

Exploring the patterns of participation and participation restrictions in school-aged children with mild to moderate autism in the United Arab Emirates

by

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DECLARATION OF ORIGINALITY


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ETHICS STATEMENT

The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research ethics approval.

The author declares that she has observed the ethical standards required in terms of the University of Pretoria's Code of Ethics for Researchers and the Policy Guidelines for Responsible Research.

ABSTRACT

Introduction: Participation is one of the most important health outcomes for children and adolescents, as it leads to increased emotional, psychological well-being and improved quality of life. Children with Autism Spectrum Disorder (ASD) participate in fewer activities and with less frequency than their typically developing peers, but little is known about their participation patterns from their own perspectives. The self-report Participation Questionnaire has been developed and designed using the different life domains of participation according to the International Classification of Functioning, Disability and Health (ICF) and was used with individuals with intellectual impairment. This study aimed to describe the patterns of participation and participation restrictions of school-aged children with mild to moderate ASD. To do this, the adapted short version of the Participation Questionnaire was used to guide structured interviews and gain the perspectives of school-aged children with ASD regarding their experiences of participation.

Methods: A quantitative non-experimental design using structured interviews was utilised in this study. The Participation Questionnaire was adapted to accommodate the population, namely children with ASD. Non-probability purposeful sampling was used to recruit 10 children between 10.0 to 17.11 years of age with ASD residing in the United Arab Emirates (UAE). Descriptive statistics were used to analyse the results and the ICF coding system was used to categorise the items into ICF life domains.

Results and conclusions: Significant participation restrictions were highlighted in the areas of communication, interpersonal interactions and relationships, mobility and in community participation. Positive trends were documented in the areas of self-care and domestic life as well as daily tasks and demands.

Keywords: Autism, children with Autism Spectrum Disorder, participation, participation restrictions, school-aged children

LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ADOS	Autism Diagnostic Observation Schedule
APRS	Activity and Participation Rating Scale
ASD	Autism Spectrum Disorder
CAPE/PAC	Children's Assessment of Participation and Enjoyment
CARS-2	Childhood Autism Rating Scale – 2 nd Edition
CBCL	Child Behaviour Checklist
GCC	Gulf Co-operation Council
HCAS	Home and Community Activities Scale
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth
ID	Intellectual Disability
LeSTE	Learner Screening Tool by Educators
PEM-CY	Participation and Environment Measure for Children and Youth
POPE	Playground Observation of Peer Engagement
PQ 30 item	Participation Questionnaire 30 item
SFA	School Functional Assessment

TQS	Ten Questions Screen
VABS-II	Vineland Adaptive Behaviour Scales-Second Edition
UAE	United Arab Emirates
WHO	World Health Organization

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Section 1: Problem statement and Literature Review

1. PROBLEM STATEMENT AND LITERATURE REVIEW

The International Classification of Functioning, Disability and Health (ICF) defines participation as “involvement in a life situation” (World Health Organization, 2001). The ICF-CY (International Classification of Functioning, Disability and Health for Children and Youth) further defines participation as “taking part, being included or engaged in an area of life, being accepted or having access to needed resources” (World Health Organization, 2007, p. 16). Participation is comprised of two main components, namely attendance and involvement (Imms et al., 2016). Attending includes being present and is a prerequisite for involvement (Imms et al., 2016, p. 35). Involvement refers to the quality of the experience and describes aspects of engagement and motivation (Imms et al., 2017).

Participation is one of the most important health outcomes for children and adolescents as it leads to increased emotional and psychological well-being and improved quality of life (Rainey, Nispen, van der Zee & van Rens, 2014). Through participation, children gain information about the world, learn cultural rules and learn to develop values and priorities (Zingerevich & LaVesser, 2009). A combination of different factors influence an individual’s ability to participate in meaningful activities, but how it is defined influences assessment, policy writing and intervention (Imms et al., 2016).

Within the literature the WHO’s definition of participation provides limited details; this makes it challenging for researchers to select the most appropriate measurement tools to examine both attendance and involvement (Adair et al., 2018). According to Granlund (2013), most definitions of participation focus on attendance in everyday activities and, as a result, assessments have measured participation as frequency of attendance. Focusing on attendance will not provide information about how important the person perceives the activity to be (Imms et al., 2016). This shows that there is a clear imbalance in the way the construct of participation is operationalised. Measures of involvement are less common and there is a need to develop assessments that cover both aspects adequately (Granlund, 2013). It is therefore important to view participation in the light of the ICF life domains.

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The ICF categories of participation have been organised into nine life domains. These are (1) learning and applying knowledge, (2) general tasks and demands, (3) communication, (4) mobility, (5) self-care, (6) domestic life, (7) interpersonal interactions and relationships, (8) major life areas, and (9) community, social and civic life (Arvidsson, Granlund, Thyberg, & Thyberg, 2012). Arvidsson et al. (2012) suggest developing assessment tools by first considering the ICF categories of participation. Within the ICF, an individual can be described according to their level of function, for example “no difficulty” (code 0), “mild difficulty” (code 1), “severe difficulty” (code 3) and participation restrictions can therefore be categorised according to this coding system (Poon, 2011, p. 793).

Participation restrictions can be defined as problems an individual may experience in the involvement of life situations; these restrictions may stem from personal or environmental factors (World Health Organization, 2001). Participation restriction may also be defined as low level of engagement and involvement (Imms et al., 2016). These restrictions are clearly evident in the lives of children with disabilities. Children with disabilities may have restrictions that interfere with their frequency of participation, as well as the variety of their activities (Yee et al., 2017). Children with Autism Spectrum Disorder (ASD), however, present with a unique set of participation restrictions which influence their everyday life (Gan, Tung, Yeh, Chang & Wang, 2014). These restrictions may be related to the complexities of their diagnosis (Gan et al., 2014).

ASD is characterised by deficits in social communication and interactions, in addition to repetitive behaviour and restricted interests (American Psychiatric Association, 2013). ASD forms part of a group of disorders called neurodevelopmental impairments, which also result in abnormal brain function and includes conditions such as intellectual impairment and Attention Deficit Hyperactivity Disorder (ADHD) (American Psychiatric Association, 2013). Research has shown that children with ASD participate in activities less frequently and with less variety than their typically developing peers and children with other disabilities (Ghanouni et al., 2019). The most commonly cited reasons for low participation among children with ASD were factors associated with behaviour such as having tantrums, not following directions, showing no interest in an activity and experiencing sensory issues (Sood, LaVesser, & Schranz, 2014). There has therefore been growing interest in better understanding participation of children with ASD across different

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contexts such as the home, school and community (Simpson, Keen, Adams, Alston-Knox, & Roberts, 2018).

Children with ASD have lifelong challenges with social communication, which involve social reciprocity, understanding nonverbal communication, as well as developing and maintaining relationships (Yee et al., 2017). Most children with ASD have limited understanding of social cues and social norms and show behaviour which interferes with everyday activities (Ghanouni et al., 2019). Subtle elements such as facial expression, body language and tone of voice are social cues which children with ASD have difficulty interpreting and may lead to misunderstanding. The lack of environmental support, such as limited financial support and social stigmatisation, may limit their opportunities to participate in social activities, and thus limit the practice and development of social skills in natural settings with peers (Ghanouni et al., 2019). Another limitation which adds to social isolation is repetitive and restrictive behaviour displayed by children with ASD (Ghanouni et al., 2019).

Repetitive and restricted behaviour, including insistence on sameness, sensory sensitivities and aversion to change, also impacts life participation across contexts (Yee et al., 2017). Children with ASD who are fixated on limited range of interests have difficulty developing friendships with peers, as they are engaged in only preferred activities and talk about preferred topics. As a result, they experienced rejection from their peers (Ghanouni et al., 2019). This has led to low levels of confidence in interpersonal relationships and low motivation to engage with others socially (Ghanouni et al., 2019). This example displays the complexities of how restrictive patterns of behaviour may limit social participation and lead to isolation of the individual with ASD. It is therefore important to support and facilitate opportunities for learning and development of persons with ASD (Ghanouni et al., 2019).

Environmental barriers play a significant role in the inclusion of children with ASD. Identified barriers within the environment involved lack of support from extended family and service providers, limited availability of programmes and services as well as negative attitudes (Askari et al., 2015). Negative social attitudes were highlighted as a noteworthy barrier to participation of children with ASD (Askari et al., 2015). An example of this can be seen within the education setting. There remains a breach between the theory and practice of inclusive education

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which hinders children with ASD to be fully engaged in mainstream schools (De Matos & Morgado, 2016). In a study by De Matos and Morgado (2016), children with ASD were present in their classes, but were still perceived as outsiders by their peers. These perceptions need to be shaped as knowledge about the participation patterns in children with ASD increases and informs future interventions. Similar barriers to participation exist in the United Arab Emirates (UAE) where research in ASD is still emergent.

Research in the field of ASD is new in the Arabian Gulf and, as a result, prevalence of ASD is unknown (Alnemary, Alnemary, & Alamri, 2017). In 2010, the Ministry of Education released a policy named “School for All”, which stipulated that schools should accommodate children with various educational needs and provide appropriate services (Kelly et al., 2016). These policies advocate for full inclusion of persons with disabilities in all spheres of life. Despite these policies, disabilities are highly stigmatised in the Gulf Co-operation Council (GCC) countries, which include Bahrain, Oman, Saudi Arabia, UAE, Kuwait and Qatar (Kelly et al., 2016). Limited understanding and awareness of ASD contributes to possible service delivery and support provided to families who have children with ASD (Alnemary et al., 2017). Due to this lack of research, it is also unclear what the patterns of participation are for children living in this region.

In a study by Kheir et al. (2012), which was conducted in Qatar, the children with ASD spent more time indoors, watching television and sleeping, compared to their typically developing peers. It was reported that this may have been attributed to the social stigma that exists in the region regarding ASD (Kheir et al., 2012). Parents were more likely to isolate their children to avoid the lack of community understanding (Kheir et al. (2012). Misinformation by health professionals and lack of understanding by parents have also been reported as contributing factors to the existing stigma regarding ASD in the region (Al Kandari, 2006, as cited in Kelly et al., 2016). Although, these participation restrictions have been reported in this region, limited research exists which describes them. It is for this reason that it would be important to investigate the patterns of participation in children with ASD in the UAE.

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1.1 Systematic Search of Measures of Participation in Children with Autism Spectrum Disorders

Although participation in a variety of activities is a worthwhile goal for children with ASD, the measurement tools available to determine progress towards this goal remain limited. (Yee et al., 2017). There is currently no evidence regarding instruments to comprehensively assess participation in children with ASD (Lami, Egberts, Ure, Conroy, & Williams, 2018). Within the body of published measures of participation, the most common diagnosis reported was cerebral palsy, followed by ASD (Adair et al., 2018).

A literature search was conducted to determine the current research base for participation measures for children with ASD. A Boolean search was conducted using the search terms: “child*” or “paeds” or “children” AND “autis*” or “autism” or “autism spectrum disorders” or “ASD” or “PDD” AND “participation” or “particip” or “involvement” or “engagement”. To narrow the search, the studies included measures of participation included in the study by Adair et al. (2018). This was administered at the full text level screening. The databases used were Scopus and Ebscohost (PsychInfo, MEDLINE and ERIC). The inclusion criteria for the studies were as follows: 1) articles published in English, 2) peer-reviewed articles, 3) articles published between 2009 and 2019, 4) articles including children from 0 to 18.11 years, and 5) studies that measured participation in children with ASD using quantitative measures. A total of 2,800 articles were identified. Duplicates were removed, which left 2,149 articles for title and abstract review. Intervention studies and systematic reviews were excluded at this stage, as well as articles that did not focus on participation. After the title and abstract screening, 123 articles were included for full text screening. A total of 13 articles were identified for review, after establishing that they made use of the measurements in the Adair et al. (2018) study. The results of the systematic search are displayed in Figure 1.

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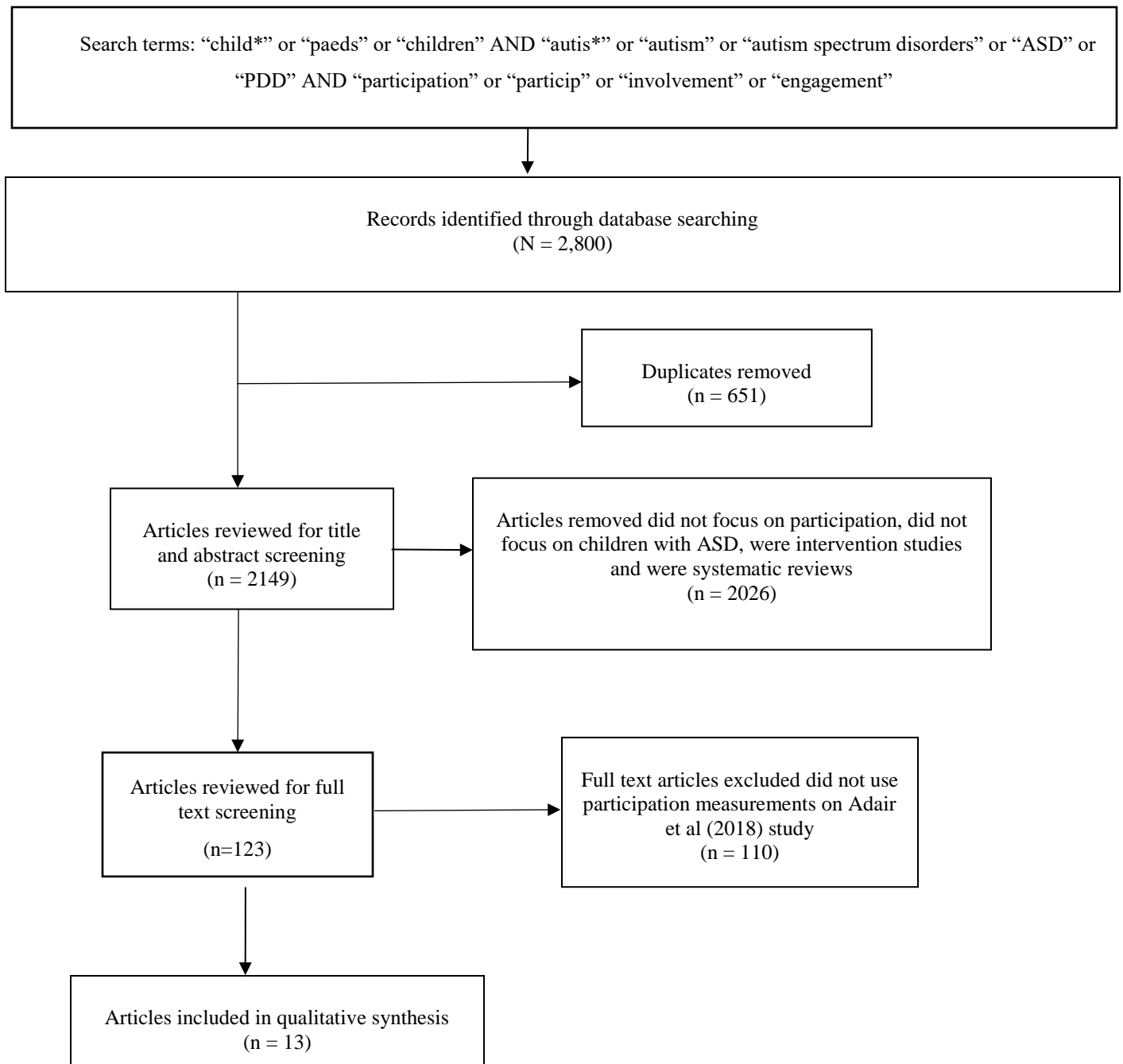


Figure 1
Systematic search of articles on participation in children with ASD

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1.1.1 Countries in which studies were conducted.

