THE STUDY

High support need and minimally verbal children with ASD receive less attention in research than their higher-functioning counterparts (e.g. Burack, Iarocci, Flanagan, & Bowler, 2004; Simmons et al., 2009; Grynzpan et al., 2013; DiStefano & Kasari, 2016; Whittaker, 2012). This may be due to the difficulty of finding a good control group (Burack et al., 2004), the group being a heterogeneous population (Jacobsen, 2000) or due to motivation, as the individuals have to sit through often tedious research procedures and tasks that may be linguistically challenging (DiStefano & Kasari, 2016; Blacher & Kasari, 2016; McGonigle-Chalmers, Alderson-Day, Fleming, & Monsen, 2013; Tager-Flusberg & Kasari, 2013). Therefore, and due to their need for assistance, these children have a need to be engaged and involved during research. Hence, research methodologies should account for motivation and engagement, as well as the heterogeneity of the group, both of which are discussed my thesis.

Technologies have been found to be motivating for individuals with ASD since the 1970s (Colby, 1973). Several reasons have been suggested for this, ranging from technologies providing a safe, controlled environment to having fewer social stimuli (e.g. Grynszpan, Weiss, Perez-Diaz, & Gal, 2013; Parsons, Leonard, & Mitchell, 2006; Wass & Porayska-Pomsta, 2013). Technologies have also shown the potential to discover abilities that standardised tests did not (McGonigle-Chalmers et al., 2013). Therefore, the development of a technology-based research approach was the focus of this research, in which the individual child’s preferences could be taken into account. I also wanted to utilise research results from previous studies to create a suitable task and environment for children with ASD.

Since absence of eye contact is one of the hallmarks of ASD and since eye contact is an important factor in developing social skills, language and ability functioning in a society, (e.g. Morales et al., 2000; Warreyn, Roeyers, Oelbrandt & De Groote, 2005), this thesis explores attending to eyes in the high support need and minimal verbal ability group. Research has already been conducted on higher-functioning individuals with ASD, and has shown discrepancies on deficits in related research in reflexive gaze following (Nation & Penny, 2008), perspective taking (Pearson, Ropar, & Hamilton, 2013) and in time spent attending to eyes (Guillon, Hadjikhani, Baduel, & Rogé, 2014; Papagiannopoulou, Chitty, Hermens, Hickie, & Lagopoulos, 2014).

It has been suggested that individual variation may be one of the causes for the mixed results in attention research (Ames & Fletcher-Watson, 2010; Bruinsma, Koegel, & Koegel, 2004). Variability in ASD has also been evident, for example, in rehabilitation (Kamio, Haraguchi, Miyake, & Hiraiwa, 2015) vocabulary event-related potentials (ERPs) (Coderre, Chernenok, O’Grady, Bosley, Gordon, & Ledoux, 2015) and in the rate of development of language in early life (Pickles, Anderson, & Lord, 2014). Since high support need individuals with ASD are more varied and heterogeneous as a group, my approach, in addition to using technologies to increase task engagement, used an individual-level analysis of performance. These methods may reveal more about the individual with ASD and also about autism as a whole.

Accordingly, the present set of studies scrutinised attention to eyes by exploring existing literature and developing a technology-based research method for high support need and minimally verbal children with ASD. Due to the discrepancies in previous research and the variability of individuals with high support needs, I wanted to eval-
uate children’s abilities on an individual level in contrast to group level performance. The approach I take is particularly important for the high support need and minimally verbal individuals, who are less often studied and about whom we therefore know less about, and who may be at a disadvantage and vulnerable in research settings due to their traits and personal histories from schooling and rehabilitation. The objective is not to generalise the results to all individuals with autism or to autism as a whole, but to provide an example of how to explore the abilities of individuals in a positive environment with the least amount of discomfort, regardless of the known difficulties.
3 LITERATURE

3.1 AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a neurodevelopmental disorder usually defined by three main characteristics or atypicalities in behaviour: impaired social interactions, impaired communication and stereotyped repetitive behaviours (e.g. Fakhoury, 2015). The individuals with ASD may experience failure to develop peer relationships, lack of engagement in play with others, problems with emotion recognition, generally poor social skills, and a tendency to evaluate meanings literally (e.g. APA, 2000; APA, 2013). Tantrums and other challenging behaviours that are frequently associated with autism are sometimes thought to be due to difficulties in social and communicative understanding.

The diagnosis of ASD is based either on the International Statistical Classification of Diseases and Related Health Problems manual, 10th revision, ICD-10 (WHO, 1992) or the Diagnostic and Statistical Manual of Mental Disorders, fifth revision, DSM-V, (APA, 2013). In Finland the ICD is used. In the ICD-10, ASD is defined as following: “A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities”. The DSM V defines the diagnostic criteria as: a) persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (including non-verbal communication and abnormal eye contact); b) restricted and repetitive patterns of behaviour, interests or activities (e.g. insistence on sameness, repetitive motor movements, fixated interests, hypo or hyperactivity to sensory input); and specifying the severity based on social communication and restricted, repetitive behaviour on a three-level scale. According to Lai, Lombardo and Baron-Cohen (2014), currently, identification can be made at around 6 - 24 months of age using early indicators for atypical development, deficits or delays, in reciprocal affective behaviour, response to own name, joint attention, verbal or non-verbal communication, repetitive behaviours, atypical visuomotor explorations etc.

Autism was first described by Kanner in 1943, and later, in 1944, by Hans Asperger (Haq & Le Couteur, 2004). The contributions of these pioneers to autism is well established, although similar but less detailed descriptions of the symptoms had been made earlier (Wing, 1997). Since Kanner and Asperger, theories of autism have varied but to date there is no single cause or theory to explain ASD and several theories have been debunked. Although Kanner already suspected a genetic link, he thought coldness and detached behaviour in mothers was the cause of autistic behaviour, which resulted in many negative emotions in the parents of children with autism (Wing, 1997). Similarly, Wakefield’s well-known claim that the Measles Mumps and Rubella (MMR) vaccine is linked to autism has been falsified (Taylor, Swerdfeger, & Eslick, 2014).

The incidence of ASD to date has been under review since the rate has increased from 1 in 5000 in year 1975, to the current rate of 1 in 88 or 1 in 68 (Centers for Disease Control and Prevention, 2014). The reasons for the increase have been hypothesised to be due to better access to healthcare, an increase in knowledge about ASD, the broadening of boundaries for the diagnosis, and earlier detection, but increasing risk
factors have not been ruled out (e.g. Lai et al., 2014; Rogers, 2008). Furthermore, it is found that boys are more often diagnosed than girls; the ratio ranges from 2.7:1 to 8.3:1 (Fombonne, 2009). Girls, on the other hand, are being under-recognised and found to be diagnosed later than boys, which may partially account for the sex difference (Lai et al., 2014).

A genetic link to autism was found in the 70s when a 36% concordance between monozygotic twins and a 0% concordance in dizygotic twins was discovered (Folstein & Rutter, 1977). More current findings from twin studies indicate that autism has heritability up to > 80% (Ronald & Hoekstra, 2011). However, no single gene has been identified to cause autism but several hundred to a thousand genes are reported to be linked to it (Lai et al., 2014). For example, in 2009, 154 genes were found to be linked with autism and 334 genes to be interacting with these genes (Wall et al., 2009). Due to the variability of the genes in ASD and the number of genes linked to it, the “many genes common pathways” hypothesis has become popular (Chen et al., 2015). It has also been suggested that evolution may have positively selected autistic traits as focus on detail may have served a purpose in terms of fixing things and acquiring information and resources (Baron-Cohen, Ashwin, Ashwin, Tavassoli, & Chakrabarti, 2009).

Apart from genetics and heritability there are other possible links to family, such as maternal and paternal age; maternal age above 35 increases the risk for ASD to 1.3 and 1.4 for a paternal age of above 40. The first-born children of older parents have a three-fold risk of ASD compared to the later-born children of younger parents: mothers 20-34, fathers > 40 (Durking, Michaud, & Mercier, 2008). Birth spacing has also been considered a risk factor: longer and shorter than typical interpregnancy intervals increased the rate of autism (Conde-Agudelo, Rosas-Bermudez, & Norton, 2016).

Before early interventions, 58 - 78% of adults with autism had poor or very poor outcomes for educational attainment, independent living, employment, and peer relationships (Lai et al., 2014). The cost of autism has been estimated, over the life of a child, at up to US $2.4 million per family (Buescher, Cidav, Knapp, & Mandell, 2014). These costs include special education services provided by psychologists and speech therapists etc. Studies also show that among individuals with autism, more than 70% have concurrent medical, developmental or psychiatric conditions (Lai et al., 2014), and that individuals with autism have 2.8 times higher mortality risk compared to unaffected people of the same age and sex (Woolfenden, Sarkozy, Ridley, Coory, & Williams, 2012).

To date, the most prominent theories include weak central coherence, executive dysfunction, systemising, impaired theory of mind and the extreme male brain hypothesis. Some of the currently known brain-based theories are closely related to these cognitive theories and include such theories as broken mirror neuron theory, neural systems disorder (a theory of frontal-posterior under-connectivity) and brain hyper-connectivity. These theories will be briefly described in the following paragraphs.

The weak central coherence theory was postulated by Frith (1989): 1) individuals with ASD have a bias to focus on the local properties of information and 2) express difficulties integrating the local properties of information into meaningful representations. With strong coherence, a person would have diminished attention to detail; in weak coherence the context would be neglected (Hill, 2004). For example, in retelling a story, one would concentrate on the overall idea of the story, and the other on the details of the story at the expense of the plot. However, not all individuals with ASD show this bias (Vanegas & Davidson, 2015).
The executive dysfunction theory, suggested by Ozonoff, Pennington and Rogers (1991), attributes cognitive and behavioural problems to deficits in planning, cognitive flexibility and inhibition. For example, when planning, children with ASD have problems in the Tower of Hanoi test, in which the participant needs to organise discs in certain sequential order. Difficulties in mental flexibility, the ability to shift to a different thought or action according to changes in a situation, can be tested using the Wisconsin Card Sorting test, where one needs to decipher the underlying implicit rule for sorting the cards (Hill, 2004). However, there are also mixed results, problems with replication and discrepancies between laboratory-based and real-life behavioural research with this theory (Vanegar & Davidson, 2015).

The systemising theory (Baron-Cohen et al., 2009) asserts that individuals with ASD acquire information through predictable associations and by following rules. This theory can be defined as the drive to analyse, understand, predict, control and construct rule-based systems. Similarly, the extreme male brain theory, based on biological differences between the sexes, infers that the driving force of autism is due to ‘empathising’ and ‘systemising’ (Baron-Cohen, 2002). It is thought that the male brain is more prone to systemising than empathising and the female brain has the opposite functionality, where empathising is about knowing others’ mental states and responses to affective states, and can be considered related to the theory of mind and mentalising.

The impaired theory of mind implies that individuals with ASD have difficulties understanding what the other person might be feeling or thinking (Baron-Cohen, Leslie, & Frith, 1985). A test often used to test this is the Sally-Ann test, in which a doll hides something, either in view of another doll or when the other doll does not witness the act of hiding. Individuals with ASD are more likely to fail to understand that the other doll does not know where the hidden object is when s/he was not present during the hiding. This theory could explain why a person has difficulties with social communication and taking the other person’s perspective.

The cognitive theories have similarities to the brain-based theories. For example, “mirror neurons” refers to neural systems that react similarly to an action and seeing that action being done (Rizzolatti & Craighero, 2004). The mirror neuron system is believed to be at the core of action understanding and imitation, and the broken mirror neuron system is thought to cause difficulties in social cognition, which could be why the theory of mind does not develop (Hamilton, 2013).

The under-connectivity theory postulates that in comparison to TDI, the brain’s degree of synchronisation of activity between frontal and posterior regions is lower, for example, during language comprehension tasks, and visuospatial processing, high-level inhibition, social processing, executive function and working memory function (Just, Keller, Malave, Kana, & Varma, 2014). Overall, this theory postulates that due to the lower connectivity, the lowered information flow will cause deficits in tasks that require frontal and posterior regions. The Hyperconnectivity theory of ASD, on the other hand, is considered at the whole-brain and subsystems levels, and across long and short-range connections, and has been linked to higher levels of fluctuations in regional brain signals. Hyperconnectivity has been predictive of the severity of symptoms in ASD, for example, the children with higher connectivity had more social impairments (Supekar et al., 2013).

Regardless of the theories presented and the myriad other theories of ASD there is still no theory that can explain all the symptoms caused by autism. In this thesis I take no stance on the theoretical underpinnings of the aetiology of autism but rather
acknowledge that symptoms may vary regardless of similar genetic or non-genetic background. This variation may be attributable to test methodology, individual variation, or even as Lopez (2015) hypothesised, cultural or social factors and contexts that may influence, through a cascading effect, the trajectories of the cognitive and brain development of individuals with autism. I have somewhat narrowed my research to look at a certain ability at a single point in time, with an emphasis on individual variability within a specific context.

3.2 HIGH SUPPORT NEED AND MINIMALLY VERBAL INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

In this thesis, I will be concentrating on high support need (Strnadová, Cumming, & Marquez, 2014) and minimally verbal (Kasari et al., 2013) individuals with autism. There are methodological and ethical reasons for conducting research within this group. It is also a group that is difficult to categorise and describe: the definitions for high support need and lower-functioning children with ASD are manifold. I am using the term high support need in this thesis as “lower-functioning” has negative connotations and has raised some concern among individuals with ASD and people working within the field. “High support need” is used as it provides a descriptive way of defining individuals who may be difficult to test using standardised tests. It also allows the use of more varied categorisations that are not limited to, for example, mental or language age. “Severe autism” and “lower-functioning ASD” were not used as their definitions are sometimes very narrow; for example, by using IQ score to define lower functioning (Reichow, Servili, Yasamy, Barbui, & Saxena, 2013). Firstly, I will begin by briefly describing “high support need” as term, and then define and describe what is meant by “minimally verbal children”.

3.2.1 High Support Need Individuals with ASD

“High support need individual with ASD” describes a person who has autism as a diagnosis and can have developmental disabilities (Lyons & Cassebohm, 2012; Strnadova et al., 2014). These individuals have difficulties with learning; their education has numerous challenges and they are reliant on assistants and/or assistive technology. The individuals also have a variety of communication, sensory and/or physical disabilities, and are sometimes referred to as individuals with “profound disabilities” (Arthur-Kelly, 2008; Strnadova et al., 2014). They are highly dependent on others, have difficulties interacting with their environment, and need assistance, for example, with eating and hygiene. They also often have behaviour that is experienced as challenging by their surroundings, and have individualised educational programmes (Strnadova et al., 2014).

It is thought that at the expense of high support need individuals with autism, their higher-functioning counterparts, with average or above IQs and typical linguistic abilities, are more involved in research (e.g. Kylliäinen et al., 2014; Tager-Flusberg & Kasari, 2013; Simmons et al., 2009). This may be due to the ease of matching (Burack et al., 2004; Jackobsen, 2000) or merely down to the fact that higher-functioning individuals are good at concentrating, understanding instructions, and sitting still for longer periods of time. An example of this bias is a study by Grynszpan, Weiss, Perez-Diaz, and Gal (2013). In
their metastudy on technology-based interventions, they found that in 67.8% of studies the IQs of participants were average or above. Similarly, it was found that in the past, children with lower IQs (<60) were systematically excluded from research as they were not considered to have pure autism (Whittaker, 2012). This bias is probably even more extreme in the high support need population. Since 50% of the ASD population have lowered IQ, research may neglect a significant portion of individuals.

Furthermore, since high support need or lower-functioning children are children for whom standardized testing is not always suitable (e.g. McGonigle-Chalmers et al., 2013) they may therefore also be left out of research and, moreover, their results in tasks may not reflect their skills. They should also be more involved in research because these individuals require the most care during their lifetimes and hence more research on their functioning should be conducted in order for methods to develop.

3.2.2 Minimally verbal individuals with ASD

Autism is associated with atypical language (APA, 2000). It has been estimated that 50% of individuals diagnosed with ASD do not develop a useful spoken language (e.g. Pickett, Pullara, O’Grady, & Gordon, 2009). Some studies suggest that the rate is currently at around 30%, which may be due to earlier interventions (e.g. Anderson et al., 2007; Tager-Flusberg & Kasari, 2013). Similar to high support need children with ASD, a paper by Kasari et al. (2013) states that minimally verbal children have been left out of studies and hence little is known about this group. Therefore, current research methodology is not developed to consider their special characteristics.

Minimally verbal children have a specific expressive language deficit and not an earlier developmental stage of language (DiStefano & Kasari, 2016). Only after reaching the typical milestones of language development and combining words into functional sentences can children be characterised as minimally verbal, which means that minimally verbal children are typically school aged (DiStefano & Kasari, 2016). For example, in the study by Skwerer et al. (2015) only children older than five years of age were included, because being minimally verbal implies the failure to develop fluent spoken language by school age.

Tager-Flusberg and Kasari (2013) found that minimally verbal children have several definitions in research literature. For example, they found that Romski et al. (2010) defined children as non-verbal if their Mullen expressive language score was below 12 months, and they expressed fewer than ten intelligible, spoken words. Yoder and Stone (2006) referred to preschool children as non-verbal/low verbal if they used fewer than 20 different words, and Kasari, Paparella, Freeman, and Jahromi (2008) described children as low-verbal (3-4 years old) if they spoke five words or fewer during observation and standard assessments. At other times, the term may mean that expressive language is extremely limited, with the use of only a couple of words and fixed phrases; it may also be used to describe minimally verbal children with some spoken language but this is primarily echolalic, stereotyped or scripted. Kasari et al. (2013) gave a definition for the minimally verbal in which they emphasised the small number of spoken words, fixed phrases, context dependent speech, echolalia, requests, and small phrases that may have been well rehearsed.

These definitions, however, may be misleading in terms of communicative abilities as individuals may be able to use alternative language, even sign language or written language, or picture exchange communication systems (Kasari et al., 2013). There is
also evidence that children over the age of five do learn how to speak or will start to speak, contrary to the popular belief that the age of five is a significant or critical time. Pickett et al. (2009) found that between 1951 and 2006, there were 167 cases of children who started speaking after age five. One should also consider that these children may be preverbal rather than non-verbal/low-verbal. The percentage of children who are preverbal before preschool and will be non-verbal or minimally verbal after preschool is around 25-30% (Andersson et al., 2007).

High support need and lower functioning children with ASD can have profound impairments in the domains of language and social cognition (e.g. Hartley & Allen, 2013). It is therefore also worth noting that language and IQ can be separate issues: IQ is not always associated with expressive and receptive language skills. For example, some children who do not acquire spoken language have lower IQs and others do not, and the same is true with children who have low receptive and expressive language skills: others have minimal expressive but good receptive language skills (Tager-flusberg & Kasari, 2013). Furthermore, this shows that no single reason exists for why some children do not learn to speak.

In general, the term “minimally verbal” has not been consistently used. Sometimes it refers to individuals with no spoken language but with non-speech sounds, whereas in other studies it means to be able to apply few words and/or fixed phrases, such as “want x”, or it may refer to echolalic or non-communicative language, while in some cases these children may be able to use alternative communication such as sign language, picture exchange communication systems, or written language (Tager-Flusberg & Kasari, 2013). Overall, skill variations in language comprehension is vast in minimally verbal individuals as some comprehend more than single words but others cannot understand more than a limited number of words (Skwerer et al., 2015). In this thesis, I will be using the somewhat wider definition of minimally verbal by Kasari et al. (2013) in according to which children have a small number of spoken words, fixed phrases, context dependent speech, echolalia, requests, and short phrases.

### 3.3 INDIVIDUAL VARIATION

According to Kasari et al. (2013) it is already recognised that great heterogeneity within the autism population is not only present in core symptoms but is also seen in comorbid features. The vast variations are predominantly seen in IQ and language, ranging from absence of these abilities to possessing superior abilities. For example, Burack et al. (2004) concluded that in intelligence, the ASD population varies from extremely intelligent to having intellectual disabilities; a person with the same intelligence score may have a very different set of skills although overall scores are the same. In general terms, Jacobsen (2000) inferred that the heterogeneity of the non-high functioning ASD population makes them difficult to research.

Burack et al. (2004) also emphasised the fact that each person with ASD has had a very different life due to his/her diagnosis, behaviour, social interaction, schooling and education, and especially due to their differing skills. The performance of individuals with low IQs is affected by their life experience of everyday tasks, which is particularly influential in artificial and unfamiliar testing situations. More than for TDI, previous failures, dependence on others, motivation to perform and wariness of others due to past experiences influences the way a person with ASD performs during research. Their impairments are also seen in social and language-related contexts and may
appear in different ways in different individuals. One individual may have problems with functional language whilst others have typical language functioning, but both may receive an ASD diagnosis based on their social and communication skills.

Additionally, Kasari et al. (2013), DiStefano and Kasari (2016) and Skwerer et al. (2015) noted that individualised methods may be the best option since standardised tests may not show more than floor effects. For example, due to not comprehending the task’s instructions or logic, or due to the context, it is difficult to engage the child in the task. The examiner may not be responsive enough, the environment can have distractions, or be unfamiliar, frustration may increase as the task gets more difficult and the possible lack of motivation for the test, that may be due to test anxiety, can influence the child’s performance. Burack (2004) notes that standardised measures may be easiest to administer, and are hence often used, but the results may not reflect the functioning they are intended to measure. For example, the Peabody Picture Vocabulary Test–Revised (PPVT-R), which is often used for matching purposes, was criticised as it does not capture the linguistic abilities that are needed to understand and perform the task, even with minimal language requirements. This may cause the results to indicate different skills or lack of skills in the ASD population in comparison to the typically developing group. This is even more pronounced in the one-word receptive vocabulary test since performance is often higher than in general or specific language functioning, which would overestimate their abilities.

Dereu, Roevers, Raymaekers and Warreyn (2012) found that performance on joint attention tasks varied considerably even when looking at an “at-risk” group of ASD. Another good example of individual variation in children with ASD showed that even though no differences were found in task performance when using a person as an instructor vs. when using computerised instructions, there were more negative behaviours when a person gave the instructions. Interestingly, however, it was also found that some children were better with person-based and others with computer based instructions (Plienis and Romanczyk, 1985). Similarly, Ploog et al. (2013), for example, inferred that any technology to be used with individuals with ASD should be adjustable to the differing needs of different individuals, and in attention research it has been suggested that individual variation may account for their discrepant results (Ames & Fletcher-Watson, 2010).

In neuropsychology it is often the case that it is almost impossible to find a group of individuals with the same impairments. Hence, group studies may not be applicable since it is the individuals’ abilities that are attempted to be clarified - and therefore single case studies are conducted. According to Crawford (2016) there are three approaches to single case studies. The first is the standardised method with normative data. The second is where no control or normative data is used to compare the individual’s behaviour and looks solely at the intra-individual comparison. The third method uses a control sample. The first method is a good measure but sometimes too time consuming with new developments in science (Crawford, 2004). The problem with the second method is that discrepant results are received on within-individual analysis vs. control performance (Laws, Gale, Leeson, & Crawford, 2005). Therefore, a case-controls method in statistics was developed in which an individual’s performance can be compared to a control group (Crawford & Howell, 1998; Crawford, Garthwaite, & Porter, 2010).

The case-controls method uses a modified t-test to analyse differences in performance between an individual and a group. It also applies interval estimates (credible intervals), on top of point estimates of effect sizes, in other words, using the same criteria
as is expected in group-based research (Crawford et al., 2010). The method resorts to Bayesian method as they both (Classical and Bayesian) provide similar intervals, based on the Crawford et al. (2010) theoretical and empirical evidence. Crawford et al. (2010) also suggest the Bayesian method to be less complex and difficult follow: the interpretation is closer to what a single case researcher is attempting to say: “there is a 95% probability that the effect size lies within the stated limits” rather than “if we could compute confidence intervals from a large number of control samples collected in the same way as the present control sample, about 95% of them would contain the true effect size”.

In this thesis, in the case of high support need and minimally verbal children with ASD, we resort to the case-controls analysis method in order to see how each individual’s abilities compare with TDI.

3.4 BENEFITS OF USING TECHNOLOGIES IN AUTISM SPECTRUM DISORDER RESEARCH

In this thesis I was interested in the use of technology as it is considered a positive context for individuals with ASD and hence also a good platform for research. I will refer to technology to mean electronic items or equipment, applications or virtual networks, the same definition used in the Odom et al. (2015) study. Technologies nowadays can be anything from desktop computers to robotics, for example, interactive video/DVD, handheld devices, internet-based collaborative environments, gaze-contingent displays, active surfaces, software tools, speech-generating devices and virtual reality, and many more (e.g. Grynszpan, 2013). All of these have been used, for example, in interventions and education in ASD, since 1973 when Colby published one of the first studies using a computerised method in language training for ASD.