All of the studies were conducted in high-income countries (World Bank Group, 2020). However, none of the studies included were conducted in the UAE nor in any of the other GCC nations, which are all high-income countries according to the World Bank Group (2020). Most (7 out of 13) of the studies were conducted across the United States of America (Dovgan & Mazurek, 2019; Little, Sideris, Ausderau, & Baranek, 2014; Little, Ausderau, Sideris, & Baranek, 2015; Potvin, Snider, Prelock, Kehayia, & Wood-Dauphinee, 2013; Reynolds, Bendixen, Lawrence, & Lane, 2011; Santillan, Frederick, Gillmore, & Locke, 2019; Zingerevich & LaVesser, 2009). Two studies were conducted in Australia (Simpson, Adams, Bruck, & Keen, 2019; Simpson et al., 2018). One study was conducted in Iceland (Egilson, Jakobsdóttir, Ólafsson, & Leósdóttir, 2017), one in Taiwan (Pan, 2009) and one in Singapore (Poon, 2011). One study was conducted in Israel (Hochhauser & Engel-Yeger, 2010).

1.1.2 Age of participants.

Most of the studies assessed younger school-aged children and fewer of the studies focused on the adolescent age range. Eleven of the studies investigated participation in school-aged children aged 5.0–12.11 years (Dovgan & Mazurek, 2019; Egilson, Jakobsdottir, et al., 2017; Hochhauser & Engel-Yeger, 2010; Little et al., 2014; Little et al., 2015; Pan, 2009; Potvin et al., 2013; Reynolds et al., 2011; Simpson et al., 2019; Simpson et al., 2018; Santillan et al., 2019; Zingerevich & LaVesser, 2009). Five studies explored participation in adolescents between the ages of 13.0 and 19.11 years (Dovgan & Mazurek, 2019; Egilson, Jakobsdóttir, et al., 2017; Little et al., 2014; Poon, 2011; Potvin et al., 2013). More studies are needed to assess participation in adolescents as they need to acquire many skills in preparation for adulthood (Poon, 2011).

1.1.3 Self versus proxy ratings.

In nine of the studies, participation was measured using reports from caregivers or teachers through interviews or online surveys (Dovgan & Mazurek, 2019; Egilson, Jakobsdóttir, et al., 2017; Hochhauser & Engel-Yeger, 2010; Little et al., 2014; Little et al., 2015; Reynolds et al., 2011; Simpson et al., 2019; Simpson et al., 2018; Zingerevich & LaVesser, 2009). Two studies made use of independent observers who completed the participation measures (Pan, 2011;

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Santillan et al., 2019). Two studies made use of self-ratings and administered the same instrument, namely the Children's Assessment of Participation and Enjoyment (CAPE/PAC) (Hochhauser & Engel-Yeger, 2010; Potvin et al., 2013). The studies by Dovgan and Mazurek (2019), Egilson, Jakobsdóttir, et al. (2017) and Poon (2011) stated parent-report as one of the limitations of their studies. Without the perspective of the child, there may be a chance of over- or underreporting of participation. Additionally, Egilson, Jakobsdóttir, et al. (2017) emphasised that views of children and parents may differ, particularly regarding aspects of involvement such as motivation and social connection. Due to communication challenges associated with the diagnosis, there may be a reluctance to involve youth with ASD in interviews (Harrington & Foster, 2017). However, this does not refute the notion that their voices need to be heard in order for comprehensive assessment of participation. According to Arvidsson, Granlund and Thyberg (2008) it is imperative that participation is measured using self-reports, due to the subjective nature of involvement within the construct of participation. This highlights the lack of self-reporting within the body of research for individuals with ASD.

1.1.4 Measures of participation.

Various quantitative instruments were used in the studies as primary instruments or as part of test batteries for comparison. These were: Participation and Environment Measure for Children and Youth (PEM-CY) (Egilson, Jakobsdóttir, et al., 2017; Simpson et al., 2019; Simpson et al., 2018), Child Behaviour Checklist (Dovgan & Mazurek, 2019), Vineland Adaptive Behaviour Scales-Second Edition (VABS-II) (Dovgan & Mazurek, 2019; Poon, 2011; Potvin et al., 2013), CAPE/PAC (Hochhauser & Engel-Yeger, 2010; Potvin et al., 2013), the Home and Community Activities Scale (HCAS) (Little et al., 2014; Little et al., 2015), the Engagement Check (Pan, 2009), Childhood Behaviour Checklist (Reynolds et al., 2011), Playground Observation of Peer Engagement (POPE) (Santillan et al., 2019) and the School Function Assessment (Zingerevich & LaVesser, 2009).

In the study by Egilson, Jakobsdóttir, et al. (2017), the PEM-CY was adapted through translation into Icelandic. In Israel, the CAPE/PAC was translated into Hebrew (Hochhauser & Engel-Yeger, 2010). Although measurements were used in other non-English-speaking nations, no further adaptations nor translations were reported.

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Table 1 illustrates the articles included for review, specifically the authors, year of publication, participation measurements used, participants, procedures and findings.

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Table 1
Measures of Participation for children with ASD (n = 13)

No.	Author(s)	Year of publication	Title	Aim	Design	Participation Measure	Participants Number Age Country Type of sampling	Procedures	Findings
1.	Pan	2009	Age, social engagement and physical activity in children with autism spectrum disorders	To examine the associations of age, social engagement and physical activity in children with ASD in structured and unstructured play activities	Quantitative correlational	Engagement Check (McWilliam, 1990)	25 children with ASD aged 7.0–12.11 years were recruited through convenience sampling methods (Taiwan)	Participants wore accelerometers for 5 consecutive school days and were observed during physical education and recess. The Engagement Check was administered by trained observers who were recruited by the primary researcher.	Age and social engagement, which are thought to be determining factors of physical activity in children with ASD, were partially found to be related. Age had positive influence on physical activity and social engagement and children with frequent social interaction with adults displayed higher levels of physical activity.
2.	ZingerevichLaVesser	2009	The contribution of executive functions to participation in school activities of children with high-functioning ASD	To describe the contribution of executive function to participation in school activities of children diagnosed with ASD while controlling sensory processing	Descriptive survey	School Function Assessment (Coster, Deenay, Haltingware, & Haley, 1998)	24 children with high-functioning ASD aged 6.0–9.11 years were recruited through convenience sampling and snowball methods (by self-referral or professional) (USA)	The questionnaires were distributed to classroom teachers who completed them by rating their students' performance.	Executive functions contribute to participation in school activities over and above the contribution of sensory processing.
3.	Hochhouser Engel-Yeger	2010	Sensory processing abilities and their relation to participation in leisure activities among children with high-functioning ASD	To characterise specific sensory processing abilities of children with high-functioning ASD and to examine their relationship to participation	Quantitative comparative survey	Children's Assessment of Participation and enjoyment-(CAPE/PAC) (King et al., 2004)	50 children aged 6.0–11.11 years: 25 children with high-functioning ASD, 25 typically developing children, recruited through	The researchers administered the CAPE /PAC by interviewing the participants.	Children with high-functioning ASD had atypical sensory processing and displayed restricted participation in leisure activities.

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No.	Author(s)	Year of publication	Title	Aim	Design	Participation Measure	Participants Number Age Country Type of sampling	Procedures	Findings
				patterns in leisure activities			convenience sampling (Israel)		
4.	Poon	2011	The activities and participation of adolescents with ASD in Singapore: findings from an ICF-based instrument	To describe the activities and participation of adolescents with ASD in Singapore and to examine the suitability of the Activity and Participation component of the International Classification of Functioning, Disability and Health for achieving this purpose	Descriptive interview	Vineland Adaptive Behavioural Scales-Second Edition (Sparrow, Cicchetti, & Balla, 2006)	20 adolescents with ASD aged 13.0–18.11 years were recruited through convenience sampling (from schools and day activity centres) (Singapore)	Parents of participants were interviewed using the VABS-II.	Adolescents with ASD displayed significant deficits in adaptive skills and participation in community environments. Analyses of the VABS-II and APRS reveal a pattern of strong relationships, although further development of the instrument is needed.
5.	Reynolds Bendixen Lawrence Lane	2011	A pilot study examining activity participation, sensory responsiveness, and competence in children with high-functioning ASD	To explore activity patterns in children with and without ASD and to measure the role of sensory responsiveness in determining children's level of competence in their participatory roles	Cross-sectional study	Child Behaviour Checklist (Achenbach & Rescorla, 2001)	26 children with high-functioning ASD and 26 typically developing children aged 6.0–12.11 years were recruited via convenience sampling. (Children were recruited via flyers and email blasts through Interactive Autism Network.) (USA)	Parents were mailed the questionnaires. They completed the questionnaires and delivered them to the research lab.	Results have shown differences in the types of activities, jobs and chores engaged in by children with ASD compared to typically developing children. Children presenting with sensory sensitivity and sensory avoiding had significantly lower competence scores, suggesting that sensory responsiveness impacts the ability to participate successfully.
6.	Potvin Snider Prelock	2013	Recreational participation of children with high-functioning ASD	To compare the recreational engagement of children with high-functioning	Cross-sectional study	Vineland Adaptive Behaviour Scales-2 nd edition (VABS-II)	30 children with high-functioning ASD and typically developing peers (31) aged 7.0–13.11	The primary researcher conducted interviews with families across 2/3 visits in their homes or other location: the	Children with high-functioning ASD differed from their peers in terms of diversity of social

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No.	Author(s)	Year of publication	Title	Aim	Design	Participation Measure	Participants Number Age Country Type of sampling	Procedures	Findings
	Kehayia S. Wood-Dauphinee			ASD and their typically developing peers		(Sparrow et al., 2006), CAPE/PAC (King et al., 2004)	years through convenience and snowball sampling (electronic mailing lists, postal mailings and word or mouth) (USA)	VABS-II was conducted with parents and the CAPE was conducted with children.	aspects, and locations of recreation.
7.	Little Sideris Ausderau Baranek	2014	Activity participation among children with ASD	To examine the associations between the dimensions of activity participation and child characteristics and family demographics	Exploratory mixed methods	Home and Community Activities Scale (HCAS) (Dunst, Hamby, Trivette, Raab, & Bruder, 2000)	713 school-age children with ASD aged 5.0–13.11 years. Participants were drawn from a larger longitudinal study, who were recruited via online autism organisations (Convenience sampling) (USA)	Parents completed electronic questionnaires via Qualtrics online survey software (Qualtrics Labs, 2011).	The six dimensions of the HCAS were highly interrelated among children with ASD. Physical activity participation was associated with social interaction skills. Age affected frequency of participation in parent-child household activities, outdoor and faith-based activities. Findings have shown that severity of ASD influenced the child's participation as well as maternal education.
8.	Little Ausderau Sideris Baranek	2014	Activity participation and sensory features among children with ASD	To investigate the extent to which sensory patterns impacted 6 dimensions of children's activity participation	Exploratory concept analysis	Home and Community Activities Scale (HCAS) (Dunst et al., 2000)	674 children with ASD aged 5.0–12.11 years were recruited through convenience sampling (an online research registry and autism organisations) (USA)	Parents completed electronic questionnaires via Qualtrics online survey software (Qualtrics Labs, 2011).	Increased hyperresponsiveness was inversely related to activity participation outside the home. Children with increased hypo responsiveness participated in more activities outside the home. Children with enhanced perception participated in activities more frequently. Children with increased sensory-seeking behaviour had limited participation outside the home setting.

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No.	Author(s)	Year of publication	Title	Aim	Design	Participation Measure	Participants Number Age Country Type of sampling	Procedures	Findings
9.	Egilson Jakobsdóttir Ólafsson Leósdóttir	2017	Community participation and environment of children with and without ASD: parent perspectives	To explore parent perspectives of participation patterns and environment supports and barriers for high-functioning children with ASD within their communities compared with a group of children without ASD	Descriptive quantitative survey	Participation and Environment Measure for Children and Youth (PEM-CY) (Coster, Law, & Bedell, 2010) translated into Icelandic	99 caregivers of children with ASD and 241 children without ASD. The children were aged 8.0–17.11 years. They were recruited through the registry of the State Diagnostic and Counselling Center, which keeps records of children diagnosed with ASD in Iceland. Purposive sampling method was used. (Iceland)	Prospective participants received an introductory letter via email. The letters contained a link to the study website. Parents logged onto the website and completed the questionnaire electronically.	Children with ASD participated less frequently, were less involved, and their parents were less satisfied with their child's participation in community-based activities. Parents reported fewer supports and more environmental barriers than parents of children without ASD.
10.	Simpson Keen Adams Alston-Knox Roberts	2017	Participation of children on the autism spectrum in home, school and community	To document patterns of participation and caregivers' views with regard to frequency and intensity of activities	Quantitative survey	Participation and Environment Measure for Children and Youth (PEM-CY) (Coster, Bedell, Law, Khetani, Teplicky, & Kao, 2011)	Caregivers of 218 children with ASD aged 5.0 years (N = 90) and 9.0–10.11 years (N = 128) were recruited through the Longitudinal Study of Australian Students with Autism (LASA) (Convenience sampling method) (Australia)	Caregivers completed the PEM-CY questionnaires online as part of the Longitudinal Study of Australian Students with Autism (LASA).	Similar patterns of participation emerged across home, school and community for both cohorts. Caregivers desired increased diversity, frequency and involvement in activities but desired a decreased use of electronics.
11.	Dovgan Mazurek	2019	Relations among activity participation, friendship and internalising problems in children with ASD	To evaluate the relations among friendship, activity participation, and internalising problems	Quantitative comparative survey	Child Behaviour Checklist (CBCL) (Achenbach & Rescorla, 2001) Vineland Adaptive Behaviour	129 children with ASD aged 6.0–18.11 years who participated in a larger study (The Simons Simplex Collection, University of Missouri, USA)	Parents were interviewed by the researchers using the Child Behaviour Checklist and the VABS-II.	Children who participated in sports, hobbies or clubs were more likely to have more friends. No relationships were found between friendships and internalising problems. No significant relation was found

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No.	Author(s)	Year of publication	Title	Aim	Design	Participation Measure	Participants Number Age Country Type of sampling	Procedures	Findings
						Scales- Second Edition (VABS-II) (Sparrow et al., 2006)	recruited via clinics, advocacy groups, web postings, radio and television advertisements. (Convenience sampling methods)		between activities and internalising behaviour.
12.	Santillan Frederick Gilmore Locke	2019	Brief report: examining the association between classroom social network inclusion and playground peer engagement among children with ASD	To explore how social network inclusion in the classroom is associated with playground peer engagement	Correlational mixed methods	Playground Observation of Peer Engagement (POPE) (Kasari, Rotheram-Fuller, & Locke, 2005)	55 children with ASD aged 5.0–12.11 years from 16 public schools north-eastern United States, recruited through convenience sampling methods (principals distributed recruitment documents)	Trained observers observed the participants during recess for an average of 15 minutes and completed the POPE.	The results have shown that children who were included in classroom's social network spent more time engaged in playground engagement. There was an association between social network inclusion and playground engagement.
13.	Simpson Adams Bruck Keen	2019	Investigating the participation of children on the autism spectrum across home, school, and community: A longitudinal study	To investigate the participation of children on the autism spectrum over a 3-year period across home, school and community	Longitudinal cross-sequential cohort	Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al., 2011)	Caregivers of 84 children with ASD aged 4.0–5.11 years and 9.0–10.11 years recruited through LASA (Convenience sampling methods were used) (Australia)	Caregivers completed the PEM-CY questionnaires online, as part of the Longitudinal Study of Australian Students with Autism (LASA).	Although participation in most activities across home, school and community remained stable, data suggested that children changed their types of socialising activities across time. There was a decline in physical activity and in participation of school activities over time.