Grynszpan et al. (2013) infer that computerised tasks and technologies have advantages, especially for individuals with ASD, such as consistency, the possibility to repeat the task at their own pace, clearly defined tasks, specific focus of attention due to reduced distraction from other unprecedented sensory input, and fewer social distractions (Grynszpan, Weiss, Perez-Diaz, & Gal, 2013; Parsons et al., 2006; Wass & Porayska-Pomsta, 2013). Technologies are often free of social demands, have instant, predictable feedback, provide the user with repeatable responses, and can use visually cued instructions. The possibility of repetition can evoke feelings of independence, success and self-sufficiency, and can also reduce the number of personnel needed in healthcare or in education (Wass & Porayska-Pomsta, 2013).

Motivation may be the key element in using technologies with individuals with ASD, as was found by Dweck (1984), who noted that people perform better when feeling secure and motivated. Furthermore, motivation and curiosity are found to produce the best outcomes in learning (e.g. Gruber, Gelman, & Ranganath, 2014). Moreover, feeling motivated and secure is particularly important to students with learning difficulties (Hart et al., 2004; Korhonen, Linnanmäki, & Aunio, 2014; Silinskas et al., 2016). Another motivating aspect of a game environment is that we can control the amount of perceptual load by sound, visual complexity, task complexity etc. which is something we are less able to do in a real world setting. Overall, studies have shown that video games can improve information processing, spatial imagery, motor skills, and auditory and visual processing (Powers et al., 2011).

Wass and Porayska-Pomsta (2013) inferred from an experiment by Duquette et al. (2008) in which they found that when exposing lower-functioning children with
ASD to a robot imitating their facial expressions, body movements and familiar actions, that this led to better shared attention and imitation with their robot than when the same was done with a human child. Bishop (2003) noted that technologies have the ability to be used individually and for different kinds of abilities, and Parsons et al. (2006) found that virtual environments can be used in small-group social skills teaching sessions as prompts. In addition, Chen, and Bernard-Opitz (1993) found that computerised instructions for 4-7 year old children with ASD were more enjoyable, supported enthusiasm and produced superior task performance in comparison with teacher-based instructions: overall, the finding was that fewer behavioural problems were present with the computerised method, however, no improved learning was found, and only one out of four children showed better learning in the computerised environment. Similarly, Kodak, Fisher, Clements, and Bouxsein (2011) found that for one-on-one instructions in a labelling task, a computerised method was superior, which meant an increase in independent responding, but no influence on the rate of correct responding.

Regardless of the benefits, however, Wass and Porayska-Pomsta (2013) noted that the paradox here is that as much as the simplified computerised environment is enjoyed, it is probably also the reason it is harder to transfer these skills to real world. Nevertheless, one could use this as a stepping stone to real world training or by simply increasing the amount of perceptual load and amount of sensory stimuli in the computer environment to accustom the person to the real world. Wass and Porayska-Pomsta (2013) also emphasised in their conclusion that technology is no different from a book, and it is not without a context in which it is being used - different forms of interaction with it may bring very different results, even opposing ones. Computerised cognitive training has had difficulties in generalising to naturalistic settings (Wass & Porayska-Pomsta, 2013). This is called “distal transfer”, meaning generalising what is learned to other contexts outside computerised tasks. It could be that it is not that these children cannot re-apply the skills in a different context but the context may be too noisy or overwhelming for them in the real world (Wass & Porayska-Pomsta, 2013): this finding is being backed up by studies finding that abnormal neural connectivity can lead to a “noisier” brain, which is not able to filter out signals from noise (Wass, 2010).

There are a few other issues that need to be addressed when discussing technologies. Their potential vs. their effectiveness, and the number of hours we should devote to technologies in our lives. In their meta-study, Grynszpan et al. (2013) inferred that there is evidence of effective technology-based interventions, but that there are still many studies that need methodological revision in order to be able to make this statement. They found, similar to Parson and Cobb (2011), that most papers emphasise potential rather than effectiveness. It was not considered a problem since technologies and their availability are growing rapidly; new software is becoming easier and faster to produce and hence there is more of it to be trialled. A meta-analysis identified the effectiveness of technology-based training for children with ASD, and also found the effect of IQ or age to be non-significant (Grynszpan, Weiss, Perez-Diaz, & Gal, 2013).

Another issue, the increase in time spent on computers and the increase in obesity in the western world has been seen to make gaming more physical in nature (Must et al., 2013). Xbox®, for one, has developed games with physical activity through their Kinect® sensor, detecting body movements during gaming by projecting the game and player onto a white screen. Positive results using Xbox Kinect® are seen in the treatment of Ataxia (Ilg et al., 2012), in physical rehabilitation (Vernadakis, Derri, Tsit-
skari, & Antoniou 2013), Parkinson’s disease (Pompeu et al., 2013), and it also been found to be motivating for children with ASD (Munson & Pasquel, 2012). Physical exercise, on the other hand, has been found to improve, for example, memory and executive functioning (Best, 2011; Pesce, Crova, Cereatti, Casella, & Bellucci 2009; Ruscheweyh et al., 2011), attention (Colcombe et al., 2004), and long-term systematic physical activity, including walking, is linked with better cognitive function and less cognitive decline in older women (Weuve et al., 2004).

Accordingly, I decided to use technology as a platform for my research and to gain the additional benefits of Kinect® technology of decreasing sedentary lifestyle and increase the added benefits of physical movement. The attempt is not to generalise the results to naturalistic settings but to explore how to develop a research method for high support need children with autism in an enjoyable context.

3.5 ATTENTION TO EYES IN AUTISM

3.5.1 Attention to eyes

Paying attention to eyes and eye contact is a vital part of human interaction. Looking a person in the eye makes us perceive information about their attention: we know what they see and cannot see (Pearson et al., 2013). It has been thought that eye morphology and making eye contact may have proven useful for hunting purposes or for knowing when a possible threat is approaching (e.g. Kobayashi & Kohshima, 2001). The eyes and their surroundings can also communicate information about important mental states to others, for example, emotions, desires, dominance, attentiveness, competence and beliefs, which helps us to function in the social world (Frishchen, Baylis, & Tipper, 2007).

Eye gaze may be perceived and intended to convey positive, negative or neutral information depending on the context. For example, direct gaze is used to regulate conversation shifts and to represent social interest, and long gaze can result in avoidance behaviours; however, the same gaze in a different context can be a sign of love and attraction (Hamilton, 2015). Eye gaze can change behaviour and physiological response. For example, people pay nearly three times more for a coffee at a university coffee room if there is a pair of eyes in a visible photograph (Bateson, Nettle, & Roberts, 2006), another person’s direct gaze can change skin conductance (Hietanen, Leppänen, Peltola, Linna-aho, & Ruuhiala, 2008) and direct gaze causes greater brain responses than averted gaze, even if the person only believes that they can be seen (Myllyneva & Hietanen, 2015). It has been proven that a face with a direct gaze is also detected faster than faces with an averted gaze; regions of the brain that are sensitive to social information respond stronger to faces with a direct gaze in comparison to an averted gaze (Mares, Smith, Johnson, & Senju, 2015). Senju and Johnson (2009) and Akechi et al. (2014) suggest that this eye contact effect may involve a rapid subcortical face detection pathway and its disruption may change or slow down the development of social cognition.

Our ability to follow eye gaze is often considered to be an innate skill and its development can be followed (as reviewed in Nation & Penny, 2008): neonates prefer faces with eyes open rather than closed and look longer at faces displaying direct gaze. At two months, the eye regions of the face are preferentially scanned and by four months gaze direction can be discriminated. By six months, children orient to gaze at
an object that is in their visual field looked at by another person, and by ten months infants follow head turns and gaze shifts spontaneously, even when the objects are not in their visual field. By ten months, the following of head turns when the eyes are open is more likely to occur than when they are closed. At 18 months, infants can accurately follow eye gaze, regardless of whether the target is nearby or far away, or irrespective of their location relative to the other person.

3.5.2 Attention to eyes in autism

In individuals with ASD, impairments in establishing and maintaining eye contact is often considered to be one of the earliest signs of ASD and are also thought to be associated with the social deficits seen in ASD (APA, 2013; WHO, 1992; Jones, Carr, & Klin, 2008; Jones & Klin, 2013). One of the first eye-tracking studies, which focused on attention to eyes in individuals with ASD, found a reduced fixation on the eye region (Pelphreys et al., 2002): when using an emotional faces viewing task, it was found that if no specific instructions were given, the five male adults with ASD showed less fixation on the eyes compared to TDI. There are, however, mixed findings: individuals with ASD are indeed less likely than TDI to look at the eyes of another person (Papagiannopoulou et al., 2014), and yet others concluded that only a few studies found reduced attention to eyes in individuals with ASD (Guillon et al., 2014).

A recent eye-tracking study found that adolescents with ASD have a preference for social stimuli similar to TDI, but not when the stimuli approached them (Crawford, Moss, Oliver, Elliot, Andersson, & Mc Cleery, 2016). Similarly, children with ASD have shown similar disengagement from faces as TDI when the task instructed attending to the eyes, but still showed atypical ERPs (Kikuchi et al., 2011). Event-related potentials (ERPs) have also indicated TDI s' preference for direct gaze versus averted gaze; however, for infants later diagnosed with ASD this was not the case (Elsabbagh et al., 2012).

There is also evidence indicating that children with ASD, in a visual search task, perform similarly to TDI, and both groups were faster to detect upright faces with direct gaze than with averted gaze, but only children with ASD performed faster with inverted faces (Senju, Kikuchi, Hasegawa, Tojo, & Osanai, 2008). However, mutual eye gaze does not facilitate performance in gender discrimination (Pellicano & Macrae, 2009) or in facial memory task (Zaki & Johnson, 2013) in individuals with ASD. Furthermore, autonomic arousal responses to direct gaze in ASD have been found to be associated with impairments in social communication and language (Kaartinen et al., 2012).

With cartoon faces, no differences were found in attending time compared to human faces in individuals with ASD (e.g. Riby & Hancock, 2009). When investigating animated faces with direct and averted gaze in individuals with ASD, averted gaze activated the social parts of the brain networks, whereas this happened in TDI with direct gaze (Von dem Hagen, Stoyanova, Rowe, Baron-Cohen, & Calder, 2013).

The subcortical areas related to unconscious processing of eye contact may be impaired or altered in ASD (Akechi et al., 2014). Therefore, it may be the unconscious processing of eye contact that is altered in ASD. Furthermore, in a subliminal condition, individuals with autism did not show the gaze cueing effect, but did so in a supraliminal condition (Sato, Uono, Okada, & Toichi, 2010). A recent finding was that gaze direction detection has been found to be less accurate in ASD, suggesting that gaze-following precision could also be one of the underlying reasons for eye contact and interaction difficulties (Forgeot d’Arc et al., 2016).
In this thesis, I was interested in exploring the methodology used for detecting diminished visual joint attention, one of the earliest signs of autism, and creating a computerised game-like research methodology for studying attending to eyes. In the next section, I will provide a short description of joint attention. I will also introduce looking to the eye area, visual perspective taking and reflexive gaze following, which are closely-related abilities that are atypical in individuals with ASD, but must be considered when developing a game to research attending to eyes.

**Visual joint attention (JA)**

Joint attention is the ability to look in the same direction as someone else or to draw others’ attention to an object or an event. The former refers to responding to JA and the latter to initiating JA (e.g. Bruinsma et al., 2004). It is the interaction between eye contact and another location - the person looking at another person looking at the third location. The two individuals have intentionally coordinated the JA to the location - they both jointly attend the same thing with awareness. Intentional action excludes passive and accidental JA, which may occur when one is not aware of another’s attention, or when attention is parallel but independent of the other person. In other words, JA requires active participation by both parties and communication about the JA through, for example, a mutual sharing look (Leavens & Bard, 2011; Carpenter & Liebdal, 2012; Tomasello, 2008). Joint attention is considered an important skill from a very early age for socialising between children and caregivers (Charman, Baron-Cohen, Swettenham, Baird, Cox, & Drew, 2001; Morales et al., 2000; Warreyn et al., 2005). Impaired JA in autism is thought to be due to lack of social reading ability (the social reading hypothesis) or the inability to decipher where the eyes are pointing at (the feature correspondence hypothesis) (Ristic, Mottron, Friesen, Iarocci, Burack, & Kingstone, 2005).