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1.1.5 Summary of studies focused on children with ASD.

Three studies made use of the PEM-CY (Egilson, Jakobsdóttir, et al., 2017; Simpson et al., 2019; Simpson et al., 2017), which is a caregiver report measure of participation. The PEM-CY includes 25 questions about a child's participation across school, home and community settings (Simpson et al., 2018). Caregivers were asked to rate frequency of participation and level of involvement on Likert scales, as well as report on their desire for change in their child's participation. Caregivers from all three studies completed the questionnaires online. The Egilson, Jakobsdóttir, et al. (2017) study compared children with ASD to typically developing children, while the studies by Simpson et al. (2018) and Simpson et al. (2019) administered cohort studies for children with ASD only.

Egilson, Jakobsdóttir, et al. (2017) aimed to describe parents' perspectives of their child's participation patterns. Children with ASD participated less frequently than their typically developing peers and parents were less satisfied with their child's participation in community-based activities (Egilson, Jakobsdóttir, et al., 2017). Both studies by Simpson et al. (2018) and Simpson et al. (2019) aimed to investigate the patterns of participation from the caregivers' perspectives. In the study by Simpson et al. (2018) the focus was on the intensity and frequency of activities; it was found that children with ASD most frequently participated in electronic-related activities as well as indoor play. Caregivers reported desire for increased participation in activities involving other children. Simpson et al. (2019) investigated the patterns of participation of children with ASD across a three-year period. They found a decline in socialising with increased age and a decline in physical activities with increased age. Across the three studies, participation outside of the home was reduced (Egilson, Jakobsdóttir, et al., 2017; Simpson et al., 2019; Simpson et al., 2018).

Egilson, Jakobsdóttir, et al. (2017) highlighted external barriers to participation outside the home, such as lack of information, suitable programmes and services for children with ASD. Parents of children with ASD also mentioned lack of finances compared to parents with typically developing children to participate in organised sports (Egilson, Jakobsdóttir, et al., 2017). They concluded that the lack of environmental support may have contributed to the lack of community participation of children with ASD (Egilson, Jakobsdóttir, et al., 2017).

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Three studies made of use the Vineland Adaptive Behaviour Scales-Second Edition (VABS-II) (Dovgan & Mazurek, 2019; Poon, 2011; Potvin et al., 2013). The VABS-II (Sparrow et al., 2006) was a standardised semi-structured caregiver interview designed to measure communication, social skills, daily living skills and motor skills. The VABS-II has strong psychometric properties and has been frequently used in the study of persons with ASD (Poon, 2011). While Poon's study (2011) focused on adolescents with ASD, Dovgan and Mazurek (2019) and Potvin et al. (2013) used children with ASD as their participants. Poon (2011) used the VABS-II in comparison with a developing instrument, namely the Activity and Participation Rating Scale (APRS) where the VABS-II was used as a benchmark to assess adaptive skills. Potvin et al. (2013), on the other hand, used the VABS-II to compare parent reports with self-rating using the CAPE as the main assessment measure. Dovgan and Mazurek (2019) similarly used the VABS-II along with other measures, namely the CBCL. Although the VABS-II was used in all three studies, the goals and outcomes were considerably different.

The study by Poon (2011) aimed to describe activities and participation of adolescents with ASD. It was found that they had more difficulties in communication and community environments than in the home setting. It was stated that there was a lack of transferability of skills from the home to the community setting (Poon, 2011). Poon (2011) also found associations between the APRS and the VABS-II, supporting the use of the instrument to assess adaptive skills. Dovgan and Mazurek (2019) investigated the relations between activity participation, friendship and internalising problems in children with ASD. They found that children who participated in hobbies, sports or clubs were more likely to have more friends (Dovgan & Mazurek, 2019). The Potvin et al. (2013) study assessed recreational participation of children with high-functioning ASD but used the VABS-II as a secondary outcome measure to the CAPE.

Two studies made use of the CAPE/PAC (Hochhauser & Engel-Yeger, 2010; Potvin et al., 2013). The CAPE/PAC (King et al., 2004) was a 55-item questionnaire based on the child's report. It examined how children and young people participate in everyday activities in following areas: diversity, intensity, enjoyment of activities and context. The CAPE/PAC was the only measure among the studies which included self-rating instead of proxy ratings. In both studies the CAPE/PAC was used in addition to other assessments. Both studies compared children with ASD to their typically developing peers.

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Hochhauser and Engel-Yeger (2010) investigated the relation between sensory processing abilities and participation in leisure activities among children with high-functioning ASD. It was found that children with ASD displayed a limited range of activities, performed them less often and had a narrower group of participants or partners with which they engaged (Hochhauser & Engel-Yeger, 2010). They engaged in activities mostly based in the home. The study also found that the more severe the sensory processing impairment, the more limited the diversity and intensity of participation was in leisure activities (Hochhauser & Engel-Yeger, 2010). Potvin et al. (2013) investigated recreational participation of children with high-functioning ASD and found that they displayed less diversity of participation, participated in fewer physical activities and reported a narrower range of recreational activities. Both studies reported on reduced participation in leisure activities for children with ASD (Potvin et al., 2013; Hochhauser & Engel-Yeger, 2010).

The HCAS (Dunst et al., 2000) was included in two studies (Little et al., 2014; Little et al., 2015). The HCAS is an 83-item parent-report instrument used to characterise the frequency of children's participation in everyday activities in the home and community (Little et al., 2014). The HCAS includes a 5-point Likert scale which uses 10 home and 10 community factors. For the sake of these studies, the Likert scale was adapted to a 3-point Likert scale and caregivers rated their child's participation.

Little et al. (2014) aimed to derive dimensions of activity participation and examined the associations between activity participation, child characteristics and family demographics. The Little et al. (2015) study examined activity participation and sensory features in children with ASD. In both studies the participants were drawn from a larger longitudinal online survey study funded by the federal government of the United States of America. Findings from the Little et al. (2014) study suggested that participation of children with ASD was characterised by parent-child household activities, routine errands, neighbourhood-social activities, outdoor activities and faith-based activities. They also found that ASD severity affected the frequency of a child's participation in activities (Little et al., 2014). Findings related to the child's chronological age have shown that younger children participated more in parent-child household activities and community activities while older children more frequently participated in outdoor and faith-based activities (Little et al., 2014).

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Results from the Little et al. (2015) study suggested that children with increased hyperresponsiveness were less likely to participate in activities outside the home, and children with hypo responsiveness participated more frequently in activities outside the home. Little et al. (2015) recommended that further research was necessary to investigate identifying sensory subtypes for children with ASD and how activity participation differs per subtype.

The POPE (Kasari et al., 2005) and the Engagement Check (McWilliam, 1990) were both observation tools that examined engagement; both tools made use of trained observers. Both measures used a momentary time sampling procedure where children were observed for an allocated amount of time and data were recorded. The Engagement Check (McWilliam, 1990) was used by Pan (2009) in addition to other assessment tools. It was reported to have suitable reliability and validity estimates for children with ASD (McWilliam & Bailey, 1995). Santillan et al. (2019) used the POPE alongside another measure, namely the Friendship Survey (Cairns & Cairns, 1994).

In terms of the aims, Pan (2009) investigated the associations between age, social engagement and physical activity in children with ASD. According to Pan (2009), age had somewhat positive influences on social engagement and physical activity, and children who had frequent social engagement with adults were more physically active. The POPE is a coding system which identifies engagement states, namely solitary engagement and joint engagement in addition to social-communicative interactions with peers in the playground (Santillan et al., 2019). The study aimed to examine the association between classroom social network inclusion and playground peer engagement of children with ASD (Santillan et al., 2019). Results indicated that children who were included to a greater degree in their classroom's social network spent more time engaged with peers in the playground (Santillan et al., 2019). The two studies differed considerably in that one study assessed engagement with peers while the other reported on engagement with adults.

Zingerevich and LaVesser (2009) made use of the School Function Assessment (SFA), which rated a learner's performance for functional tasks that support participation in school activities. The SFA was completed by teachers and was divided into participation, task supports and activity performance. Only one subtest was used for this study, namely the participation subtest. Zingervich and LaVesser's study (2009) aimed to describe the contribution of executive

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functions on participation in school activities of children with ASD while controlling sensory processing. It was found that the more typical the sensory processing of the child, the better they participated in school activities (Zingervich & LaVesser, 2009). It was also found that executive functions contributed to participation in school activities (Zingervich & LaVesser, 2009).

Reynolds et al. (2011) and Dovgan and Mazurek (2019) made use of the Child Behaviour Checklist (CBCL), which is part of the Achenbach System of Empirically Based Assessments. It is a rating scale used to assess childhood emotional and behavioural problems (Dovgan & Mazurek, 2019). The CBCL was used differently across the two studies. Dovgan and Mazurek (2019) used the CBCL as a secondary measure to the VABS-II, while Reynolds et al. (2011) used the CBCL as a primary measure. The CBCL was administered by parents who answered questions relating to activities, social and school performance. Parents were asked to list activities their children participated in and rate them according to a 3-point Likert scale. The Reynolds et al. (2011) study aimed to examine activity patterns in children with and without ASD and also investigated the role of sensory responsiveness in determining a child's level of competence (Reynolds et al., 2011). Results have shown that children demonstrating more frequent sensory sensitivity and sensory avoiding had significantly lower competence scores than children with fewer behaviour traits associated with ASD (Reynolds et al., 2011). Findings also indicated that children with ASD more frequently engaged in solitary leisure activities in comparison to their typically developing peers. It was similarly reported that children with ASD were more engaged in chores or jobs that involved self-care, while their peers were more likely involved in chores that included the care of others (Reynolds et al., 2011). These results agree with results in previously mentioned studies.

1.1.6 ICF life domains of participation.

While reviewing the ICF life domains for participation, it was clear that most studies focused on assessing skills within the domain of interpersonal interactions and relationships along with leisure activities, which is a major life area. There was very limited focus on major life events except for leisure, mobility and general tasks and demands. There is a marked gap in the literature regarding the scope of ICF life domains covered by the existing evaluation tools of participation.

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Table 1 has illustrated that all studies ($n = 13$) included assessed participation in children with ASD using the following measures: PEM-CY (Coster et al., 2010), VABS-II (Sparrow et al., 2006), CAPE/PAC (King et al., 2004), HCAS (Dunst et al., 2000), POPE (Kasari et al., 2005), Engagement Check (McWilliam, 1990), CBCL (Achenbach & Rescorla, 2001) and the SFA (Coster et al., 1998). None of the studies reviewed were conducted in the UAE. All of the above-mentioned measures made use of proxy ratings (PEM-CY, VABS-II, HCAS, SFA) or observations (POPE, Engagement Check, CBCL) except one (CAPE/PAC). This highlights that there is a lack of self-rating participation measures for children with ASD.

According to Lami et al. (2018), a good measure of participation should be able to assess the extent of involvement and satisfaction with the activities in which they are engaged. For that reason, self-reporting tools are deemed the most appropriate (Lami et al., 2018). There is limited evidence using self-rating of children with ASD, which indicates a significant gap in the literature (Keith, Jamieson, & Bennetto, 2019). Many existing assessments make use of proxy responses instead of directly asking the child; in this way, the child's perspective is not considered (Imms et al., 2016). Arvidsson et al. (2012) have developed the self-report Participation Questionnaire (PQ), which was designed using the different life domains of participation according to the ICF. The PQ was administered with individuals with intellectual impairment. The instrument has been developed to assess the perceived importance and perceived performance of everyday tasks and has not yet been used with individuals with ASD (Arvidsson & Granlund, 2016).

This study aims to describe the patterns of participation and participation restrictions of school-aged children with mild to moderate ASD. To do this, the adapted short version of the PQ, namely the PQ 30 item (Arvidsson, 2019), will be used to guide structured interviews and gain the perspectives of school-aged children with ASD regarding their experiences of participation.

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2. METHODOLOGY

2.1 Research Aims

2.1.1 Main aim.

The current study aims to describe the patterns of participation and participation restrictions in different life domains of participation in school-aged children with mild to moderate ASD in the UAE.

2.1.2 Sub-aims.

The sub-aims of the study are to describe:

- i. the patterns of participation through frequency of attendance in children aged 10.0 to 17.11 years with mild to moderate ASD; and
- ii. participation restrictions in terms of non-attendance of important activities in children aged 10.0 to 17.11 years with mild to moderate ASD.

2.2 Design and Phases of the Study

This study was a quantitative non-experimental design. Non-experimental designs describe relationships between different phenomena without manipulating the conditions (McMillan & Schumacher, 2014). A structured interview with children with ASD utilising the PQ 30 item (Arvidsson, 2019) was conducted. Structured interviews involve using formulated questions, which allow participants to answer from a set of choices (McMillan & Schumacher, 2014). The advantages of structured interviews are that they have a high response rate, may be used with persons who cannot read or write and are adaptable (McMillan & Schumacher, 2014). According to Preece (as cited in Harrington & Foster, 2013), structured interviews which mostly contain closed-ended questions are appropriate for individuals with ASD as these individuals have difficulty recalling and narrating personal experiences or events. The disadvantages of structured interviews are that they are time-consuming, are not anonymous and subject effects may influence data collected

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(McMillan & Schumacher, 2014). An interview schedule was used to reduce these subject effects.

The research was administered in two phases, namely the preparation phase and the main study, as outlined in Figure 2.