**Looking at the eye area**

Looking at the eye area is simply studying the amount of time a person spends looking into the eyes (e.g. Guillon et al., 2014). For example, time can be viewed in a specific task in which eye contact is crucial, or in free viewing in which the person has no named task at hand. It is often thought that attention to eyes is impoverished in individuals with ASD and that they dwell less on the eye area, which may lead to problems in learning social communication.

**Visual perspective taking (VPT)**

Visual perspective taking has two levels. VPT 1 is the skill of judging what another person can and cannot see, for example, whether an item is occluded from their line of sight or, for example, a toy behind another toy or a person (Pearson et al., 2013). This skill helps one to understand that other people may be able to see different things, and when turning in different directions they are no longer able to see the same things. These tests can be passed by typically developing two-year-olds. Level 2 VPT refers to the ability to understand that the other person sees the object differ-
ently, depending on the point of view. Even adults have shown difficulties with level 2 tasks in naturalistic contexts (Moll & Tomasello, 2004, 2006; Pearson et al., 2013). Baron-Cohen (1989) studied perspective taking in children with autism using a line of sight experiment in which the children were asked to pinpoint what the experimenter was looking at. They found that most children with autism passed this test, similar to TDI. More recently, perspective taking has been studied, for example, by Falck-Ytter et al. (2012) and Riby et al. (2013), in tasks in which children needed to see where the other person was looking. Falck-Ytter et al. (2012) found that children with ASD show less accurate gaze following (correct/incorrect gaze shifts) and made fewer correct gaze shifts than typically developing children when looking at gazed-at items. Riby et al. (2013) found that children with ASD looked less at the face and eyes, were not as accurate at naming gazed-at items as controls and even when cued, children with ASD did not spend more time looking at the gazed-at objects.

Overall, it is thought that perspective-taking ability is associated with empathising and the ability to understand the other person’s point of view (Mattan, Rotshtein, & Quinn, 2016). Studies on perspective taking have found both intact and impaired ability in individuals with autism (Pearson et al., 2013). Additionally, in TDI, if one assumes that a virtual character cannot see due to a blocking opaque glass, it affects their gaze following, which indicates that cues are social in nature since the participants’ knowledge of the virtual character’s ability to see influenced their gaze following (Teufel et al., 2010). However, other studies have found that obstacles in the line of sight did not influence gaze following (Cole, Smith, & Atkinson, 2015).

Reflexive gaze following (RG)

Reflexive gaze following means that human beings have a tendency to look in the same direction someone else is looking (Nation & Penny, 2008). This is demonstrated by presenting a picture of a face with gaze to the left or right: the participants are faster to detect the target that subsequently appears in the direction of the eye gaze (or head orientation) in comparison to the non-gazed-at location (e.g. Frischen et al., 2007). We can separate gaze following from joint attention: without communication attention is unidirectional and can be described as the use of a cue by another person (Tomasello, 2008). It distinguishes itself from perspective taking as reflexive gaze following is an attentional shift, whereas in perspective taking the person is mentalising what the other person is seeing (Bukowski, Hietanen, & Samson, 2015). The results from reflexive gaze found that reflexively orienting to eye gaze is intact in individuals with ASD (Kylliäinen & Hietanen, 2004) which is true even when joint attention is found to be impaired (Chawarska, Klin, & Volkmar, 2003). A review, however, found discrepant results in studies on reflexive gaze following in individuals with ASD (Nation & Penny, 2008).

3.6 ATTENTION TO EYES IN THE PRESENT STUDY

I chose to explore attending to eyes in high support need and minimally verbal children as this has not been studied before, to my knowledge. I began by reviewing previous research in impaired JA in autism, a skill requiring eye contact that is important for human interaction. I reviewed JA literature to analyse the generality of the JA
impairment and to explore what methodologies had been used in the past. Based on the research methodology findings, I then designed a computer game not requiring verbal responses to see if high support need and minimally verbal children with ASD attend to eyes similarly to typically developing children.

As attending to eyes is a crucial part of joint attention, a game (in which attention to the eyes of a virtual character was mandatory to find a correct box on the screen) was designed and produced. In this thesis I was interested in exploring computer games to support and engage high support need and minimally verbal children with ASD in research, to further explore their skills. By using a computer game to engage the children, I wanted to see if attention to eyes is impaired in comparison to typically developing children. A similar task approach has been recently trialled on a group level with ASD and verbal abilities; receptive language was studied using eye-tracking systems and hence no verbal response was required. The child’s ocular responses to an image or words were recorded using eye tracking (Bavin et al., 2014; Venker et al., 2013).

In my game, the data collection was planned so that the children did not have to actively answer questions or do tasks that seemed irrelevant to them. The players’ correct and incorrect decisions were recorded to see if they chose the boxes randomly or according to where the virtual character was looking. Using an eye-tracking system, we also recorded the duration of time each player spent in the eye area to see if there were temporal differences in attending to eyes between children with ASD and TDI. Each child’s performance was analysed separately and compared with a typically developing control group. I concentrated on individual-level analyses to detect individual performance, which has been suggested to influence attention research on a group level (e.g. Ames & Fletcher-Watson, 2010; Bruinsma et al., 2004).

As mentioned earlier, people generally perform better if they feel secure and motivated, which is particularly important to students with learning difficulties, and in learning the best outcomes are connected to motivation and curiosity. Since computerised procedures are useful for individuals with ASD, I wanted to explore computers as a methodology for research; however, I altered a computer game with a positive user experience for the task.

To further increase motivation and engagement, I used changeable visual stimuli as acknowledgement of children’s personal interests, as their preferences have been found to enhance assessment, academic and social skills performance (e.g. Baker, 2000; Boyd, Conroy, Mancil, Nakao, & Alter, 2007; Charlop, Kurtz, & Casey, 1990; Jacobsen, 2000; Kryzak & Jones, 2014; Mancil & Pearl, 2008; McGonigle-Chalmers et al., 2013; Naoi, Tsuchiya, Yamamoto, & Nakamura, 2008; Vismara & Lyons, 2007). In this game approach, a context with a positive undertone can be created and it is also possible to look at each individual separately.

I concentrated on JA, VPT ability and time looking at eye area. I first reviewed the JA literature to explore the extent of its impairment and the assessment methodology, after which I designed a computer game testing this ability. However, I defined the task as perspective-taking because in the game I will present later, there cannot be joint attention, per se. This is because the virtual character who the player needs to look in the eye is not interactive; hence, the player and the virtual character do not know together what the other person sees and do not communicate their shared attention (e.g. Carpenter & Liebal, 2012).

Nevertheless, the JA review enabled us to see the value in individual-level analysis and that preference-based tasks were not commonplace, both of which guided us to
see their importance in the game design process. However, since designing a simple game with a clear JA task was found to be troublesome due to the virtual character and its ability to interact, I designed a task that had a crucial component of JA: attention to eyes. The task became a VPT task in which attention to eyes and line of sight are as crucial as they are in JA. The task is similar to the one in the Baron-Cohen (1989) and Warreyn et al. (2005) studies in which the participant identifies what object the experimenter is looking at. These tasks were classified as level 1 VPT, and suggested to be the clearest way to assess VPT1, by Pearson et al. (2013) in their review on VPT.

The task could also be seen as declarative or imperative joint attention in which the virtual character’s gaze is just a means to an end to get the other person to do something (Carpenter & Liebal, 2012). In a similar approach, however, a virtual character’s eye and pointing prompts were categorised as JA (Alcorn et al., 2011). One could also consider the task as reflexive gaze following, since the eye cue is merely pointing to the right direction in our game, working as a gaze cue. For the purposes of this thesis we define this as a level 1 VPT task, whereby a player must look at the eyes of a virtual character to infer which one of the three boxes s/he needs to open.
4 RESEARCH QUESTIONS

The research questions of this thesis were:

1. How common is joint attention impairment in children with ASD (study 1)?
2. What methods have been used to assess joint attention in children with ASD (study 1)?

After the review, the aim was to develop a game (study 3) based on a pre-existing game that produced a positive user experience in children with ASD (study 2) as a method to research attending to eyes, a crucial part of joint attention. These two studies (2 & 3) were descriptive of the game development process. In studies 4 & 5, I analysed the children’s game performance. Accordingly, the following questions were explored:

3. Do high support need and minimally verbal children with ASD find the correct box to open in the game, at better than chance level, when attention to the eyes of a virtual character is needed to do so (study 4)?

The following were specifically scrutinised:

4. Do high support need and minimally verbal children with ASD, as individuals, make more errors finding the box than typically developing children (study 4)?

5. Do children with ASD have shorter attending time to eyes when making correct decisions in comparison to the controls (study 5)?
5  METHOD

The set of studies presented in this thesis each fulfilled a purpose in terms of exploring attention to eyes. First, a decade of research was systematically reviewed to gain an overall picture of the research on joint attention. The next two studies described how the games used to explore attention to eyes in this thesis were developed. In the fourth study I utilised the choices children made in the game to reveal if the task was understood and how they performed in relation to TDI. Finally, in the fifth study, eye-tracking methodology was used to explore the locus and time of the children’s attention for decision making in comparison to TDI. The overall methodology applied in the analyses of the children’s behaviour and eye movements represented an individual approach in which one person’s results can be compared to those of a group of people.

5.1  STUDY 1: REVIEW

The literature review was based on the guidelines of American Psychological Association (2010). They define literature review as the following “critical evaluations of material that has already been published...authors of literature reviews consider the progress of research toward clarifying a problem. In a sense, literature reviews are tutorials, in that authors define and clarify the problem, summarize previous investigations to inform the reader of the state of research, identify relations, contradictions, gaps, and inconsistencies in the literature, and suggest the next step or steps in solving the problem.”. Previous review articles were used to construct the study design to align with the research questions and purpose.

Three databases that were used in order to cover publications, ranging from education and psychology to neuroscience were: the Web of Knowledge, PsychINFO and ERIC. The following keywords were used: “autism”, “autism spectrum disorder”, “ASD”, “autism spectrum condition” and “joint attention”.

The inclusion and exclusion criteria were the following: (a) to measure JA, (b) to include children 2–18 years of age as participants, (c) to use either DSM-IV or ICD-10 criteria to diagnose autism, (d) to focus on results that were published between January 2002 and April 2013 and (e) to review articles that were published in English language peer-reviewed journals. The exclusion criteria were the following: (a) intervention studies, (b) reflexive gaze-cueing studies and/or (c) pharmacological trials.

The articles were coded for the following information: where the study was conducted (laboratory, school, clinic and home), participants’ age group (2–5 years old, 6–12 years old, and 13 years and above), how the data were gathered (eye-tracking, reaction time, video, observation and electrophysiologically), whether it was a group study or a case study, whether the study had a control group and whether typical JA was detected.

5.2  STUDIES 2 & 3: GAME(S)

The original game. The Catching Game is a body movement game for children with autism spectrum disorders and high support needs. It was developed in a research project called CASCATE (Children with Autism as Creative Actors in a Strength-
based Technology-enhanced Learning Environment). Initially, commercially available Kinect® games were played in the project, after which the Catching Game was designed and created (Voutilainen, Vellonen, & Kärnä, 2011). It is a single-player game in which moving objects, chosen by the player, need to be caught using the hands or legs. The design had four principles: 1) the use of a child’s skills and strengths in order to make these strengths visible, 2) children’s creativity and active roles as actors and developers, 3) the modifiability of the technology and 4) the transformability of the solution for use in everyday contexts (Voutilainen et al., 2011). The game aimed to explore how the individual’s preferences, strengths and needs can be taken into account and acknowledged in the game design and in gameplay so that the game not only has a purpose but is also enjoyable. The game design also acknowledged the need for independent playing without outside guidance to empower the child. The game can help the children’s caretakers or teachers to observe the children and their actions in a new context. The teachers’ knowledge from outside game playing was used to make the game more enjoyable, a tactic that could also be used in the classroom or in home settings.