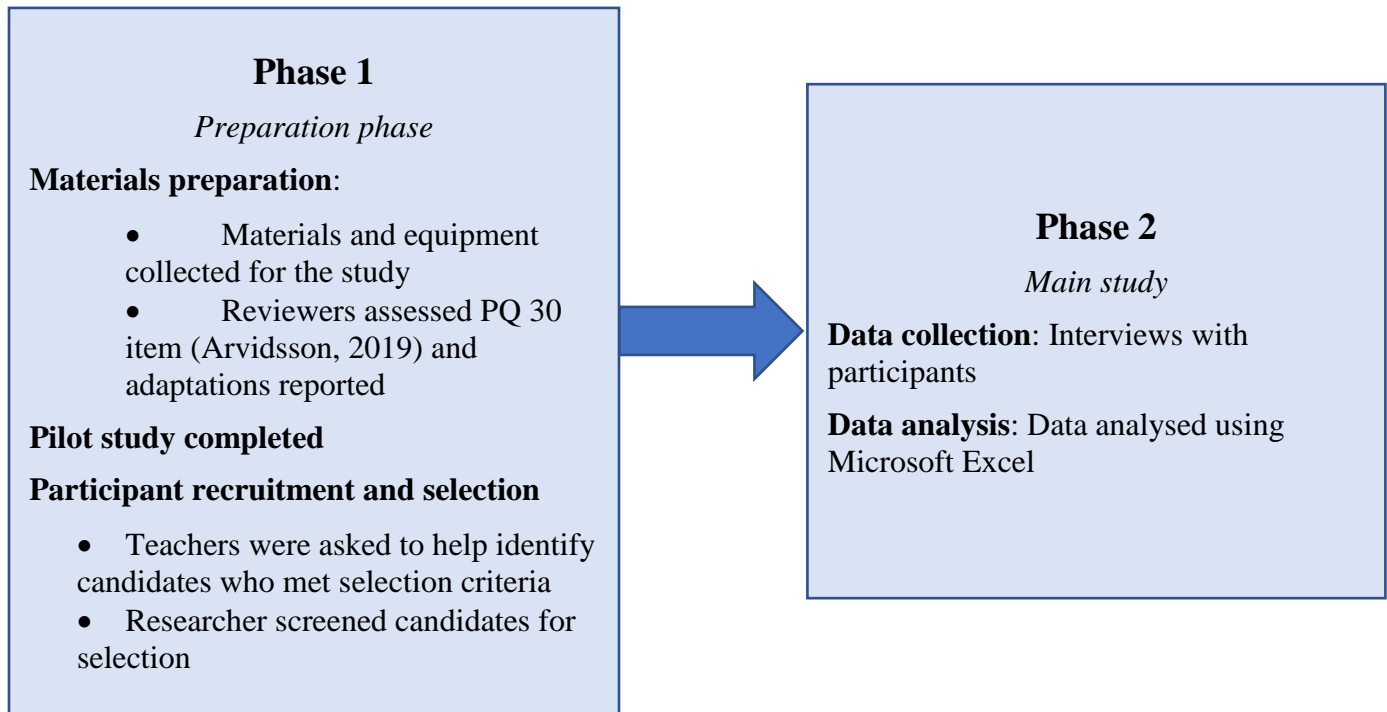


Figure 2
Phases of the study

2.3 Recruitment and Sampling

2.3.1 Setting.

The UAE consists of 90% expatriates who make use of the private school system and 10% Emirati nationals (World Population Reviews, 2020) who receive free public education. According to the federal law of the Abu Dhabi Government (29 of 2006), people with disabilities have equal rights, care and opportunities in education, training, healthcare and rehabilitation with emphasis on education in the private and public sectors (Abu Dhabi Government, 2006). Two independent special needs schools were approached in Abu Dhabi and Dubai, UAE. The language of instruction was English. The schools were co-educational schools which housed approximately 200 students ranging from 3.0 years to 18.11 years. Staff ratios varied from 1:2 to 1:8. The classes had a maximum of 10 students per class. Certain classes were satellite classes that were situated within

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mainstream schools across the suburbs of Abu Dhabi. The special needs schools followed different intervention approaches such as Applied Behaviour Analysis. The students followed a personalised curriculum based on individual education plans which were prescribed by a clinical team (educator, behaviour analyst, occupational therapist and speech therapist) on an annual basis. The schools had a limited number of students who attended inclusion at mainstream schools and were accompanied by a qualified shadow teacher from the special needs school.

School A was approached in January 2020 and permission was granted in the same month. Recruitment commenced on January 19, 2020. At School A, a total of 22 students were identified by teachers as possible candidates for the study. One candidate was removed from the list due to upcoming discharge from the special needs programme. A total of 21 research packs were distributed to caregivers and 13 were returned. Eleven (11) candidates provided consent to participate in the study and 8 declined consent. Two (2) candidates gave no response to consent for the study. One possible participant was excluded because he did not meet the age criteria of the study. One student who was previously discharged was recruited by the inclusion staff. Ten participants met the selection criteria after providing consent and completing the administration of the Childhood Autism Rating Scale – 2nd Edition (CARS-2) (Schopler, Van Bourgondien, Wellman, & Love, 2010).

School B was approached for recruitment of participants in February 2020. The researcher received a response from the school one month after requesting permission. Due to the Covid-19 outbreak, all schools in the UAE were closed indefinitely as of March 2020 and all research requests were declined. The researcher was informed that no participants could be approached at this time.

2.3.2 Participant selection.

Non-probability purposeful sampling was used to recruit participants. Participants were selected from one independent special needs school for children in the UAE. Purposeful sampling is less costly and a high participation rate is possible; however, results may be difficult to generalise due to poor representation of the identified population (McMillan & Schumacher, 2014).

Participants who met the selection criteria for the study are presented in Table 2 below.

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Table 2
Participant Selection Criteria

Criterion	Justification	Measure used
Participants should be between 10.0 and 17.11 years.	Children with disabilities as young as 8 years old have the ability to interpret questionnaires (Egilson, Olafsdottir, et al., 2017).	Ten Questions Screen-Parent Questionnaire (Durkin et al., 1994)
Confirmed diagnosis of ASD using the ADOS (Lord et al., 2000).	There is a limited body of research in participation of individuals with ASD (Egilson, Olafsdottir, et al., 2017).	Autism Diagnostic Observation Schedule (ADOS) completed on admission to the school for all participants (Lord et al., 2000).
Mild to moderate diagnosis of ASD.	Participants with mild-moderate ASD are better able to understand the expectation of participation in the study and express their opinions. High-functioning children with ASD can report on quality of life issues reliably (Egilson, Olafsdottir, et al., 2017).	The CARS-2 (Schopler et al., 2010) was used as a pre-assessment to describe the participants within their severity classification (Schopler et al., 2010).
Participants needed to attend at least two years at school with English as medium of instruction.	The interviews were conducted in English.	Teacher questionnaire Learner Screening Tool by Educators (LeSTE) (Naudé, 2014)
Functional hearing, vision and motor skills.	Participants should have been able to answer questions within a structured setting. Verbal instructions were provided in administration. Pictures were used in the interview materials. Data collection required the participant to point at pictures.	Teacher questionnaire (LeSTE) (Naudé, 2014)

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2.3.3 Participant description.

The participants were 10 school-aged children with ASD between the ages of 10.0 years to 16.8 years. Two (2) participants were female and 8 were male. One (1) of the participants attended a satellite special needs class at a mainstream school, while the rest of the participants were inclusion students, each with their own shadow teachers. Nine (9) of the participants were Emirati nationals while one participant was Palestinian/Jordanian. Below in Table 3 are graphs displaying the age distribution, gender, difficulties according to parents, difficulties and abilities according to teachers in addition to ASD severity according to the CARS-2.

Table 3

Description of participants

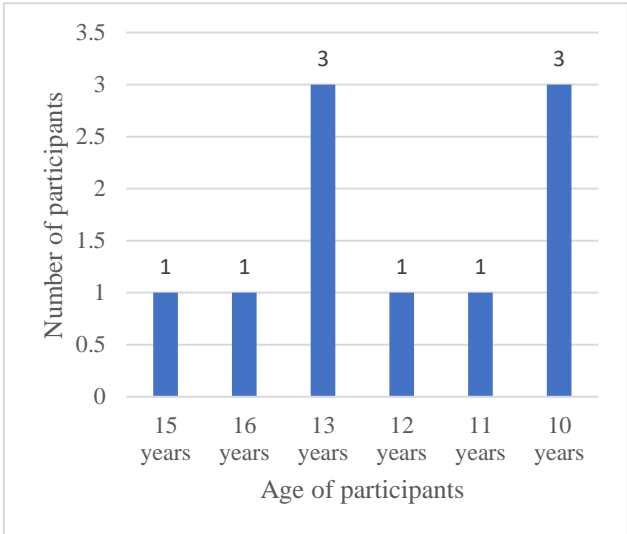
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Age distribution	 <table border="1" data-bbox="711 984 1333 1514"> <caption>Data for Figure 3.1: Age distribution of participants</caption> <thead> <tr> <th>Age of participants</th> <th>Number of participants</th> </tr> </thead> <tbody> <tr> <td>15 years</td> <td>1</td> </tr> <tr> <td>16 years</td> <td>1</td> </tr> <tr> <td>13 years</td> <td>3</td> </tr> <tr> <td>12 years</td> <td>1</td> </tr> <tr> <td>11 years</td> <td>1</td> </tr> <tr> <td>10 years</td> <td>3</td> </tr> </tbody> </table>	Age of participants	Number of participants	15 years	1	16 years	1	13 years	3	12 years	1	11 years	1	10 years	3
Age of participants	Number of participants														
15 years	1														
16 years	1														
13 years	3														
12 years	1														
11 years	1														
10 years	3														

Figure 3.1 illustrates the age distribution of the participants. The mean age of the participants was 12.2 years. Approximately 30% (n = 3) were aged 10.00–10.11 years; 30% were aged 13.0 years (n = 3); 10% were aged 15.0–15.11 years (n = 1); 10% were aged 16.0–16.11 years (n = 1); 10% were aged 11.0–11.11 years (n = 1) and 10% were aged 12.0–12.11 years (n = 1).

Figure 3.1

Age distribution of Participants

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Description	Figure
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Gender

Figure 3.2 shows that 80% of participants were male (n = 8) and 20% of the participants were female (n = 2).

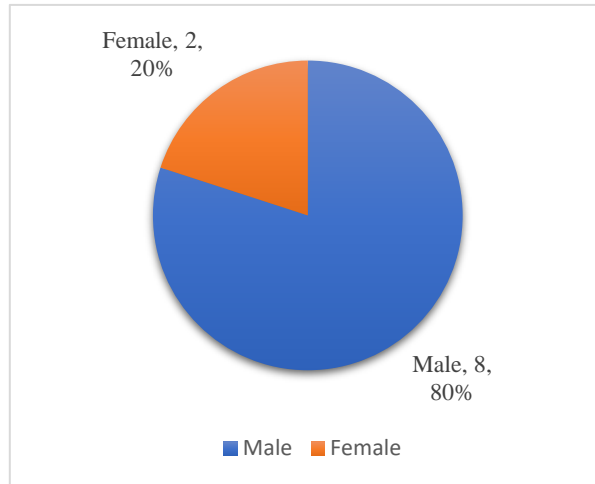


Figure 3.2
Gender of Participants

Difficulties according to the caregiver (TQS)

Caregivers completed the TQS (Durkin et al., 1994) and the caregiver responses are illustrated in Figure 3.3. Four caregivers (40%) indicated that their child was mentally slow (n = 4). Two caregivers (20%) reported their child to have language delay (n = 2). Four caregivers (40%) considered their child to have speech difficulties (n = 4). Three caregivers (30%) reported their child to have learning difficulty (n = 3). One caregiver (10%) reported their child to have fits or loss of consciousness (n = 1). None of the caregivers reported difficulties in walking or moving. None of the caregivers reported difficulties in understanding. One caregiver (10%) stated hearing difficulties (n = 1) and one caregiver (10%) indicated their child to have visual difficulties (n = 1). None of the

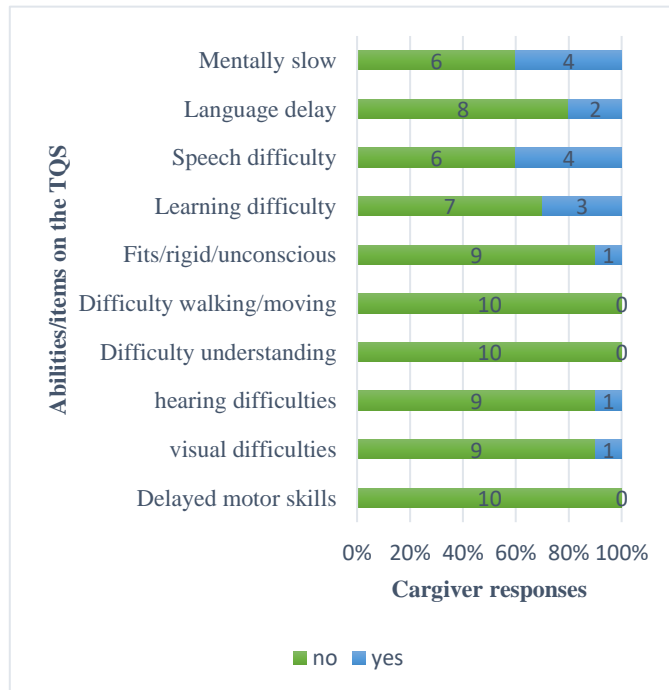


Figure 3.3
Difficulties according to the Caregiver (TQS)

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Description

caregivers stated delayed motor skills in their children.

Figure

Teachers perceptions of children’s abilities according to the LeSTE

Teachers completed the LeSTE (Naudé, 2014). According to teachers’ reports, 3 participants (n = 3) did not recognise PCS symbols and 7 (n = 7) were able to recognise PCS symbols. All of the participants (n = 10) were reported to understand English as their language of instruction. One teacher identified cognitive difficulties (n = 1), while 9 (n = 9) reported no cognitive difficulties. All of the participants (n = 10) had no reported motor difficulties. Two participants (n = 2) were reported to have hearing difficulties and 8 participants (n = 8) did not have hearing impairments. Seven participants (n = 7) were reported to have no visual difficulties while 3 (30%) were reported to have visual impairments.

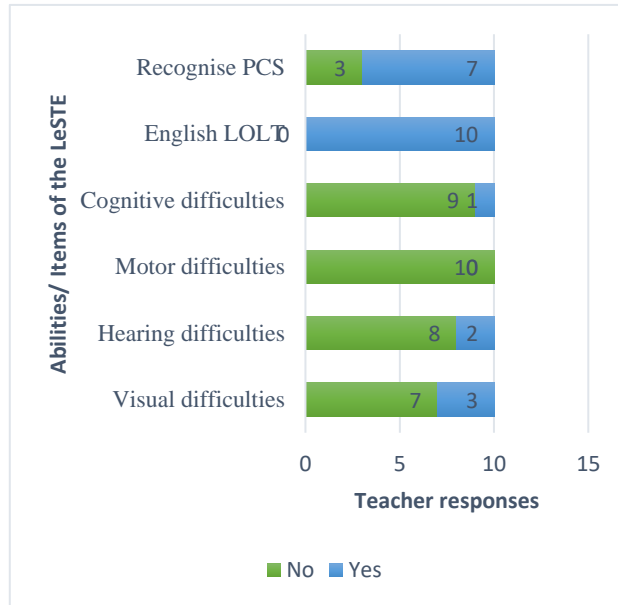


Figure 3.4

Abilities and Difficulties according to the Teacher (LeSTE)

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Description	Figure
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Autism severity according to CARS-2 administration

Figure 3.5 illustrates the results of the CARS-2 (Schopler et al., 2010) administered by the researcher. All of the participants (n = 10) had a total raw score between 15 and 27.5, which placed them all within the category of minimal to no symptoms on the autism spectrum.

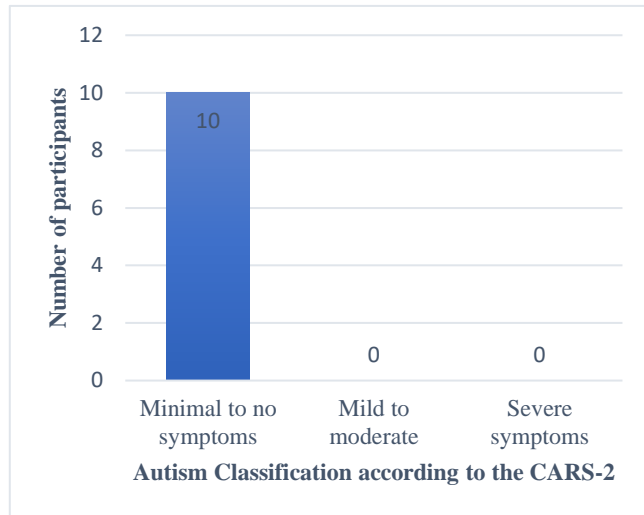


Figure 3.5

Autism Severity according to CARS-2

2.4 Pilot Study

A pilot study was conducted on one participant with ASD who met the selection criteria as outlined for the main study. The pilot study was administered to ensure that the procedures and measurements are appropriate for the study. The procedures were the same as those outlined in the Procedures section (section 2.6) below. The data collection procedures were refined after the pilot study had been administered.

2.4.1 Participant.

One child took part in the pilot study. The child selected passed the selection procedures for recruitment and selection. He was a boy aged 9.9 years and was predominantly English-speaking. He had a raw score of 30 on the CARS-2, which was rated as mild to moderate symptoms of ASD.

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2.4.2 Aims, materials, procedures, results and recommendations.

Table 4 provides the summary of aims, materials used, procedures used, the results and the subsequent recommendations.

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Table 4:

Pilot study aims, materials, procedures

Aim	Materials	Procedures	Results	Recommendations
To review and adapt the PQ 30 item (Arvidsson, 2019) to children with ASD living in the UAE	The Appropriateness Questionnaire	The Appropriateness Questionnaire was completed by English/Arabic speaking Emirati national adults.	Most reviewers deemed the PQ 30 item (Arvidsson, 2019) appropriate for use by children with ASD living in the UAE.	It is recommended that the PQ 30 item (Arvidsson, 2019) be used with minimal adaptations.
To determine the appropriateness of the recruitment strategy to identify potential participants	Teacher questionnaire (LeSTE) (Naudé, 2014)	The LeSTE was completed by the teacher.	The participant was able to participate in the study because it was identified that he had no other comorbidities such as vision, hearing, motor and cognitive impairments as seen on the LeSTE.	It is recommended that the same criteria be used for the main study.
To determine the appropriateness of the parent consent and parent questionnaire to identify potential participants	Parent consent form and parent questionnaire (Ten Question Screen) (Durken et al., 1994)	Both were completed by the caregiver.	According to the questionnaire, the participant did not present with medical history of cognitive, visual, nor motor abilities.	It is recommended that the same criteria be used for the study.
To determine the appropriateness of the CARS-2 to identify potential participants	CARS-2 (Schopler et al., 2010)	Screening measure administered by the researcher prior to data collection	The participant passed the screening procedures.	It is recommended that the same criteria be used for the study.

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Aim	Materials	Procedures	Results	Recommendations
To determine the appropriateness of PQ 30 item (Arvidsson, 2019) for children with ASD	PQ 30 item (Arvidsson, 2019) Picture supports	The interview was conducted with the participant and the PQ 30 item (Arvidsson, 2019) administered by the researcher.	The participant was able to understand and follow the instructions provided during the data collection process. The participant pointed at the picture supports provided.	It is recommended that the same wording be used during data collection. Keep changes as suggested by reviewers' recommendations.
To determine the procedural integrity of data collection	Audio recorder Procedural checklist	The interview was conducted by the researcher using the PQ 30 item (Arvidsson, 2019).	The researcher was able to complete all the procedures except requesting assent twice. The procedures were completed in one visit instead of the recommended two sessions. The participant was very distracted by the voice recording device at the beginning of the session.	It is recommended that only one contact session is necessary to complete all procedures on the checklist. It is recommended that assent be requested once. It is recommended that the iPad be placed face-down not to distract participants during the interview.
To determine the appropriateness of audio recording	iPad Air Otter meeting software	The assent procedure and interview were recorded using the Otter meeting software.	The quality of the recording was clear; however, the written transcriptions were inaccurate.	It is recommended that the same software be used.
To determine whether data recording and scoring had procedural integrity	PQ 30 item (Arvidsson, 2019) scoring forms Audio recordings (Otter meeting software) Microsoft Excel	A trained independent individual completed the scoring form while listening to the audio recording and form was compared to the researcher's original results. The trained individual also checked the scoring sheet and reviewed it with data	The data were documented accurately and scoring was administered correctly.	It is recommended that the trained individual continues to check and review data collection methods.

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Aim	Materials	Procedures	Results	Recommendations
		<p>captured onto the Excel spreadsheet.</p>		
<p>To determine whether the strategy selected for recording and analysing data was appropriate for this study</p>	<p>Microsoft Excel</p>	<p>Data captured by researcher onto Microsoft Excel</p>	<p>It was noted that data were easily captured on Microsoft Excel.</p>	<p>It is recommended that the data analysis procedure remains the same using Microsoft Excel.</p>

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2.4.3 Review and adaptation of Participation Questionnaire 30 item

The PQ 30 item (Arvidsson, 2019) was originally developed in Sweden for adolescents with Intellectual Disability. It was important to adapt the PQ 30 item (Arvidsson, 2019) for use with the ASD population in the UAE. The Questionnaire Appropriateness Form (Appendix O) was developed to ensure that the PQ 30-item (Arvidsson, 2019) had face validity. Face validity indicates that a questionnaire appears to be appropriate for the study purpose and content area. Face validity evaluates the appearance of the questionnaire in terms of clarity of wording, likelihood that the target audience would be able to answer the questions, as well as the layout (Parsian & Dunning, 2009). This form was administered prior to the pilot study. It was comprised of a list of questions that focused on different aspects of the questionnaire.

The Questionnaire Appropriateness Form was emailed to expert reviewers. The expert reviewers were Emirati national Arabic-English speaking individuals and needed to have at least two years' experience working with children. Eight forms were sent and eight were returned; however, three reviewers were excluded as they had less than two years' experience. The remaining reviewers were comprised of one male and four female Emirati national professionals. They completed the Questionnaire Appropriateness Form alongside the PQ 30 item (Arvidsson, 2019) and picture supports. Each question was structured as a Likert scale, with space to add comments. Each item had a statement, such as "The questions are clear". Possible responses were "Agree (1)", "Somewhat agree (2)" and "Disagree (3)". The graph below (Figure 4) displays the summary of responses using this 3-point Likert scale.

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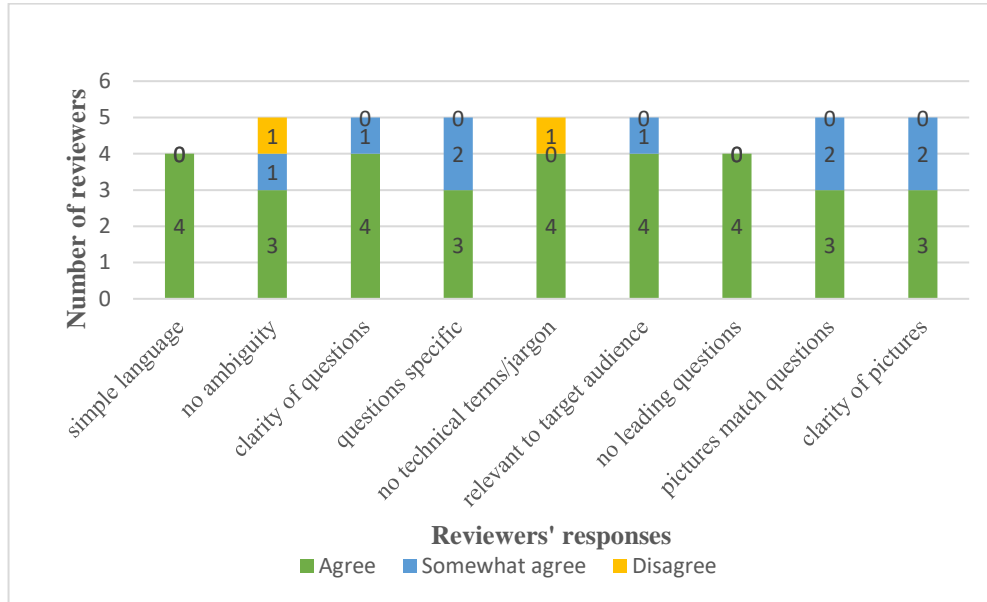


Figure 4

Results of Questionnaire Appropriateness Form

Figure 4 has illustrated that most reviewers rated the PQ 30 item (Arvidsson, 2019) as appropriate for use in children with ASD living in the UAE. The additional comments were collated, as seen in Table 5 below. The following adaptations were made according to these comments. Item 8 was rephrased as people do not typically watch the news on television. Examples of appropriate cultural activities were added for item 26. For item 29, examples of suitable outdoor activities were added.

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Table 5
Reviewer comments regarding Participation Questionnaire 30 item (Arvidsson, 2019)

Question on the PQ 30 item (Arvidsson, 2019)	Comments given by the reviewers	Adaptation	Adaptation made
7. Do you understand the text in a book or a newspaper?	We don't use newspaper. If you said read from iPad or book.	Disregard	No changes made.
8. Do you understand the TV news?	It's not typical for people to watch the news on TV, mostly on mobile phones.	Accept	Rephrase: Do you understand the news?
9. Do you take part in a discussion?	What kind of discussion?	Disregard	No changes made.
11. Do you travel by car, as a passenger?	Maybe no need for "passenger".	Disregard	No changes made.
16. Do you (roughly) know how to take care of yourself to keep healthy?	The word "roughly" may not be understood.	Accept	Omit the word "roughly" verbally.
22. Do you know how to make contact with someone new that you would like to know better?	Rephrase: Do you know what do to know someone new better?	Disregard	No changes made.
24. Do you handle your own money?	Might not be understood. Do you decide what to do with your money on your own?	Disregard	No changes made.
26. Do you participate in any cultural activity (e.g. theatre, playing music)?	The examples will clarify what is meant.	Accept	Add more examples, for example concert/ shows.

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29. Do you do activities in the countryside like hiking, picking fruit or fishing?

Change to: like camel-riding, falconry, go to the farm, play or help with looking after animals.

Accept

Add activities: camel-riding, falconry, going to the farm, play or help with looking after animals.

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2.5 Materials and Equipment

2.5.1 Letters.

The following letters of permission, consent and assent were used in this study.

2.5.1.1 Permission letter: School.

A school permission letter (Appendix B) was given to the Chief Executive Officer/principal of all schools to request permission to conduct research on their premises and to be allowed access to participants for the study. The letter contained information such as the purpose of the study, the method of data collection and how the data were used and stored as well as information regarding confidentiality of information and voluntary participation.

2.5.1.2 Permission letter: Graduate Studies Department at School.

A permission letter (Appendix C) was given to the Graduate Studies Department of the schools to ensure that families who were already involved in research projects were not approached to participate in this study. The letter outlined a brief description of how the research study was conducted in addition to the expectations from the staff and research participants.

2.5.1.3 Teacher consent letter.

The teacher consent letter (Appendix D) was given to teachers who were asked to identify students who suited the selection criteria outlined in Table 2. The consent letter included information regarding the aim of the study and selection criteria, and requested their willingness to complete the teacher questionnaire and assist with identifying suitable candidates for participation in the study.

2.5.1.4 Questionnaire reviewer consent letter.

The questionnaire reviewer consent letter (Appendix E) was given to English/Arabic speaking individuals who were asked to assist in completing the questionnaire appropriateness form. The consent letter included information regarding the aim of the study and requested their willingness to complete the questionnaire.

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2.5.1.5 Parent informed consent letter.

The parental informed consent letter (Appendices F1 and F2) was sent to parents to obtain permission for their children to participate in the research study. The parental informed consent letters were sent to a registered translation service company, where it was translated from English to Arabic. The documents were blind back-translated by an independent Arabic speaker to ensure that the information was accurate. Both English and Arabic consent letters were sent to parents, who completed their preferred translation. The letters contained relevant information such as the purpose of the study, selection criteria, data collection procedures and data storage. Parents were also provided with information regarding the confidentiality of the data and assured that participation was voluntary and that they could withdraw from the study at any time.

2.5.1.6 Participant Assent Letter.

The assent form (Appendix G) was completed with the participant and had picture support for ease of comprehension. The letter entailed details such as what would be expected from the participants and that they were able to withdraw or stop at any point.

2.5.2 Standardised measures.

2.5.2.1 Childhood Autism Rating Scale (CARS-2).

The CARS-2 (Schopler et al., 2010) (Appendix H) is a brief questionnaire, which distinguishes children with ASD from other developmental disorders and categorises severity according to presenting symptoms (Schopler et al., 2010). The instrument has 15 items, which assesses social communication and behavioural flexibility. The assessment was administered by a trained observer (the researcher) and a graded scale was used from non-autistic to severely autistic. The CARS-2 has shown good inter-rater reliability and good internal consistency (Schopler et al., 2010).

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2.5.3 Questionnaires

2.5.3.1 Ten Questions Screen.

The parent questionnaire (Appendices I1 and I2) (English and Arabic) was divided into two sections: Section A comprised the biographical information of the child and Section B the Ten Questions Screen (TQS). The TQS (Durkin et al., 1994) is an easy-to-use questionnaire, which was given to parents to complete regarding their child. It was a screener used to detect neurological impairment in children in resource-poor countries (Mung'ala-Odera et al., 2004). It has shown usefulness in Asia, Africa and the Caribbean (Mung'ala-Odera et al., 2004). The TQS consists of 10 questions addressing vision, hearing, movement, seizures, cognition and other health concerns. Reliability coefficients have been established within the range 0.6–0.8 (Mung'ala-Odera et al., 2004). The test-retest reliability is excellent for vision, motor, seizures and speech and questions on cognition; it is also fair for questions on developmental milestones and hearing (Mung'ala-Odera et al., 2004). The parent questionnaires (TQS) were sent to a registered translation service company where they were translated from English to Arabic. The documents were blind back-translated by an independent Arabic speaker to ensure that the information was accurate. English and Arabic questionnaires were sent to parents who completed their preferred translation.

2.5.3.2 Teacher Questionnaire: Learner Screening Tool by Educators

This questionnaire (Appendix J) included information that assisted in the selection of participants for the study, including their age, language abilities and participation within the classroom setting. The LeSTE (Naudé, 2014) was a questionnaire that teachers completed for each participant. It comprised 18 closed-ended questions intended to provide information on the learners' abilities pertaining to vision, hearing, motor skills, cognitive ability and language of learning and teaching.

2.5.3.3 Questionnaire Appropriateness Form

The Questionnaire Appropriateness Form (Appendix K) consists of nine questions regarding the face validity of the PQ 30 item (Arvidsson, 2019). The form was completed by Arabic- and English-speaking reviewers to ensure that the PQ 30 item was appropriate for use with children in

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the UAE. Each question was structured as a Likert scale, with space to add comments. Each item had a statement such as “The questions are clear”. Response options were “Agree (1)”, “Somewhat agree (2)” and “Disagree (3)”.