The eye gaze and perspective taking game. The game used in this research was developed based on the Catching Game and its principles, described above. The game was designed as a perspective-taking game in which the children must rely on the gaze of the virtual character (a cartoon character) to play the game. Hence, attending to eyes and using eye-gaze direction as a cue have practical purposes and are positively rewarded. I designed the game so that to choose the correct object, the player infers a spatial location from the virtual character’s gaze—an object is hidden in one of three boxes on the screen—and the player must choose the correct location. The box opens and an object appears, and the player needs to catch the object using his/her hands. The game environment was designed so that the participant is able to choose a preferred object before the game begins, which allows the child to take an active role in the game. The object chosen will be the object they need to find based on the correct spatial location determined by the cue provided by the virtual character’s eye gaze. The preference-based object start screen is familiar to the players from the Catching Game. A cartoon character was designed and chosen instead of a real human being, as research indicates that there are no differences in attending to eyes of individuals with ASD when watching social dynamic scenes featuring cartoon or human interaction (Riby & Hancock, 2009). The cartoon character’s eyes must have a white background since research shows that the gaze direction is difficult to infer without this (Frischen et al., 2007). Also, providing continuity with the previous game by using similar objects is a key factor (e.g., the cartoon objects). Moreover, to our knowledge, there is no research on mixing real faces with a cartoon context for children with ASD; hence, the use of such an unknown variable was avoided.

5.3 STUDIES 4 & 5

Studies 4 and 5 were based on the perspective-taking game. I was looking at two different data sets. In study 4, we looked at game performance based on log file data, a method that could be easily used in any game environment, and that told us about the players’ capabilities in performing a perspective-taking task. In the fifth study, the data were the eye movements of the player since we wanted to see if time spent in the eye area were different or same in children with ASD and TDI. Since studies 4
and 5 have the same game design, the same data collection sessions and the same participants, we will first describe the participants and then the game will be presented for both studies. Finally, the data-gathering method and study design of each study will be described.

5.3.1 Participants

Children with Autism

A convenience sampling method was used. Four pupils from a school for individuals with special needs – which used an adjusted syllabus owing to the pupils’ academic performance – took part in the study. The study took place in their own school in a familiar setting. All the children were previously diagnosed with ASD (based on ICD-9 criteria) and can be defined as high support need (e.g. Štrnadová et al., 2014) and minimally verbal (e.g. Tager-Flusberg, & Kasari, 2013) according to the school services reports (medical doctor and speech therapist). A teacher-rated Autism Spectrum Screening Questionnaire was used (ASSQ: Mattila et al., 2012): the scores were all above the cut-off score of ≥ 22, with sensitivity / specificity 0.73 / 0.74 for clinical populations (ASSQ scores for the four participants: 23, 36, 41, 30). The participants were all male, and their age levels were equivalent to those in Finnish primary and secondary school (ages in years: 9, 12, 14 and 11). We could not collect standardized test results (language or cognition) as tests were stopped due to the children’s systematic task-irrelevant behaviour, for example, by inventing their own play action, which was unrelated to the task. More subjectively, by the teachers and researchers, these children can be characterised as having very limited use of verbal language, mainly using single words, expressing echolalic speech and most often communicating non-verbally (See appendix A for more detailed descriptions of the children). All children participated on the basis of their own, parental and school consent and the research was approved by the Research Ethics Committee of the University of Eastern Finland.

Typically developing children

A convenience sampling method was used. Finnish universities have teacher training schools that are designed to work in collaboration with researchers. We involved all consenting and typically developing second grade primary school children from the university training school, gaining their own consent and that of their parents and the school. The second grade was selected to ensure that the youngest participants were age-matched to the youngest individual with ASD: the mental and language age in the control group was therefore on the same or higher level as for the youngest child with ASD, but not likely to be on a lower level. This selection and assumption were made since the children with ASD had too much task-irrelevant behaviour during testing; therefore, we do not know their mental and language ages.

The school reported that the participating children had no medical, psychological or neurological diagnoses, or other learning disabilities or difficulties. To exclude potential individuals with ASD, a teacher-rated Autism Spectrum Screening Questionnaire was used. For a whole population sample the sensitivity / specificity was 1.00 / 0.94 and the cut-off ≤ 7 (ASSQ: Mattila et al., 2012). The ASSQ scores in the TDI
group were all below the cut-off as all scores were < 3. Altogether, 17 children between the ages of 8 and 9 participated in the study (9 males and 8 females). The study took place in the familiar setting of their school. The researchers have opted to use statistics appropriate for single case studies. The sample size used for the control group in case-control studies can be modest; the sample size for the 98 single case studies that directly compared a single case to controls was 11.69, SD = 10.66 (Crawford, Garthwaite, & Porter, 2010). The eye-tracking glasses were too large for one child and hence these data are missing from the fourth study.

5.3.2 Game apparatus

The game ran on Visual Studio® software on a PC using the Microsoft Windows® operating system with a Kinect sensor, Microsoft Xbox 360® (version 1.8). The Kinect sensor’s operating range is from 0.8 to 4.0 metres, a 640x480 resolution, with a 30 frames per second rate. The game was played on a white screen with a VGA connection to a projector (Xbox Kinect® uses body movement in its games. See Ilg et al., 2012; Munson & Pasquel, 2012).

The Kinect sensor was placed in front of the player below the white screen. No physical contact with the screen was needed. The player saw a silhouette of him/herself and used his/her hand’s silhouette to select and catch items on the screen by placing either hand on top of the item. The software was programmed to only allow hands for selection. The distance to the screen was altered by the player by moving around the room, hence the visual angle was not constant. The size of the screen was 2.6 (width) x 2.01 (height) in metres (m), the image projected was 2.1 m x 1.54 m. A cartoon character and images were used to maintain the game-like feature. The character’s height was 97 centimetres (cm) and eye area dimensions 20 cm x 13.2 cm.

5.3.3 The task

To project the least amount of discomfort for the children, the gameplay was designed on the basis of existing activities at the participants’ school. The gameplay was also based on a computer game with a positive user experience (Mäkelä, Berdnarik, & Tukiainen, 2013). The new computer game was a game in which attention to eyes in a perspective-taking task was fundamental to successfully playing the game, a similar task to that of Gould, Tarbox, Hora, Noone, and Bergstrom (2011). Their original task consisted of pictures on a table in which a person was looking in one of four directions: up, down, left or right. The children needed to understand where the person was looking and name the object the person was seeing, for example: ‘what does he see?’

In our game, the player first chose an object of his/her preference, like a bird, a bee, a plane, etc., by placing either hand on top of that item. Then s/he needed to know the direction in which the virtual character was looking (there were three boxes on the screen: up, down, or middle) and open the box in that location with the help of eye gaze cues or with eye gaze and arrow cues: ‘what does he see?’ If the participants tried to open the incorrect box, it would not open - it would shake for a moment and would then make a sound to invite players to try again. There were three attempts before the new cue would appear. Once they chose the correct box, the participants needed to catch the flying object, which would emerge from the box.
There were two kinds of trials in the game: 1) only the eye gaze cue indicated which box to choose (hereafter ‘eye cue’) and 2) the eye gaze cue and an additional arrow cue at the same time indicated which box to choose to make the task easier (hereafter ‘double cue’). The double cue was added to increase the likelihood that the children would not find the task too difficult, reducing the risk of having a negative experience from participating. The idea was based on earlier visual perspective-taking task results by Gould et al. (2011).

5.3.4 Study 4: data collection by decisions

The data collection started after the practice trials for both TDI participants and for the individuals with ASD. This was done because we did not know whether the target behaviour was part of their repertoire, and task failure could have evoked negative feelings in the children with ASD and resulted in refusal to play and participate in similar activities in the future. The practice trials had two eye cue trials and five double cue trials. The practice measurements involved only two attempts on the eye cue condition to avoid multiple failures, as guided by Morgan and Morgan (2009). Similarly, due to the pilot nature of the study, the trial numbers were kept low (in the practice and real trials). At the practice trials, the eye cue trials came before the double cue trials to ascertain whether the children were able to play the game when only eye gaze cues were given: two eye cue trials (length of the arrow: trial 1 = no arrow and trial 2 = no arrow). There was only one attempt for each eye cue trial. After the two eye cue trials, five prompted trials using the fading procedure (number of dashes in the arrow on each trial: trial 1 = 5, trial 2 = 4, trial 3 = 3, trial 4 = 2, trial 5 = 1) with three attempts were used to help the player understand the game and to encourage a sense of control. The TDI had one practice trial, after which they were able to understand the game (with reference to their own comments).

After the practice trials, in the two playing sessions that were analysed, there were six double cue trials and three eye cue trials to provide easier than more difficult trials (the assumption was that arrow cues should make the task easier. See Gould et al., 2011). In the double cue trials, the game used a fading procedure in which each cue had a shorter arrow cue than before and eventually no arrow cue. The order was according to the fading procedure: the length of the arrow started with 5 dashes, then 4, 3, 2, and finally 1, and then the three final trials without the arrow (amount of dashes: 5-4-3-2-1-0-0-0). All trials allowed three attempts before proceeding to the next trial. The decision data were automatically saved to computer log files.

5.3.5 Study 4: Design

A case-control method was used. A statistical programme (DISSOCS_ES.EXE) was applied to test whether participants’ scores on eye cue and double cue trials were significantly lower than those of a control sample, and whether the scores in the eye cue and double cue trials differ from one another (Crawford et al., 2010). The dependent measure is the relative percentage of errors made in the game in the eye cue and double cue trials.
5.3.6 Study 5: Data collection by eye-tracking apparatus

Portable Senso Motoric Instruments (SMI) (Germany, www.smivision.com) eye-tracking glasses were used for data recording. Two cameras captured the eye movements on the rim of the glasses and fixations were mapped onto a scene video camera coinciding with the participant’s line of sight. There was a binocular 30 Hz sampling rate and up to 0.5° accuracy, combined with a 24 Hz field-of-view camera. The gaze-tracking range was 80° horizontal and 60° vertical. A one-point calibration procedure was used, in accordance with the manufacturer’s recommendations. We used the children’s finger pointing as a cue whilst they were looking at a small screen for calibration: ‘touch the red circle with your finger’. The screen was held at arm’s length (a 5-inch touchscreen at approximately 50 cm distance). When they touched the red circle we knew where they were looking and calibrated the device to that point. As recommended by the manufacturer, the device was held slightly downward (15–20 degree angle) from the eye level for calibration purposes.

I performed systematic offline calibration (offset correction) to an attractive, looming stimulus using the Begaze® (Version 3.3) software (www.smivision.com) before each trial, as sometimes the children moved the glasses after the initial calibration procedure. The correction was performed on the only moving object on the screen, if their gaze followed it, and was fixated in the close vicinity of the object. A tracking ratio was used for exclusion criteria: participants with < 30% tracking ratio would be excluded (Amso, Haas, & Markant, 2014). The area of interest (AOI) was defined using SMI BeGaze software and the analysis was performed using semantic gaze mapping. The AOI was the eye region, broadly defined as eye area: the character’s height was 97 cm, with the eyes being 20 cm x 13.2 cm. The AOI was 1.2% of the overall screen size.

It was of interest to find out where the children were looking when choosing a correct box in the game and, more specifically, for how long they attended the eye area (dwell time) during the eye cue condition when no other cues were present. The dwell time (in milliseconds) was measured from the time when the virtual character turned his eyes to the box until the correctly chosen box began to open. Only correct trials were chosen, as there can be multiple reasons for errors. We only analysed the eye cue trials, and not the double cue trials, since we were interested in attention to eyes when no support was given.

5.3.7 Study 5: Design

A case-control method was applied to test whether participants’ total dwell times in the area of interest were equal, longer or shorter than those of a control sample when playing the VPT game and making correct decisions. The dependent measure is the dwell time in the AOI in the eye cue condition during correct trials.
6 OVERVIEW OF THE ORIGINAL STUDIES

6.1 STUDY 1


The first study reviewed joint attention literature. The objective of the review was to look at the JA literature and to explore the extent of JA impairment in children with ASD. We also looked at the assessment methodologies to see whether they could impact the results. It was our interest to examine whether there are indications of intact JA abilities in individuals with ASD. We also looked at the kinds of assessment methodologies that are currently being used for JA.

After applying the inclusion and exclusion criteria we were left with 26 articles in which JA was assessed. Four studies found evidence of intact joint attention: Dereu et al. (2012) found individual differences in JA behaviour, and Paparella et al. (2011) provided evidence of similar JA emergence in individuals with ASD at the group level. Leekam and Ramsden’s (2006) study was unable to differentiate between developmentally delayed and ASD groups, indicating that the lack of JA might not be directly linked to ASD. The Sigman and McGovern (2005) study showed that the responses to JA bids were correct 80% of the time, providing evidence of typical behaviour.