2.5.3.4 Participation Questionnaire 30 item (scoring booklet)

The original Participation Questionnaire was a 68-item questionnaire which was developed and tested in Sweden. Regarding self-rated performance, the Cronbach’s alpha was 0.86 and perceived importance was 0.83. This indicated that the internal consistency of the Participation Questionnaire was high (Arvidsson, Granlund, Thyberg, & Thyberg, 2014). The PQ 30 item (Arvidsson, 2019) was developed and tested with typically developing children in South Africa.

The PQ 30 item (Appendix L) has been adapted from the 68-item Participation Questionnaire, which was designed from the nine life domains of participation in the ICF (WHO, 2007). The Participation Questionnaire had a high Cronbach’s alpha which indicated optimal internal consistency of the instrument (Arvidsson et al., 2012). The PQ 30 item (Arvidsson, 2019) contained 30 questions and has been adapted to accommodate English-speaking participants. The questions contained responses based on a 3-point Likert scale namely “yes, often”, “yes, sometimes” and “no, seldom/never”. According to McMillan and Schumacher (2014), Likert scales provide flexibility because they vary in nature of the question and they provide accurate assessment of beliefs or opinions (McMillan & Schumacher, 2014). The Likert scales had visual supports, which displayed the responses “always”, “sometimes” and “never/seldom”.

This scoring booklet (Appendix L) was used to capture the data systematically and summarise the scores of each participant. On the cover page, details of the researcher, participant and date of administration were completed. The 30 questions were clearly stated with space left for answers to be added – “often”, “sometimes” and “seldom/never” – as well as the follow-up questions. On the last two pages, the answers were summarised and collated into frequency and importance scores.

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2.5.4 Data collection materials.

2.5.4.1 Procedural checklist.

A procedural checklist (Appendix M) was used to guide the data collection process and to help the researcher keep all conditions as unified as possible for procedural integrity.

2.5.4.2 Participation Questionnaire 30 item interview schedule.

The interview schedule (Appendix N) provided systematic guidelines of how to administer the structured interview using the questionnaire. It explained how visual support materials needed to be used for optimal use and standardised administration. In addition, the document stipulated how data collection and scoring should be administered correctly.

2.5.4.3 Participation Questionnaire 30 item picture supports.

The PQ 30 item (Arvidsson, 2019) contained pictures (Appendix O) used to represent each activity discussed. These pictures were black and white line drawings and were supported with text. A visual representation of “sometimes”, “often” and “seldom/never” aided in supporting participant responses.

2.5.5 Equipment.

2.5.5.1 Audio recording application.

An audio recording application, Otter Voice Meeting, was used to audio record all the interviews. Otter is an English-only voice recording application, which transcribes voice messages into meeting notes. It provided high quality voice recordings and organised recordings into folders. The application was uploaded onto an iPad Air 2 device.

2.5.5.2 iPad Air 2.

The iPad Air 2 had model number MGKL2AE/A. The Otter Voice Meeting application was downloaded onto this device. This device was used to record and store audio recordings.

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2.6 Procedures

2.6.1 Ethical procedures.

Ethical and legal responsibilities needed to be adhered to for research to be conducted with human participants (McMillan & Schumacher, 2014). The researcher submitted a research proposal to the ethics committee of the Faculty of Humanities at the University of Pretoria. Full ethical clearance was granted for the purpose of this study (Appendix A). Permission to conduct research was obtained from the Graduate Studies Department of the selected schools in Abu Dhabi, UAE (Appendix C). The schools approached were independent bodies; therefore, permission from United Arab Emirates Ministry of Education was not required.

Once institutional permission from Graduate Studies Department had been granted, teachers completed consent forms (Appendix D) to assist in selecting appropriate candidates for the study. The reviewer-informed consent forms (Appendix E) were distributed simultaneously so that reviewers could assist with review and adaptation of the PQ 30 item (Arvidsson, 2019). The teachers were asked to assist with the distribution and collection of the parent consent and parent questionnaires in sealed envelopes. The study was conducted using the principle of full disclosure where participants and their caregivers were informed about the purpose and procedures of the research (McMillan & Schumacher, 2014). This was done by ensuring that details were included on the consent letters of all parties involved. Each parent received English and Arabic consent letters (Appendices F1 and F2) and parent questionnaires (TQS) (I1 and I2) to complete the form in whichever language they preferred.

Once parental consent had been obtained, the teachers completed teacher questionnaires (Appendix J). The participant assent letter (Appendix G) was read to each participant before direct data collection and screening procedures were administered. According to McMillan and Schumacher (2014), no person should be forced or coerced into participating in research. All participants were informed that their participation was voluntary. Only after each participant had granted assent could data collection take place. Participation in this research study did not place participants at risk of harm or discomfort and participants were told that minimal risk was involved in this study.

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Confidentiality entails ensuring that the research is not connected to an individual subject's name (McMillan & Schumacher, 2014). The participants were each given a specific number and were referred to by their number instead of their names. All documentation made use of this numbering system. Confidentiality was maintained by ensuring that no person was able to access documents except the researcher and their supervisor. The data were delivered to the Centre for Augmentative and Alternative Communication (CAAC) for storage for 15 years in a locked cupboard. All audio recordings were stored electronically in password-protected files.

Teachers were consulted about the most appropriate time to conduct the study to ensure that it did not interfere with their academic time.

2.6.2 General procedures.

The researcher contacted one of the schools in person and arranged meetings with the Graduate Studies Department as well as the assistant director of transition and inclusion departments. Written permission was given by the Graduate Studies Department of the school. The researcher contacted the research team to co-ordinate the distribution of consent forms and allocation of contact time with possible participants. Informed consent was distributed to teachers, reviewers and caregivers. Teachers completed the LeSTE forms (Appendix J) after consent had been obtained for each participant. The questionnaire appropriateness form (Appendix L) was distributed to reviewers before the pilot study and data collection commenced.

2.6.3 Data collection.

Data collection took place face-to-face with seven participants. Although appointments had already been arranged, data collection was suspended when schools in the UAE were closed due to the Covid-19 outbreak on 5 March 2020. Schools were closed for two weeks; thereafter, distance learning programmes were introduced. Once distance learning had commenced, the researcher was allowed to continue data collection via Zoom or Microsoft Teams with the remaining three participants. The researcher administered the CARS-2 (Schopler et al., 2010) (Appendix H) with all the participants at a pre-arranged time to identify whether they had mild to moderate ASD. This was done by classroom observation and report of the classroom/shadow teacher. The teachers of

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the participants who were interviewed via Zoom were contacted via Microsoft Teams to provide information regarding the participants for the completion of the CARS-2.

Thereafter, the researcher administered the interview with each participant on the school premises in a quiet room or online.

The researcher used the audio recording of the session and administered the structured interview, PQ 30 item (Appendix L), alongside picture supports (Appendix O). For example, for question number 25, the researcher presented the picture representing sports. See the example below.



Figure 5
Picture support for PQ 30 item

The researcher then asked the question, “Do you participate in any sports activities?” The participant was asked to respond vocally or by pointing at the graphic representation or picture depicting the Likert-scale options “often”, “sometimes” and “seldom/never” (Figure 6).

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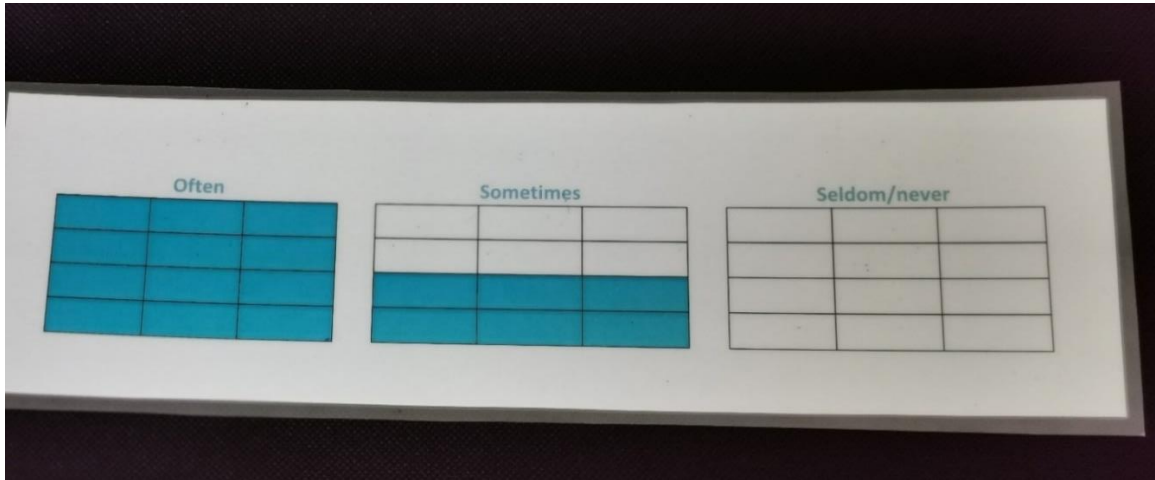


Figure 6

Response picture support for PQ 30 item

The researcher recorded data by marking the answers on the PQ 30-item scoring booklet (Appendix L) and asked the follow-up questions where applicable. If the participant had said “yes, often”, the researcher continued to the next question. If the participant responded with “sometimes/seldom/never”, a follow-up question was asked, for instance “Is this a problem for you?” The participant then answered “yes” or “no” to the question by pointing or answering vocally and the answer was marked onto the scoring sheet. For the online sessions, all picture supports were placed on the screen. Please see example in Figure 7 below.

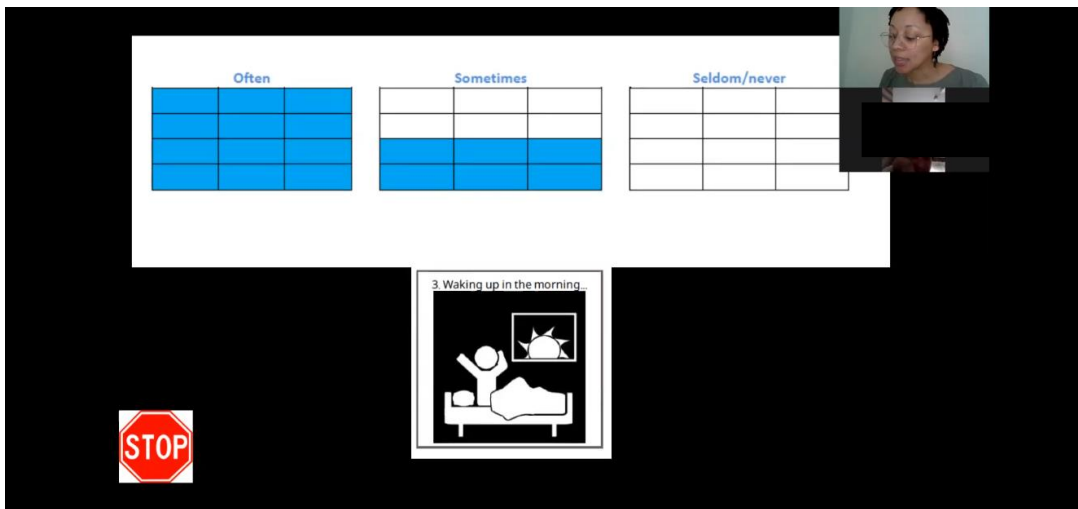


Figure 7

Picture layout for online data collection

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At the end of each session, once the interview had been completed, the participant received a preferred item of their choice as a token of appreciation. The researcher presented the participants with various stationery items to choose from. The online participants were thanked verbally.

2.6.4 Reliability.

2.6.4.1 Procedural reliability.

The researcher used the procedural checklist (Appendix M) and the PQ 30 item interview schedule (Appendix N) to ensure that the data collection process was administered in the same manner each time. Inter-rater reliability was used to ensure procedural reliability (McMillan & Schumacher, 2014). An independent rater checked 40% of the audio recordings and compared them with the procedural checklist (Appendix M). Inter-rater reliability was scored using the following formula (McMillan & Schumacher, 2014):

$$\frac{\textit{Number of agreements}}{\textit{Number of agreements and disagreements}} \times 100 = \%$$

2.6.4.2 Data reliability.

Inter-rater reliability was used to ensure data reliability (McMillan & Schumacher, 2014). The data were captured onto an Excel spreadsheet which was used to perform statistical analysis. An independent rater checked that 100% of the scoring sheets have been correctly transferred onto the Excel spreadsheet. The independent rater assessed a minimum of 40% of the questionnaires selected randomly and the ratings were compared using the following formula (McMillan & Schumacher, 2014):

$$\frac{\textit{Number of agreements}}{\textit{Number of agreements and disagreements}} \times 100 = \%$$

2.6.5 Data analysis.

Descriptive statistics was used to analyse the data collected in this study. Descriptive statistics is important for summarising and organising data (McMillan & Schumacher, 2014). It simplifies interpretation of quantitative data and determines general trends in the data (McMillan & Schumacher, 2014). Data were captured by the researcher using Microsoft Excel.

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The data consisted of 30 questions on a Likert scale. The responses were evaluated according to level of frequency and importance.

The following coding system was used:

Frequency	Importance
Seldom/never (1)	Not important (1)
Sometimes (2)	Important (2)
Often (3)	

The data were displayed in tables which presented the sum of all raw scores for each code mentioned above. Summary scores of frequency of attendance were calculated by combining the sum of raw scores per item on the PQ 30 item (Arvidsson, 2019). The summary of importance of activities were calculated by combining the raw scores per item on the PQ 30 item (Arvidsson, 2019). The ICF coding system was used to categorise the 30 items into ICF life domains (WHO, 2001). The ICF provides a functional description of outcomes for participation into nine life domains that are universally acknowledged (WHO, 2001). The life domains of participation, which have been previously mentioned, were mapped on this coding system. Table 6 below displays the ICF codes for the items on the PQ 30 item (Arvidsson, 2019) and how they fit into the different domains and subsections of the ICF.

Table 6
ICF Coding for data analysis

ICF Life Domain	Life Domain description	Selected item (ICF code)	PQ 30 item number
1. Learning and applying knowledge	This includes skills needed to learn, think, solve problems and make decisions.	Reading (p166)	1
		Writing (p170)	2
		Waking up in the morning (p230)	3

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ICF Life Domain	Life Domain description	Selected item (ICF code)	PQ 30 item number
2. General tasks and demands	This covers the skills needed to complete single or multiple tasks, for organising routines and for handling stress.	Getting to school in time (p230)	4
		Getting to bed in time (p230)	5
		Handling stress (p2401)	6
3. Communication	This includes skills needed to communicate in different ways, for receiving and giving messages and for using devices to communicate.	Understanding newspaper (p325)	7
		Understanding news (p310)	8
		Discussion (p355)	9
		Email or text messaging (p360)	10
4. Mobility	This includes moving the body in different positions and using different forms of transportation	Going by car (p470)	11
		Going by bus or taxi (p4702)	12
5. Self-care	This includes looking after the body by washing, dressing, eating and staying healthy	Showering or washing (p510)	13
		Brushing teeth (p5201)	14
		Knowing what to eat (p5201)	15
		Knowing to be healthy (p5702)	16
6. Domestic life	This includes domestic and everyday tasks such as household cleaning, shopping and assisting others	Buying/shopping (p620)	17
		Cooking or preparing food (p6300)	18
		Cleaning (p6402)	19
7. Interpersonal interactions and relationships	This includes skills needed to participate in basic and complex interactions which are context appropriate	Hanging out with friends (p7500)	20
		Making new friends (p7200)	21
		Making contact (p7200)	22
8. Major life areas	This includes tasks related to education, work and economic life	Going to school (p820)	23
		Handling money (p860)	24
9. Community, social and civic life	These include skills needed to participate in organised social life outside of family, within the community	Participating in sports activities (p9201)	25
		Participating in cultural activities (p9202)	26

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ICF Life Domain	Life Domain description	Selected item (ICF code)	PQ 30 item number
		Going to restaurants or cafes (p920)	27
		Going to the movies (p920)	28
		Doing countryside activities (p920)	29
		Going on holiday (p920)	30

Section 3: Results

3: RESULTS

The results were checked for procedural and data reliability. Inter-rater reliability for procedural integrity was calculated at 98%, which was considered to be excellent (McMillan & Schumacher, 2014). For data reliability, the rater checked 100% of data transferred from scoring sheets to the Excel spreadsheet. The transfer of data was 100% accurate. Inter-rater reliability for the questionnaires was 95.5%, which indicated good data reliability (McMillan & Schumacher, 2014).

Table 7 illustrates responses for the frequency of attendance for the PQ 30 item (Arvidsson, 2019). Raw scores were used in this table. The summary score represented the total of frequency scores for the item across all participants. No data were missing for frequency of attendance.

Table 7
Frequency of Attendance (N = 10)

Number	Item	Based on ICF code	Often	Sometimes	Seldom/never	Summary score
1	Reading	p166	4	6	0	24
2	Writing	p170	7	3	0	27
3	Waking up in the morning	p230	6	4	0	26
4	Getting to school in time	p230	4	6	0	24
5	Getting to bed in time	p230	6	4	0	26
6	Handling stress	p2401	5	3	2	23
7	Understanding newspaper	p325	6	3	1	25
8	Understanding news	p310	3	4	3	20
9	Discussion	p355	3	7	0	23
10	Email or text messaging	p360	6	3	1	25
11	Going by car	p470	9	1	0	29
12	Going by bus or taxi	p4702	1	6	3	18
13	Showering or washing	p510	9	1	0	29
14	Brushing teeth	p5201	10	0	0	30

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Number	Item	Based on ICF code	Often	Sometimes	Seldom/never	Summary score
15	Knowing what to eat	p5701	5	5	0	25
16	Knowing to be healthy	p5702	7	2	1	26
17	Buying/shopping	p620	0	10	0	20
18	Cooking or preparing food	p6300	0	3	7	13
19	Cleaning	p6402	1	6	3	18
20	Hanging out with friends	p7500	4	6	0	24
21	Making new friends	p7200	3	6	1	22
22	Making contact	p7200	6	3	1	25
23	Going to school	p820	9	1	0	29
24	Handling money	p860	5	3	2	23
25	Participating in sports activities	p9201	6	3	1	25
26	Participating in cultural activities	p9202	5	4	1	24
27	Going to restaurants or cafes	p920	1	8	1	20
28	Going to the movies	p920	3	6	1	22
29	Doing countryside activities	p920	3	2	5	18
30	Going on holiday	p920	3	6	1	22

Table 7 above displays the raw scores of the PQ 30 item (Arvidsson, 2019) in terms of frequency of attendance ratings. The items reported as *often* by most participants were the items Brushing teeth (p5201) (n = 10), followed by Going to school (p820) (n = 9), Showering and washing (p510) (n = 9) and Travelling by car (p470) (n = 9). This indicated high frequency of attendance for these items. The following items were rated *often* once (n = 1): Going to restaurants or cafes (p920), Going by taxi or bus (p4702) and Cleaning (p6402). The items that had no ratings for *often* were Buying or shopping (p620) along with Cooking or preparing food (p6300).

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The items with the most *seldom/never* ratings were Cooking or preparing food (p6300) (n = 7) followed by Doing countryside activities (p920 (n = 5), in addition to Cleaning (p6402) (n = 3), Going by bus or taxi (p4702) (n = 3) and Understanding the news (p310) (n = 3). This shows that there is low frequency of attendance for these activities.

In terms of the summary scores, the items with the highest summary scores were the items Brushing teeth (p5201) (n = 30), followed by Going to school (p820) (n = 29), Showering or washing (p510) (n = 29) and Going by car (p470) (n = 29). The lowest summary scores were Cooking or preparing food (p6300) (n = 13), thereafter Going by bus or taxi (p4702) (n = 18), Cleaning (p6402) (n = 18) and Doing countryside activities (p920) (n = 18).

According to the ICF life domains (World Health Organization, 2001), domain 5, Self-care, which includes the items Showering or washing (p510), Brushing teeth (5201), Knowing what to eat (p5701) and Knowing to be healthy (p5702) had the highest number of *often* ratings, followed by domain 2, General tasks and demands, which includes the items Waking up in the morning (p230), Getting to school in time (p230), Getting to bed in time (p230) and Handling stress (p2401). The life domain with the highest *seldom/never* scores was life domain 9, Community, social and civic life, including the items Participating in sports activities (p9201), Participating in cultural activities (p9202), Going to restaurants or cafes (p920), Going to the movies (p920), Doing countryside activities (p920) and Going on holiday (p920). This was followed by life domain 6, Domestic life, including the items Buying or shopping (p620), Cooking or preparing food (p6300) and Cleaning (p6402).

Table 8 illustrates the responses for level of involvement in relation to frequency of attendance ratings on the PQ 30 item (Arvidsson, 2019). The importance ratings need to be viewed in the light of the premise that items which were answered with the *often* rating for frequency did not have a rating for importance. This means that the table contains importance ratings made when participants answered *sometimes* or *seldom/never* for frequency of attendance.

Section 3: Results

Table 8
Participants' ratings of importance of activities (N = 10)

Number	Item	Sometimes or seldom/never attended but rated		Often attended
		Important to attend	Not important to attend	Not rated
1	Reading	5	1	4
2	Writing	2	1	7
3	Waking up in the morning	3	1	6
4	Getting to school in time	5	1	4
5	Getting to bed in time	4	0	6
6	Handling stress	3	2	5
7	Understanding newspaper	4	0	6
8	Understanding news	4	3	3
9	Discussion	7	0	3
10	Email or text messaging	2	0	8
11	Going by car	1	0	9
12	Going by bus or taxi	3	6	1
13	Showering or washing	1	0	9
14	Brushing teeth	0	0	10
15	Knowing what to eat	4	1	5
16	Knowing to be healthy	3	0	7
17	Buying/shopping	8	2	0
18	Cooking or preparing food	6	4	0
19	Cleaning	7	2	1
20	Hanging out with friends	3	2	5
21	Making new friends	4	3	3
22	Making contact	3	1	6

Section 3: Results

Number	Item	Sometimes or seldom/never attended but rated		Often attended
		Important to attend	Not important to attend	Not rated
23	Going to school	1	0	9
24	Handling money	4	1	5
25	Participating in sports activities	4	0	6
26	Participating in cultural activities	3	2	5
27	Going to restaurants or cafes	4	5	1
28	Going to the movies	4	3	3
29	Doing countryside activities	3	4	3
30	Going on holiday	6	1	3

In Table 8, the items rated as most *important* were the items Buying or shopping (p620) (n = 8), Cleaning (p6402) (n = 7) and Discussion (p355) (n = 7), followed by Going on holiday (p920) (n = 6). This indicates that these may be possible participation restrictions because they had attendance ratings of *sometimes* or *seldom/never*. The items rated as least *important* were the items Going by bus or taxi (p4702) (n = 6), Going to restaurants or cafes (p920) (n = 5), Cooking and preparing food (p6300) (n = 4) and Doing countryside activities (p920) (n = 4).

The items with the most “non-rated” for importance scores were the items Brushing teeth (p5201) (n = 10), Showering or washing (p510) (n = 9), Going by car (p470) (n = 9) and Going to school (p820) (n = 9). The items with the least “non-rated” items were the items Buying or shopping (p620) (n = 0) and Cooking or preparing food (p6300) (n = 0), followed by Going to restaurants or cafes (p920) (n = 1), Cleaning (p6402) (n = 1) and Going by bus or taxi (p4702) (n = 1). Of the items which were rated for importance, the most ratings for *not important* was the item Going by bus or taxi (p4702) (n = 6) and then Going to cafes or restaurants (p920) (n = 5). These scores would not indicate possible participation restrictions, as the participants did not deem these activities as being important.

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The ICF life domain which had very high scores for importance was life domain 3, Communication, which includes the items Understanding newspaper (p325), Understanding news (p310), Discussion (p355) and Email or text messaging (p360) with ratings between (n = 4) and (n = 7). This may indicate likely participation restriction. Similar findings were reported for the life domain, Domestic life, including the items Buying or shopping (p620), Cooking or preparing food (p6300) and Cleaning (p6402), where importance scores were high (n = 6), (n = 7) and (n = 8) respectively. The third life domain which had high importance ratings was life domain 9, Social, civic and community life, including the items Participating in sports activities (p9201), Participating in cultural activities (p9202), Going to restaurants or cafes (p920), Going to the movies (p920), Doing countryside activities (p920) and Going on holiday (p920) where scores ranged between (n = 3) and (n = 6).

Table 9

Comparison of items with low level of attendance and high level of importance (N=10)

Item	Lowest scores for frequency of attendance (summary scores)	Item	Highest scores for participant ratings of importance of activities
Cooking and preparing food	13	Buying/shopping	8
Doing countryside activities	18	Discussion	7
Going by bus or taxi	18	Cleaning	7
Cleaning	18	Going on holiday	6
Buying/shopping	20	Cooking or preparing food	6
Going to restaurants or cafes	20	Reading	5
Understanding news	20	Getting to school on time	5

Table 9 shows that there were items that scored low for attendance and high for importance at the same time. The items Cleaning (p604), Buying/shopping(p620), Cooking and preparing food (p6300) were amongst the lowest scores for Frequency of attendance and were amongst the highest scores for Importance ratings. These items all form part of the Domestic life domain on the ICF. These scores display a possible participation restriction in this life domain. Although Doing countryside activities (p920), going by bus or taxi (p4702), Going to restaurants or cafes (p920) and Understanding news (p310) were amongst the lowest scores for frequency of attendance, they were not amongst the highest scores for importance of activities. This may imply that these activities may not have been important to the participants. The items Discussion (p355), Going on holiday (p920), Reading (p166) and Getting to school on time (p230) were

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rated amongst the highest for importance, but were not amongst the lowest scores for attendance. This may imply that these activities are important, but do not necessarily pose as participation restriction.

Section 4: Discussion

4: DISCUSSION

This study investigated the patterns of participation and participation restrictions in different life domains of school-aged children with ASD. These results will be discussed using the two-sub-aims: 1) to explore the patterns of participation through frequency of attendance and 2) to explore the patterns of participation restrictions in terms of non-attendance of important activities in different life domains of participation in school-aged children with ASD in the UAE.

4.1 Patterns of Participation – Frequency of Attendance

The life domain Self-care, including the items Showering or washing, Brushing teeth, Knowing what to eat and Knowing to be healthy, was rated the highest for frequency of attendance in the PQ 30 item (Arvidsson, 2019) across all participants. This is in line with previous literature by Reynolds et al. (2011) who reported that children with ASD were more engaged in chores or jobs that involved self-care and organisation, while their peers were more likely involved in chores that included the care of others. Poon (2011) had similar findings where adolescents with ASD rated self-care as the least problematic.

The life domain General tasks and demands, which includes the items Waking up in the morning, Getting to school in time, Getting to bed in time and Handling stress, was rated *often* for most participants (60%) except for the item Going to school on time (40%). In terms of importance ratings, this domain was rated moderately as about half of the participants rated these items as *important*. In the study by Poon (2011), this life domain was rated less problematic than the life domains Domestic life, Major life areas, Communication and Interpersonal interactions and relationships.

For the item Participation in sports activities, 50% or more participants in this study had a rating of *often* or *sometimes*, meaning that they reported high levels of participation in sports. The participants who had rated *sometimes* for frequency of attendance rated this item as *important*. High levels of attendance are measured by frequency of attendance and the range of activities the person partakes in, while involvement is measured by the quality of the experience such as motivation and social connections (Imms et al., 2016). These finding conflict with Little et al. (2014) who stated that adolescents with ASD participated less frequently than typically developing

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peers in recreational activities and community activities; however, proxy reports were used. This means that frequency of attendance was measured, but not involvement.

4.2 Patterns of Participation Restrictions

With regard to the life domain Mobility, the results have shown that Going by car was rated *often* for 90% of participants, while one participant rated Going by bus or taxi as *often*. It is important to note that most participants in this study rated Going by bus or taxi as *not important*. This suggests that participants mostly travelled by car and did not make use of public transportation. It may be possible that they did not view access to public transportation as a necessity. Poon (2011) stated that many persons with ASD do not know how to access public transportation, although Mobility was rated the least problematic by adolescents with ASD. The life domain Mobility may not be viewed as a participation restriction, because it was not considered as important from the perspective of the participants.

For the Community, social life and civic life domain, which includes Participating in sports activities, Participating in cultural activities, Going to restaurants or cafes, Going to the movies, Doing countryside activities and Going on holiday, all of the items were rated as *often* for less than half of the participants, except for Going on holiday. This indicates that community participation was less frequent than home participation. Community, social and civic life was also rated the third highest for importance ratings in relation to lack of frequency of attendance. This may indicate possible participation restrictions in the life domain of Community, social and civic life. A similar conclusion was reached by Poon (2011) where adolescents with ASD rated participation in the community as problematic. These findings were consistent with Potvin et al. (2013) who stated that children with ASD participate in activities in fewer locations than their peers, such as the home and a relative's home. The fact that children with ASD spend more time within the home setting versus the community may pose as a possible participation restriction.

Regarding the Interpersonal interactions and relationships life domain, which includes Hanging out with friends, Meeting new friends and Making contact, the results show that less than half of the participants ($n = 4$) had a frequency score of *often* and only the item Making contact was marked as *often* for most participants ($n = 6$). The importance ratings were relatively low at ($n = 3$) and ($n = 4$). This suggests low to moderate social interaction with others. These findings

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were supported by Reynolds et al. (2011) who stated that deficits in social skills lead to a failure to seek out or develop peer relationships and limit opportunities for children with ASD to learn from social activities. Although children with ASD desire to have friends, they often have difficulty with social success (Dovgan & Mazurek, 2019). This premise is also supported by Egilson, Jakobsdóttir, et al. (2017) who stated that children with ASD are more likely to engage in activities alone or with adults instead of with their peers. This life domain may display a possible participation restriction in this study because it was rated high for importance and low for frequency of attendance. Dovgan and Mazurek (2019), as well as other researchers, have attributed barriers in social interaction to difficulties in communication.

Apart from taking part in Discussions ($n = 7$), low frequency scores were reported for the rest of the Communication life domain, which includes Understanding newspaper, Understanding news, Discussion and Email or text messaging on the PQ 30 item (Arvidsson, 2019). It was similarly rated as the most important domain in relation to frequency of attendance, indicating possible participation restrictions. These results tie well with previous studies. The study by Poon (2011) found that adolescents with ASD have significant difficulties in communication, including abnormal prosody, reciprocity of interactions and poor language use, which appeared to be significant participation restrictions.