The review found the assessment methodologies to be similar: the early social communication scale (Mundy, Delgado, Block, Venezia, Hogan, & Seibert, 2003) or similarly structured tests were commonly used to detect JA behaviour in structured settings. None of the reviewed studies used children’s interests or preferences to create the test situation and none of the studies reported data looking at intra- and inter-individual variations.

Three of the studies used a more objective measure, in other words, eye-tracking. Eye-tracking studies showed group differences (Falck-Ytter et al., 2012; Norris et al., 2012) and found that the individuals with ASD differed from the controls in latency, overall looking time to the face, frequency of looks to the eyes and the face, and in the total number of correct looks to the examiner’s face. However, in two studies, the pattern of looking at the face was similar to their typically developed counterparts (Johnson, Gillis, & Romanczyk, 2012; Norris et al., 2012).

There are two ways in which these results are thought to occur: due to the testing methodology or due to the individuals’ abilities. If the latter is the case, individuals with ASD might not have categorically impaired JA. If the former is true, then individual preferences might impact the results and, again, JA could exist if the context was favourable. Individual preferences and interest in the task might explain the less frequent and sometimes variable JA behaviour. Other reviews have also come to the conclusion that group and individual differences within ASD research should be considered more thoroughly when studying attention (Ames & Fletcher-Watson, 2010) and have suggested that context could also have an influence on the JA assessment procedure (Bruinsma et al., 2004). Similar to our review, Nation and Penny (2008) provided examples of discrepancies in reflexive gaze cueing in ASD research. Because the assessments do not take into account the individual preferences that may
influence willingness to participate, we wish to emphasize the need for future focus on the potential strengths and abilities of individuals with ASD in the social world, using their individual interests as a premise in order to provide better interventions, more specialized teaching protocols and better understanding of ASD.

6.2 STUDY 2


The aim of the second study was to describe the development process of a game, and the idea behind it, that would later be adapted into a perspective taking game. The review (Study 1) indicated that there were no studies in the joint attention literature in which testing methodology was based on a task that the participants were previously found to have liked. Hence, the game in this thesis was based on an earlier game that was designed to be fun for children with ASD: the Catching Game.

The original game was developed as a part of an interdisciplinary research project. The Catching Game design began with trying out commercially available Kinect games as stepping stones towards designing a simple and fun research task. The results seem to support the idea that the modifiability of the game content is a strength because we can apply the children’s preferences directly to the game via changeable stimuli with different shapes and speeds. The game’s simple layout and logic has made it possible for the children to grasp the concept of the game within the first few play sessions. It is also possible to move through all the stages of the game quickly, which creates feelings of accomplishment in the child, supports his/her motivation to play the game and can also increase his/her level of concentration. The children have also been observed using their bodies in many ways and the game has the potential to aid in motor and visuospatial rehabilitation.

The gameplay seems to suit the children in the project: three out of the four participants analysed by three researchers were found to have positive user experiences with the game (Mäkelä, Berdnarik, & Tukiainen, 2013). Overall, the Catching Game prototype seems to be fertile ground for the development of other tasks, activities and games for individuals with ASD. Incorporating children’s own preferences may be crucial for successful task performance. Based on these observations and experiences I started to develop a game for my thesis.

6.3 STUDY 3


The third article was also descriptive in nature. The game can be used to study visual perspective taking, the ability to see the world from another person’s perspective which is sometimes considered to be impaired in individuals with ASD. The inability
to use gaze information or to take another person’s position into account will reflect negatively in social behaviour. Social skills are important for everyday functioning, and being able to understand others and their motivations is crucial when communicating one’s own beliefs and desires. The study examined previous research when developing and designing the game. Game design and psychological research on attention to eyes and eye tracking were used in order to create a testing context for children with ASD and high support needs.

The game has been developed based on the CASCATE project’s previous Kinect-based game in order to provide a familiar environment and tasks for the children. The idea for it was adapted from a study by Gould et al. (2011), but rather than using table-top tasks, Microsoft Kinect® was used as a platform due to its motivational and activity-based features. An additional advantage of Kinect, where movement is inherent to gameplay, is the notion that individuals with ASD have a more sedentary behaviour in comparison to typical counterparts. Ultimately, I have designed a computer game based on an activity that is preferred by children with ASD, in a context in which individuals with ASD usually feel at ease. Hence, we can find out more about the attentional engagement of the children through their overt behaviour, but also about their implicit eye movement processes. The game has log file and eye-tracking data gathering properties in order to analyse the player’s performance. In order to use eye-tracking glasses during the visual perspective-taking game, the children had been wearing a pair of safety glasses and a rucksack while practising at the Kinect work station. The rucksack was to be used for the hand-held computer that is attached to the eye-tracking glasses, and the glasses were used to help the children become familiar with the use of eyewear while playing games.

It was observed, despite the difficulty in getting feedback from the children due to communication differences, that after the first few sessions, the children seemed almost indifferent to the glasses. However, the children did adjust the glasses while playing the games: the eye-tracking software had a manual correction capability for the calibration process. One child with ASD, who only took part in the design phase, demonstrated a reluctance to wear the glasses with a cord that goes to the rucksack, simulating the conditions of the eye-tracking glasses. The reason for this reluctance was likely because the cord was attached to the glasses with adhesive tape, and the child could feel the cord creating unnecessary sensory stimulation on the back of the ear and neck. Hence, we allowed this child to use the glasses without the cord. Typically developed children have indicated that the glasses were not a nuisance during game-playing sessions before the actual research began.

6.4 STUDY 4


Study 4 entailed looking at the performance of each child with ASD in comparison to the control group in the task requiring attention to eyes in the perspective-taking game described earlier. The goal was to see whether these children can successfully play a game in which they need to know where the other person is looking, and how their performance compares to the control group.
As individuals with ASD enjoy and are motivated in computerized contexts due to, for example, the freedom to work at one’s own speed with few distracting social factors, we used an altered computer game with a positive user experience for our perspective-taking task. To our knowledge, this has not been explored before with perspective taking in high support needs and minimally verbal children with ASD. To further increase motivation and engagement, we used changeable visual stimuli as an acknowledgement of children’s personal interests, as preferences have been found to enhance assessment, academic and social skills performance.

The study was based on error rates saved on log files on the computer after the person playing the game made a choice. The errors made in the game were counted and reported as percentages. Errors were divided into two categories based on the cue type: 1) eye cue; 2) double cues. In contrast to group-level analyses with conflicting results on impaired perspective taking and attention to eyes, and due to the heterogeneous nature of the group, we concentrated on individual-level analyses.

The above-chance error performance and the fact that no participant tried to choose a box before the cues appeared, indicates understanding of the purpose of the cues. Apart from participant no. 3, the participants did not differ from controls in the eye cue condition. There was dissociation between the two conditions for each child with ASD showing that the arrow cues made performance worse, and all participants were significantly poorer with arrow cues compared to controls. Hence, it seems that the ASD children did not benefit from the additional arrow.

Overall, using eye cues for perspective taking seemed to be intact in three out of the four children with ASD. A possible explanation for the difference between participants and controls in the double cue condition with the additional arrow cues is the complexity of the scene. It has previously been suggested that using too numerous or too complex stimuli may explain the discrepant attention research results observed among children with ASD. However, since in our study children with ASD performed better with the eye cues, they may have only been distracted by the arrow cues that relate to visual complexity. The control group made fewer errors using the additional arrow cues as they may not have distracted them.

The lack of interest or ability in the standardised tests and willingness to play the game may be taken to indicate that interesting games can be seen as a possible alternative to standardised methods. It is likely that we will be able to see the emergence of greater potential in high support need children when the context is supportive of the individual. Hence, individual-level analysis can reveal insights about autism and about the individual with autism. Overall, we would like to see high support need children with ASD receiving more attention in research and in the design of research methodology in order to include them in research more systematically, instead of using methodologies that may exclude them as a group or as individuals.

6.5 STUDY 5


In the fifth study, the same game-playing sessions were used as in the fourth study. The goal was to look at the participants’ attention through eye movements and performance in the game. Key diagnostic criteria of ASD are impairments in establishing
and maintaining eye contact, which are also considered to be associated with the social
deficits seen in ASD. However, recent reviews have produced contradictory results
on eye tracking, finding that individuals with ASD are indeed less likely than TDI to
look at the eyes of another person, but also concluded that only few studies found
impaired attention to eyes in individuals with ASD. The question we were interested
in for this study was: is attention to eyes reduced in time in comparison to TDI in a
visual perspective-taking task? To our knowledge this has not been studied in high
support need and minimally verbal children with ASD.

We were interested in the trials when they made correct decisions for two reasons:
1) it is difficult to know why children make errors 2) we wanted to know if attention
to eyes is different to controls when being successful in the game. We looked at the
dwell time on the eye area, which has been thought to be an indicator of impaired eye
contact. The total dwell time was counted in milliseconds (ms). Correct choices were
seen from the eye-tracking recordings and log files.

Participant no. 1 spent significantly less time in the AOI than the controls. Participants 2 and 3 did not differ in total dwell time in comparison to the control group.
The fourth child with ASD was excluded as no dwell time data were available. These
results suggest that time may not be the key element for ability to perform typically in
a task requiring attention to eyes for all individuals. The relevance of attention to eyes
and dwell time may therefore be more appropriately determined for each individual
separately.

The benefits of our findings are that we can apply them in real life. Differences
between individual functioning in daily life and school are acknowledged in edu-
cation and rehabilitation, and hence research and assessment could also be devoted
to specific abilities to help target the strengths or the problem areas in high support
need individuals with ASD. Different types of assessments have been categorised in
literature as impairment level and functional level. The first refers to processing deficit
(e.g. memory tests such as recalling a list of digits) and the latter to a wider context
in which daily functioning is mapped out, for example, being able to dial a phone
number or communicate in everyday life. As these two types of measurements have
been found to complement one another and since, for example, the Psycho-educa-
tional Profile, PEP, and Adult and Adolescent Psycho-educational Profile, AAPEP,
are used to assess the functional capabilities of children and adolescents with ASD,
we suggest further development of impairment level measures in a positive context
to gain a more comprehensive view of an individual’s strength and impairment level.
Our results support the role of impairment-level analysis; assessing specific impair-
ments in isolation can demonstrate strengths or impairments that may not appear in
functional-level analysis.
7 DISCUSSION

7.1 MAIN FINDINGS

In this thesis, my goal was to explore previously published research results and methods (pre-existing tasks or games) to provide a description of how we can support and engage high support need and minimally verbal children with ASD in research, and explore their performance on an individual level. More specifically, I explored attention to eyes. This is an additional contribution to the field as these individuals may often be left out of research due to their lack of task motivation or their heterogeneous abilities and features.

In terms of the first research question, the generality of joint attention impairment, it was found that most studies reported children with ASD to have impaired joint attention. There were, however, studies that found children to have intact abilities. These findings are linked to the second research question about the methods used to assess joint attention, and how individuals have been taken into account. The review method and its focus were partly constructed to provide final data to guide the game design. The review itself could have benefitted from a more systematic approach, as it was constructed based on previous reviews to guide the design. However, the design of the review was carefully planned based on several review articles. The construct of the review was therefore specifically planned for these research questions. Nevertheless, very similar methods were used to assess JA and it is possible that the impairment is more visible when the children’s preferences, engagement and motivation are not directly taken into account. Individual performance may not have been seen as an important research avenue as no study mentioned children’s preferences nor did they report any individual-level analysis of it.

Subsequently, I designed a computer game based on a game already designed for children with ASD, keeping in mind how to engage the children by using their own interests and preferences. Using a computer game with a positive user experience provides not only several motivational aspects, but it also gives us a possibility to research children in a context in which they feel at ease. I found that designing data collection as part of a game is a good method of researching a skill without an extra stressor for the person playing the game. Log files and eye tracking can both give valuable information about the players and their abilities.

The third research questions were about measuring whether the children were able to play the perspective-taking game at better than chance level, showing that they understood the logic of the game, and whether they could use the eye cues correctly. The error rates and the absence of attempts by the children to choose items before the cue indicate that the children understood the game. The fourth question about the game was: does a child with ASD make more errors than the typically developing children? The error rates show that one child did make more errors but the other three did not differ statistically from the control group. The fifth research question concerned whether the dwell times on the eye area differ from the control group’s dwell times when making correct decisions. One child’s dwell time on the eye area was shorter but the other two did not differ from the controls. This means that longer dwell time may not be a determinant of the correct decisions, and also that not all children with ASD have diminished attendance to eyes.
Based on the review and the task results it can be inferred that there is support for the idea that we should more systematically explore abilities individually. The process of designing the game for data collection was a relatively straightforward process in which previous research was used to create the game. Our experience supports the idea that in the future this sort of research will be easier as making games gets simpler and quicker, and as computers and their usage becomes more commonplace every year. Case-control methodology provides us with an opportunity to explore how an individual compares to a control group. Since in the ASD literature there seems to be a consensus that technologies are mostly found to be positive, our approach of conducting research by playing a game is a plausible one. The results support the idea that technology and games could be used in research; in particular, the already-preferred context is something that can be considered to be a strength-based approach, where the person has a calm environment in which they feel at ease and comfortable. Although technology was used in this research, the activity could be anything for which the child has a preference and enjoys doing.

7.2 EVALUATION OF RESULTS

7.2.1 Individual variation

High support need and minimally verbal children groups have been difficult to match given the variability within the group (e.g. Jacobsen, 2000; Tager-Flusberg & Kasari, 2013). Therefore, when assessing a skill, there should be more emphasis on looking at the individual’s skill in an environment where motivation is based on that individual, as has been suggested by Burack et al. (2004), Kasari et al. (2013) and Skwerer et al. (2015). I also found this when we used standardised tests, as they did not prove to be of much use for testing these children. Context and instruction comprehension or motivation to perform was lacking for the participants. Hence, the level of subjective interpretation of their skill would be too vast and therefore not recommendable. If we can use preferred contexts, for example, computer games, to assess skills in a context in which the person does not feel anxious, then perhaps the groupings and matching of the individuals for research would be somewhat different. It may also help task comprehension and motivation.

Burack et al. (2004) states that there are two aspects to be considered when carrying out a comparison of one group to another group: normalcy and uniqueness. Normalcy refers to the extent to which one or more functions are similar or different from one group to the other. Uniqueness, on the other hand, refers to the extent to which specific characteristics are only found in the group of interest and are not found in the control group. In this thesis, it was found that more often than not research does not report the variability within the sample in the joint attention literature; so even though group differences are found, we do not know if this is the case with each individual. This could also mean that the variables we use for grouping individuals and for matching purposes may not be the correct ones, as a third or a fourth variable may be the one affecting the individuals’ performance. Variability was also visible in the decisions and the eye-tracking data in my research. This means that the individuals were found to be similar and different from the group (normalcy) and that these skills are therefore not only a part of the TDI group (uniqueness). Although individual variation is not always
reported in research, it would be of interest to do this in future studies, in addition to looking at previous studies’ data and determining what kind of results we would see on an individual level, whether they would show a similar trend and at what magnitude.

I did not attempt to carry out comparisons to a developmentally delayed (DD) group as the idea of this study was to interpret the behaviour of ASD and TDI on an individual level. Although, I do recommend having a DD group as a control in the next study in order to see which performances are due to autism and which are due to developmental delays - although with high support need and minimally verbal individuals, it may be a difficult task to separate other developmental issues from autism as noted, for example, by Erbetta et al. (2015). The participant selection criteria and subgroups are very important issues in ASD studies especially when dealing with high support need and minimally verbal individuals with autism, and as individual variation has been suggested to account for some of the discrepant results in the literature. Using DD individuals as controls would partly mitigate the aspect of variation due to differences in diagnoses and group variance.

The disadvantage of individual designs is generalisability - we cannot say to what extent these conclusions are applicable to a wider population. However, not being able to gather background information on cognitive and language abilities does create a problem for making interpretations and inferences on actual skills in relation to the heterogeneous group and in relation to the control group. These factors are restrictions on this research and they emphasise the importance of developing new methods and gathering larger amounts of data with individual designs. For the moment, it is difficult to identify the impact of accounting for individual variation, and to determine to what extent our results would have been different using a more conventional group design. Due to differing abilities, however, it is a necessity to develop different research methods and assessment procedures that are engaging and motivating for children, and which do not require high-level verbal skills.

### 7.2.2 Game design

The method of using computerised games for this research was based on: 1) previous success on using computerised methods 2) utilising a computer game that was already familiar and additionally proven to be enjoyable (positive user experience) 3) the modifiability of the original game and 4) the ease of data collection during the activity. We chose the idea of preferred environment since it had not been used in the research literature in the review that we conducted on JA. These aspects, in tandem, can create a comfortable research setting that may lessen the burden of standardised methods (e.g. Skwerer et al., 2015). However, when designing the game it became evident that a game-like joint attention task, for which we had reviewed research methods, was difficult to construct. Simulating interaction with a virtual character was troublesome without losing the game being quick to construct. Artificial intelligence can potentially resolve this problem, but at the moment, it is not a reasonable solution for most research groups because of its costs. Hence, the game was designed as a perspective-taking task, and in the game the player needed to see where the other person was seeing (a line of sight). Using an existing and previously enjoyed game or activity may make the study design process less time-consuming (for comparison, see Bernardini, Kaska, Porayska-Pomsta, & Smith, 2014) and more convenient for researchers. However, additional research is needed to verify this claim.
Preferred and familiar environments can be considered key factors for individuals with ASD to perform well. It may be inferred, therefore, that the environment is an even more significant factor for high support need and minimally verbal children with ASD. Not only can these individuals benefit from a familiar and positive environment but the instructions need to be easily comprehended, and stimuli and context in the game need to consider the person’s perceptual capabilities (e.g. Kasari et al., 2013; Kylliäinen et al., 2014). We had already seen that the original game had created a positive user experience among high support need and minimally verbal children with ASD, and in the game the children could choose a preferred object and catch flying objects as in the original game. In this respect we provided the children with an environment with which they already knew how to cope and the session was not based on unresponsive adults. The task was not too difficult to understand and it did not require extensive language abilities. Better than chance performance in the game indicates that the children did not randomly make choices in the game and understood the game’s logic since playing was in accordance with the game.

Ploog et al. (2013) criticised technology studies of autism for not being systematic enough and being exploratory in nature, which means their effectiveness is hard to interpret. However, they also said that this is almost always the case when there is considerable development in any field of research. Therefore, the next step would be to carry out more rigorous studies, for example, larger numbers of individuals, different control groups (e.g. developmental disability with no ASD) or using a randomised control method with different tasks and methods.

The advantages of this approach are clear, however, there are also disadvantages that need to be addressed in the future. The generalisability of the data to larger groups or to different contexts is not clear. We should also design a method to compare the overt behaviour of these children at school or in their homes to validate whether the skills are seen elsewhere or if they are task and context specific. Furthermore, a comparison of the game results with other tasks that have been used with this group, such as the AAPEP (Mesipov, Schopler, & Caison, 1989) or the PEP-R (Steerneman, Muir, Merckelbach, & Willems, 1997), for which assessment is carried out in a typical environment, would be both interesting and necessary. Further studies should also be conducted into the other literature dealing with attention to eyes, such as free viewing (where children look at images without being given a specific task), perspective taking and reflexive gaze following, to see how many preference-based tasks or environments have been created, and if the method used can account for the engagement, and hence influence the results of this group.

### 7.2.3 Attention to eyes

Reviews have indicated variation in the processing of eye information. In study 1 it was discovered that even studies with matching participants found differing results on JA. This suggests that other factors may be playing a role that could explain the discrepant results. Individuals may, for example, process cues differently or context difficulty could affect their performance. In studies 4 and 5, the children with autism showed both similar and differing performance in comparison to typically developing children, indicating similar variation as in previous studies.

In my research I did not assess whether the children used the eye cues as social cues or just features indicating the right direction. I analysed whether they could use
the cues and pay attention to eyes long enough to correctly decipher the direction in which the virtual character was looking. There are studies in which behavioural responses show no differences to TDI and which demonstrate atypical brain activation for social and non-social cues in individuals with ASD (e.g. Greene, Colich, Iacoboni, Zeidel, Bookheimer, & Dapretto, 2011), hence it seems the brain may not therefore distinguish the cue type as in TDI. It is however hard to say whether this difference tells us about the processing difference or the difference between the processes within the group. On the other hand, a recent eye-tracking study found that social looking may not be completely disrupted in children with ASD, as in the structured vs. free-looking context (Falck-Ytter, 2015).

The advantages of looking at the processing of eye information and using decision data are that we are not only using free viewing in which there may be no motivation for looking in the eyes. The task has a goal for which they need to process the eye information, which provides a purpose and does not seem arbitrary to the participants, in addition to the task already being familiar. Hence, we may have been able reduce potential reasons for diminished attendance to eyes or not using eye information in particular contexts. Using eye-tracking methodology also gives us more objective knowledge on their processing or what is necessary for the processing of eye information. Taking children’s interests into account has been found to affect gaze between social and non-social objects (Sasson & Touchstone, 2014) which could also provide motivation in the perspective-taking game as the children get to choose the object at the beginning of the game.

The limitation is that we cannot control for all the possible confounding variables. It could be that there are many reasons for why the children performed as they did, and these could be different for each child. For example, we do not know if the participants had different reasons for not benefitting from the additional cues. It could be that they were a distraction for some and confusing for others. Nevertheless, we did see that all individuals performed better than chance and that it is beneficial to look at these individuals as individuals rather than as a group. In this respect, the study showed that individual variation is something we should study more and that games and preferred activities could be used for research purposes. The task is also similar to previous studies on perspective taking (e.g. Alcorn et al., 2011; Bukowski et al., 2015; Gould et al., 2011; Samson Apperly, Braithwaite, Andrews, Scott, & Bodley Scott, 2010) and hence we can assume that we are measuring the same thing. The larger size of the eyes, however, is one specific variable that was changed in the task that makes it more difficult to compare dwell time data to previous studies. Large human eye size is thought to be particularly important for social communication (e.g. Tomasello, Hare, Lehmann, & Call, 2007) and hence larger size may increase attention to eyes and dwell times.

There are also studies looking at attention to eyes and processing of eye information from alternative points of view. For example, as conscious vs. unconscious processing (Akechi et al., 2014; Sato et al., 2010), task motivation and test methodology (Skwerer et al., 2015), complexity of the scene (Ewing, Pellicano, & Rhodes, 2013), and speed of stimuli (Foss-Feig, Tadin, Schauder, & Cascio, 2013). Considering these studies in relation to my own, I find that the conscious vs. unconscious processes are not relevant as the task was inherently a conscious decision-making process. Individual variation and task motivation were considered in the results, as the game was designed to be an enjoyable event and performance was analysed on an individual level. Task motivation or engagement has potential to influence the results positively for some, as the
participants may be more willing to participate. The complexity studies show that the more complex an image was, whether a face or a car, the more impaired the processing of the image was (Ewing et al., 2013). In my game, the scene and the virtual character’s face were kept as simple as possible which is another potential reason they were able to play the game successfully. However, complexity should be explored more thoroughly and compared to different levels of complexity. Finally, since it has been found that children and adolescents with ASD are substantial superior at perceiving direction of briefly presented high-contrast, moving stimuli (Foss-Feig et al., 2013), the influence of this should also be considered in future studies, perhaps especially in the reflexive gaze-following studies.

7.3 ETHICAL ASPECTS

This research was reviewed and supported by the Committee on Research Ethics of the University of Eastern Finland. Research ethics were particularly important in this thesis since it involves children who were especially vulnerable due to their diagnoses, background and history. Research ethics were involved on two levels: 1) why we are conducting the research 2) how the research was carried out.

The heterogeneity within autism spectrum disorder is recognised and, for the moment, a large part of the research has concentrated on higher-functioning individuals with ASD, which is why I am conducting research with high support need and minimally verbal individuals. These children’s life experiences, academic failures, dependence on others, motivation to perform, and wariness of others due to their experiences, comprehension of the task, environmental distractions, all may influence the way they perform in research settings and how they engage with a task. For these reasons more research should be concentrated on how to engage and approach this group. It appears that there is demand for conducting research in this population, and to explore and attempt to develop new avenues for research (Kasari et al., 2013; Kylliäinen et al., 2014). Otherwise these individuals may be neglected in research and their lives, education, and rehabilitation may not receive the benefits of research.

The second level of ethical issues concerns the data collection. As mentioned above, the children may have limited language and low IQs, and personal histories that may not have a surplus of positive or encouraging experiences. Therefore, it was an imperative to consider the level of difficulty and the processes in the game, in order to avoid any unnecessary negative experience that may lead to negative feelings about participation and trying out new task or procedures. Hence, the game and data collection in this thesis was designed to include practise trials so that there were fewer difficult trials; and the instructions needed to play the game were minimal, which was possible to do since the game was based on a recognisable and positive game with familiar procedures. The attempts to collect background information by using standardised tests were also stopped as the children were not engaged or did not understand the tasks and concentrated on their own interpretation of the tasks. The small number of participants is not, as such, an ethical issue but it would be counterintuitive to recruit more high support need and minimally verbal children with ASD to participate before we have any preliminary results on the game-playing research methodology.

Researchers have also voiced their concerns about technologies for individuals with ASD, which should be considered: Howlin (1998) thought that the non-social
nature of computer-based tasks may be so appealing that these individuals may become too reliant on the technology at the expense of real world interaction. Durkin, (2010) was worried about the isolative impact; virtual reality may be too safe and too attractive, and can lessen engagement in the real world. Subsequently, it has been found that children with ASD do have one hour more sedentary activity vs. TDI in a day (Must et al., 2013) and that 98% of the sample of individuals with ASD used computers five hours a day (Kuo, Orsmond, Coster, & Cohn, 2014). Regardless, I believe, we should explore every avenue to provide individuals with ASD the best means to make the most of their lives. In relation to my research, I acknowledge these issues but inferred technologies as tools to lighten the burden of research and to provide positive experiences which are linked to better outcomes. Moreover, Kinect-like, movement-based games are a way to mitigate the sedentary-natured technologies and planning to use technologies can overcome the time spent on computers. Positive and encouraging experiences in playing a game may further empower a child to try out other activities as well.

7.4 IMPLICATIONS FOR FURTHER RESEARCH

1) If a research context is created for assessment, we can consider that a different context, in which the person being tested would feel more at ease, may have a positive impact on the perceived abilities but would also be a more ethical way of conducting research. This is an important factor as research in learning, education, and disabilities recognises the role of motivation as having a significant influence on the abilities seen in an individual. Therefore, planning research in an already positive and familiar context has significance for motivation and being supportive of the individuals.

2) These studies suggest that research should also explore more thoroughly the variability of skills in different individuals and across different studies.

3) We could also look at previously acquired group data to evaluate each individual’s performances to see if the discrepant findings in different studies were found to be due to the individual’s performance.

4) If similar findings appear in future studies, then research could also be devoted to specific abilities to help target the strengths or the problem areas of daily life in high support need individuals with ASD in order to provide a more comprehensive view. Looking at specific impairments and strengths is particularly important for high support need individuals with ASD since they may not adapt to the standardised methodologies being used, and due to their more variable strengths and weaknesses.

7.5 PRACTICAL APPLICATIONS

1) In the future, I hope to see the development of assessment and educational procedures and contexts in which the child’s preferences are taken into account. This may motivate children to participate in the tasks and show skills or impairments that are truly in need of more support and development and that could be taken into account. Familiar environments and game-type tasks may also provide greater incentive to take part in research and perform well in a task.
2) Similarly, in adults, these aspects may help individuals to show their abilities, and find skills that may, for example, help them to acquire a job, and build up their CV profiles.

3) Computerised procedures could provide more help for individuals with ASD if they are designed as enjoyable tasks/games and not merely as drills to learn a particular ability. The games could work as a stepping stone to real life training and to instil feelings of competence.

7.6 FINAL WORDS

My thesis used a computer game as a way to provide a motivational platform for exploring an ability of high support need children with ASD. The idea stemmed from the premise that computers are preferred by individuals with ASD. Being able to engage a child in a task provides a plausible way of exploring what children can and cannot do. I did not, however, evaluate whether using a computer game is better than a non-computerised method as this aspect has been covered in previous research, and since this was not the goal of this thesis. I also used similar visual properties in the perspective-taking task to previous studies and it is therefore likely that the results reflect each child’s actual performance on the task, comparable to previous research.

I wish to note that I do not attempt to promote technologies as a solution to all situations or contexts; one should carefully evaluate when and for whom they may be the best option. We should be open to possibilities, and plan technologies for different purposes and to investigate how they work. Preferred contexts, on the other hand, seem to be justifiable avenues for any future research. Hence, I wish to emphasise that creating contexts to engage a person in a task is an important factor in order to perform at one’s own level: doing simple calculus may be easy but if one has to do it in rough seas in a small kayak the difficulty level may be entirely different. Similarly, a task with many verbal and social cues may distract these children from the task or cause anxiety, affecting their performance. Hence, using a preference-based context is a plausible solution to increase task engagement in research and in education.

In support of this, for example, Lojowska, Gladwin, Hermans, & Roelofs (2015) found that in a threatening or frightening situation visual perception can deteriorate for high detail stimuli and improve for low detail images. Accordingly, it could be that if children and individuals with ASD are in stressful situations, their visual perception may not be at an optimal level. This, nevertheless, does not explain all the discrepancies found in ASD research literature and hence it is essential to study each case separately and explore individuals as a part of a bigger group but also as individuals to account for the variation. With high support need and minimally verbal children this aspect may be more relevant due to the group’s heterogeneity that creates difficulty in interpreting what is the group’s defining feature for membership and what this may be in the future.

The most rewarding and the most difficult part of this thesis was putting to one side some aspects and rules guiding experimental research. This was done in order to consider other important variables that may influence research such as personal preferences, task engagement and the variability of skills among the participants, and by carrying out research from the perspectives of psychology, special education and computer science. It meant that I could not control, for example, all the factors in the testing situation and participant matching. The method used was neither a user
experience study nor systematic game design research, and it was not a psychological group study either. I used components from different walks of science as building blocks to create a game that could be used for explorative data collection taking into account the special nature of the children participating in the study. Admittedly, this approach has its imperfections but, on the other hand, it has the potential to encourage research that can pave the way for new solutions and ideas. Collaboration between different fields of sciences has been, nevertheless, extremely fruitful, constructive and has produced new ways of thinking and problem solving.


Bukowski, H., Hietanen, J. K., & Samson, D. (2016). From gaze cueing to perspective taking: Revisiting the claim that we automatically compute where or what other people are looking at. Visual Cognition 23(8), 1020–1042. doi:10.1080/13506285.2015.1132804


durk


Distefano, C., & Kasari, K. (2016). The window to language is still open: Distinguishing between preverbal and minimally verbal children with ASD. Perspectives of the ASHA Special Interest Groups, 1(1), 4-11. doi:10.1044/persp1.SIG1.4


Lyons, G., & Cassebohm, M. (2012). The education of Australian school students with the most severe intellectual disabilities: Where have we been and where could we go? A discussion primer. Australasian Journal of Special Education, 36(1), 79-95. doi: http://dx.doi.org/10.1017/jse.2012.8


Strnadová, I., Cumming, T. & Marquez, E. (2014). Parents’ and teachers’ experiences with mobile learning for students with high support needs. Special Education Perspectives, 23(2), 43-55.


APPENDIX A

CHILDREN WITH ASD: DETAILED DESCRIPTIONS

Aaron was a 9-year-old boy, with an ASSQ score of 23, who has developmental delays and hence has extended schooling planned. He was still learning how to dress himself and needed aid using the toilet. Aaron had sensory sensitivities which made, for example, cutting hair or doing physical examinations difficult. He appeared happy in everyday life but had difficulties in concentrating on tasks, and if irritated he may have scratched or head-butted the person next to him. Aaron had good gross motoric skills but needed aid and training in fine motor skills, for example, using a pencil/pen, and in general was often restless in his motor actions. He also needed aid in outdoor activities, in public spaces he needed careful supervision, and inside he needed aid and guidance in eating. Aaron understood clear context-related instructions but had trouble with comprehending more abstract concepts. He was able to name individual everyday items but could not use plurals, he was not able to produce L, K, R sounds and J and N sounds could only be used as individual sounds. Aaron was able to produce some sentences by combining two words, however intelligibility was often inadequate and he felt irritated when asked for clarification. As an aid he used a picture communication folder for communication, which contained several pictures that could be used to form a sentence to ask for something.

Billy was a 12-year-old boy, with an ASSQ score of 36, who had developmental delays. Billy was a child that could not be left alone without supervision, and he needed aid using the toilet, washing up and brushing his teeth. Although Billy was able to complete 25-piece puzzles, he was still training to use pens and pencils but was able to use scissors to cut paper into triangular shapes. He had a tendency to get easily frustrated if there was no planned activity. Billy was able to understand clear short instructions but he communicated with pictures and supportive sign language. The school found that Billy’s day was best organised by using a pictorial calendar.

Clark was a 14-year-old boy, with an ASSQ score of 41, who had developmental delays and therefore had extended schooling planned. Clark took very little contact with others and got distracted easily and went into his own thoughts, but with verbal guidance he was easily brought back to the task. Sometimes Clark would grab the hair of or pinch the person next to him for seconds to minutes at a time without a specific reason and, when disappointed, the time was often longer. His motor skills were repetitive and his fine motor abilities needed training; using a pencil or scissors was difficult, but luckily he liked physiotherapy in which he needed verbal and manual aid and guidance. Clark’s activity level was very varied; sometimes he needed constant guidance but often tasks were done without any aid. Clark used words to communicate, and did not use signs or pictures, and moreover had frequent echolalic speech and often recited sentences from cartoons. Although limited in language use he was able to write his own name, recalled most numbers, and was able to name geometric shapes (square, circle, house, heart).

Derek was an 11-year-old boy with an ASSQ score of 30. Derek was almost always a cheerful child who had made progress in play and did not only do certain play activities, and was also more willing to be guided by an adult. When he was stuck,
giving time and showing pictures helped him to move on. He was eager to play but only for a short while, and he needed adult supervision and guidance to plan and execute activities. In motor play activities, Derek was hesitant and was still in the process of learning fine motor skills, such as holding a pen. For Derek, big social events at the school were a challenge but those could be addressed through encouragement and pictorial planning of the events. Derek communicated with words, gestures and pointing. Although he used the same phrases frequently, with 1-3 words, and was able to name colours, numbers and play-related items. He was able to ask for help by using words such as *help* or *give* and additionally used a picture communication file to communicate with adults.
ARTIKKELI I
AUTISM SPECTRUM DISORDER AND IMPAIRED JOINT ATTENTION: A REVIEW OF JOINT ATTENTION RESEARCH FROM THE PAST DECADE. NORDIC PSYCHOLOGY, 66 (2), 94-107. DOI: 10.1080/19012276.2014.921577

ARTIKKELI II
CATCHING GAME: A BODY MOVEMENT GAME FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS. IN PROCEEDINGS OF WORLD CONFERENCE ON EDUCATIONAL MULTIMEDIA, HYPERMEDIA AND TELECOMMUNICATIONS 2014 (PP. 2057-2061). CHESAPEAKE, VA: AACE.
Korhonen, V., Virnes, M., & Kärnä, E. (2014)

ARTIKKELI III
AN EYE-GAZE AND PERSPECTIVE-TAKING LEARNING GAME FOR CHILDREN WITH AUTISM SPECTRUM DISORDER. IN PROCEEDINGS OF WORLD CONFERENCE ON EDUCATIONAL MULTIMEDIA, HYPERMEDIA AND TELECOMMUNICATIONS 2014 (PP. 2004-2008). CHESAPEAKE, VA: AACE.
Korhonen, V., Virnes, M., & Kärnä, E. (2014)

ARTIKKELI IV
A PILOT STUDY: A COMPUTER GAME BASED ASSESSMENT OF VISUAL PERSPECTIVE TAKING OF FOUR CHILDREN WITH AUTISM WITH HIGH SUPPORT NEEDS. SCANDINAVIAN JOURNAL OF DISABILITY RESEARCH. ADVANCE ONLINE PUBLICATION DOI:10.1080/15017419.2016.1178169

ARTIKKELI V
HIGH SUPPORT NEED CHILDREN WITH AUTISM: A PILOT EYE-TRACKING STUDY LOOKING AT INDIVIDUALS’ VISUAL PERSPECTIVE TAKING ABILITIES AND ATTENDANCE TO EYES
Korhonen, V., Kärnä, E., & Räty, H. (in review)
12. Teemu Valtonen. An Insight into Collaborative Learning with ICT: Teachers’ and Students’ Perspectives. 2011.


78. Emilia Valkonen: *"Me myymme ja markkinoimme kursseja" Markkinaorientaation piirteet kansalaisopistoissa*. 2015

High support need and minimally verbal children with autism are a heterogeneous group. They are also less studied than their higher-functioning counterparts. Observing children as individuals may reveal capacities previously unseen in children's performance. This study's results indicate that it is plausible to design a research methodology that acknowledges the specific challenges of high support need and minimally verbal children.