None of the participants rated the Domestic life domain, which includes Buying or shopping, Cooking or preparing food and Cleaning, as *often* on the frequency ratings. This was the lowest scored life domain for frequency ratings in this study. It was also rated as the second most important domain in relation to frequency of attendance. This may pose to be a possible participation restriction as independence in domestic life facilitates independence as children transition to adulthood (Poon, 2011). According to Poon (2011) most adolescents with ASD have low levels of independent living and heavily rely on their parents for day-to-day tasks. Egilson, Jakobsdóttir, et al. (2017) reported that the body of research available regarding children with ASD and their participation in household tasks is limited. They also found that 27% of parents required their children with ASD to do no chores in the home as opposed to 7.6% of their peers who had to do chores (Egilson, Jakobsdóttir, et al., 2017). Possible participation restrictions in the life domain Domestic life may affect participation in other life domains, such as major life areas.

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In terms of the life domain 8, Major life areas, most of the participants ($n = 9$) reported that they go to school *often* while half ($n = 5$) indicated that they handle their own money *often*. This finding is consistent with current literature where it was reported that most children with ASD attend school, mostly in special needs settings. Unfortunately, limited literature was found regarding money management in children with ASD and therefore no comparison could be made to previous studies. It may be possible that, seeing that parents take a more active role as they mature, a child with ASD may not necessarily have the exposure to handle their own money. This may pose a possible participation restriction if they do not actively participate economically.

In the light of the findings from this study, it is important to consider the cultural aspects which may have influenced the results. An example would be that in many Arab homes, children have several live-in nannies/domestic workers who are responsible for different duties such as child-care, cooking, cleaning and shopping. In certain households, the families have an employed driver who drives the family car daily. There remain significant differences in child-rearing practices of boys and girls. Asian cultures have traditionally kept persons with disabilities at home and away from community participation (Poon, 2011). As mentioned before, stigmatisation of children with special needs and the perceived shame of having a child with special needs are still widespread in this region. However, this is changing.

Section 5: Critical Evaluation, Implications and Conclusions

5: CRITICAL EVALUATION, IMPLICATIONS AND CONCLUSIONS

5.1 Critical Evaluation of the Study

The first limitation of this study was its small sample size. The strict selection criteria may have made sampling a challenge, along with the Covid-19 outbreak, which occurred during this time. This study was a descriptive analysis that described patterns of participation and participation restrictions, but did not permit causal inferences to be made. Due to the sample size, limited statistical analysis could be administered.

Additionally, only children with high functioning ASD were used in this study. According to the CARS-2, the participants included in the study had minimal symptoms of ASD, which placed them into the category of high functioning ASD, thus the results would have implications on this population.

Another limitation was that recruitment only took place from one site. It would have been more beneficial to have participants from various sites to be able to make better inferences regarding children with ASD in the region.

It is hoped that the strength of the study was reliable in terms of the data collection procedures applied, although data collection took place face-to-face as well as virtually. The external environment was easier to control in face-to-face conditions, as opposed to the virtual setting where environmental noise or interruptions were more likely to occur.

A strength of this study was that children with ASD were asked directly regarding their participation and no proxy ratings were used. This study has shown that the PQ 30 item (Arvidsson, 2019) can be used to assess participation in English-speaking children in the UAE with limited number of adaptations.

5.2 Clinical Implications

Due to the probable participation restrictions in the areas of communication, community life and interpersonal relationships, it may be necessary to have interventions that target these areas in children with mild to moderate ASD. This study also highlights that the ICF coding is an effective tool to analyse participation in a holistic manner.

Section 5: Critical Evaluation, Implications and Conclusions

5.3 Recommendations for Further Studies

It is recommended that this study be replicated using a larger sample size, so that statistical analysis would be more easily applied. It would also be recommended to include participants along the severity of ASD, such as children moderately affected. This would assist in making the findings easier to generalise to the wider population of children with ASD.

It would be beneficial to see the PQ 30 item (Arvidsson, 2019) used alongside another reliable measure of participation to compare results and gain more knowledge about participation patterns in children with ASD.

A mixed quantitative and qualitative design would provide more insight into the participants' perceptions that would not have been captured in this study. An example would have been to add a section for why an activity was or was not important to the participant.

It is recommended that further research be administered regarding participation of adolescents with ASD who are at school-leaving age in order to provide the necessary support and services for transition into adulthood.

5.4 Conclusion

This study investigated the patterns of participation using frequency of attendance and participation restrictions in school-aged children with ASD. The PQ 30 item (Arvidsson, 2019) was used to interview school-aged children with ASD using frequency of attendance and importance ratings in relation to frequency of attendance. Possible participation restrictions were highlighted in the areas of communication, interpersonal interactions and relationships, mobility and in community participation. Positive trends were documented in the areas of self-care and domestic life as well as daily tasks and demands. However, the results display that participation restrictions appeared more marked for some participants in this study.

References

REFERENCES

- Abu Dhabi Government. (2006). Federal Law No. (29) of 2006 Concerning the Rights of People of Determination. Retrieved 5 November 2019 from: <https://www.tamm.abudhabi/en/aspects-of-life/peopleofdetermination/peopleofdeterminationrights/LawsandRegulations/federal-law-no-29-of-2006-concerning-the-rights-of-people-of-determination>
- Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for the ASEBA school-age forms & profiles*. Burlington, VT: University of Vermont, Research Centre for Children, Youth & Families.
- Adair, B., Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: A systematic review. *Developmental Medicine & Child Neurology*, 60(11), 1101-1116. doi:10.1111/dmcn.13959
- Alnemary, F. M., Alnemary, F. M., & Alamri, Y. A. (2017). Autism research: Where does the Arab world stand? *Review Journal Autism Developmental Disorders*, 4(2), 157-164. doi: 10.1007/s40489-017-0104-6
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th Ed.). Arlington, VA: American Psychiatric Association.
- Arvidsson, P. (2019). *Participation questionnaire - Short 6-16 version*. Sweden. Council of Europe. European Commission.
- Arvidsson, P., & Granlund, M. (2016). The relationship between intelligence quotient and aspects of everyday functioning and participation for people who have mild and borderline intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31(1), e68-e78. doi: 10.1111/jar.12314
- Arvidsson, P., Granlund, M., Thyberg, I., & Thyberg, M. (2014). Important aspects of participation and participation restrictions in people with a mild intellectual disability. *Disability and*

References

Rehabilitation, 36(15), 1264-1272, doi: 10.3109/09638288.2013.845252

- Arvidsson, P., Granlund, M., Thyberg, I., & Thyberg, M. (2012). International classification of functioning, disability and health categories explored for self-rated participation in Swedish adolescents and adults with a mild intellectual disability. *Journal of Rehabilitation Medicine*, 44(7), 562-569. doi:10.2340/16501977-0976
- Arvidsson, P., Granlund, M., & Thyberg, M. (2008). Factors related to self-rated participation in adolescents and adults with mild intellectual disability - a systematic literature review. *Journal of Applied Research in Intellectual Disabilities*, 21(3), 277-291. doi: 10.1111/j.1468-3148.2007.00405.x
- Askari, S., Anaby, D., Bergthorson, M., Majnemer, A., Elsabbagh, M., & Zwaigenbaum, L. (2015). Participation of children and youth with autism spectrum disorder: A scoping review. *Review Journal of Autism and Developmental Disorders*, 2(1), 103-114. doi: 10.1007/s40489-014-0040-7
- Cairns, R., & Cairns, B. (1994). *Lifelines and risks: Pathways of youth in our time*. New York, NY: Cambridge University Press.
- Coster, W. J., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Lilfenquist, L., Kao, Y. C. (2011). Psychometric evaluation of the participation and environment measure for children and youth. *Developmental Medicine & Child Neurology*, 53(11), 1030-1037.
- Coster, W. J., Deeney, T., Haltingware, J., & Haley, S. M. (1998). *The School Function Assessment (SFA)*. San Antonio, Texas: Psychological Corporation, Skills Builder Division.
- Coster, W. J., Law, M., & Bedell, G. (2010). *Participation and environment measure for children and youth*. Boston, Mass.: Boston University.
- De Matos, I., & Morgado, J. (2016). School participation of students with autism spectrum disorders. *Journal of Research in Special Educational Needs*, 16, 972-977. doi: 10.1111/

References

1471-3802.12240

- Dovgan, K. N., & Mazurek, M. O. (2019). Relations among activity participation, friendship, and internalizing problems in children with autism spectrum disorder. *Autism, 23*(3), 750-758. doi: 10.1177/1362361318775541
- Dunst, C. J., Hamby, D., Trivette, C. M., Raab, M., & Bruder, M. B. (2000). Everyday family and community life and children's naturally occurring learning opportunities. *Journal of Early Intervention, 23*(3), 151-164. doi.org/10.1177/10538151000230030501
- Durkin, M. S., Davidson, L. L., Desai, P., Hasan, Z. M., Khan, N., Shrout, P. E., Thorburn, M. J., Wang, W., & Zaman, S. S. (1994). Validity of the ten questions screen for childhood disability: Results from population based studies in Bangladesh, Jamaica and Pakistan. *Epidemiology, 5*(3), 283-289.
- Egilson, S. T., Jakobsdóttir, G., Ólafsson, K., & Leósdóttir, T. (2017). Community participation and environment of children with and without autism spectrum disorder: Parent perspectives. *Scandinavian Journal of Occupational Therapy, 24*(3), 187-196. doi: 10.1080/11038128.2016.1198419
- Egilson, S. T., Olafsdottir, L. B., Leósdóttir, T., & Saemundsen, E. (2017). Quality of life of high-functioning children and youth with autism spectrum disorder and typically developing peers: Self-and proxy-reports. *Autism, 21*(2), 133-141. doi: 10.1177/1362361316630881
- Gan, S.M., Tung, L. C., Yeh, C. H., Chang, H. Y., & Wang, C. H. (2014). The ICF-CY-based structural equation model of factors associated with participation in children with autism. *Developmental Neurohabilitation, 17*(1), 24-33. doi:10.3109/17518423.2013.835357
- Ghanouni, P., Jarus, T., Zwicker, J. G., Lucyshyn, J., Chauhan, S., & Moir, C. (2019). Perceived barriers and existing challenges in participation of children with autism spectrum disorders: "He did not understand and no one else seemed to understand him." *Journal of Autism and Developmental Disorders, 49*(8), 3136-3145. doi: 10.1007/s10803-019-04036-7

References

- Granlund, M. (2013). Participation-challenges in conceptualization, measurement and intervention. *Child: Care, Health and Development*, 39(4), 470-473
- Harrington, C., & Foster, M. (2017). Engaging young people with autism spectrum disorder in research interviews. *British Journal of Learning Disabilities*, 42(2), 153-161. doi: 10.1111/bld.12037
- Hochhauser, M., & Engel-Yeger, B. (2010). Sensory processing abilities and their relation to participation in leisure activities among children with high-functioning autism spectrum disorder (HFASD). *Research in Autism Spectrum Disorders*, 4(4), 746-754. doi:10.1016/j.ras.2010.01.015
- Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016). "Participation": A systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Developmental Medicine and Child Neurology*, 58(1), 29-38. doi: 10.1111/dmcn.12932
- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2017). Participation, both a means and an end: A conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine and Child Neurology*, 59(1), 16-25. doi: 10.1111/dmcn.13237
- Kasari, C., Rotheram-Fuller, E., & Locke, J. (2005). *The development of the playground observation of peer engagement (POPE) measure*. Los Angeles, Calif.: University of California Los Angeles.
- Keith, J. M., Jamieson, J. P., & Bennetto, L. (2019). The importance of adolescent self-report in autism spectrum disorder: Integration of questionnaire and autonomic measures. *Journal of Abnormal Child Psychology*, 47(4), 741-754. doi:10.1007/s10802-018-0455-1
- Kelly, M. P., Alireza, I., Busch, H. E., Northrop, S., Al-Attrash, M., Ainsleigh, S., & Bhuptani, N. (2016). An overview of autism and applied behavior analysis in the Gulf Cooperation

References

- Council in the Middle East. *Review Journal Autism Developmental Disorders*, 3(2), 154-164. doi: 10.1007/s40489-061-0073-1
- Kheir, N, M., Ghoneim, O, M., Sandridge, A, L., Hayder, S, A., Al-Ismail, M, S., & Al-Rawa, F. (2012). Concerns and considerations among caregivers of a child with autism in Qatar, *BMC Research Notes*, 5, 2-7. Retrieved from <http://www.biomedical.com/1756-0500/5/290>
- King, G., Law, M., King, S., Hurley, P., Rosenbaum, P., Hanna, S., et al. (2004). *CAPE/PAC manual: Children's assessment of participation and enjoyment & preferences for activities for children*. Hamilton, ON, Canada: Centre of Childhood Disability Research McMaster University.
- Lami, F., Egberts, K., Ure, A., Conroy, R., & Williams, K. (2018). Measurement properties of instruments that assess participation in young people with autism spectrum disorder: A systematic review. *Developmental Medicine and Child Neurology*, 60(3), 230-243. doi: 10.1111/dmcn.13631
- Little, L. M., Ausderau, K., Sideris, J., & Baranek, G. T. (2015). Activity participation and sensory features among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 45(9), 2981-2990. doi: 10.1007/s10803-015-2460-3
- Little, L. M., Sideris, J., Ausderau, K., & Baranek, G. T. (2014). Activity participation among children with autism spectrum disorder. *American Journal of Occupational Therapy*, 68(2), 177-185. doi: 10.5014/ajot.2014.009894
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. C., et al. (2000). The Autism Diagnostic Observation Schedule - Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205-223. doi:10.1023/A:1005592401947.
- McMillan, J., & Schumacher, S. (2014). *Research in education: evidence-based inquiry* (7th ed.). Essex. Pearson Education.

References

- McWilliam, R. A. (1990). *The engagement check*. Chapel Hill, NC: Frank Porter Graham Child Development Center.
- McWilliam, R. A., & Bailey, D. B. (1995). Effects of classroom social structure and disability on engagement. *Topics in Early Childhood Special Education, 15*(2), 123-147.
- Mung'ala-Odera, V., Meehan, R., Njuguna, P., Mturi, N., Alcock, K., Carter, J. A., & Newton, C. R. J. C. (2004). Validity and reliability of the 'ten questions' questionnaire for detecting moderate to severe neurological impairment in children aged 6-9 years in rural Kenya. *Neuroepidemiology, 23*(1-2), 67-72. doi: 10.1159/000073977
- Naudé, T. E. (2014). *The effect of a mathematical aided language stimulation programme for subtraction word-problem solving for children with intellectual disabilities* (Doctoral thesis). University of Pretoria.
- Pan, C. Y. (2009). Age, social engagement, and physical activity in children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3*(1), 22-31. doi: 10.1016/j.rasd.2008.03.002
- Parsin, N., & Dunning, T. (2009). Developing and validating a questionnaire to measure spirituality: A psychometric process. *Global Journal of Health Science, 1*(1), 1-11. doi:10.5539/gjhs.v1n1p2
- Poon, K. K. (2011). The activities and participation of adolescents with autism spectrum disorders in Singapore: Findings from an ICF-based instrument. *Journal of Intellectual Disability Research, 55*(8), 790-800. doi: 10.1111/j.1365-2788.2011.01397.x
- Potvin, M. C., Snider, L., Prelock, P., Kehayia, E., & Wood-Dauphinee, S. (2013). Recreational participation of children with high functioning autism. *Journal of Autism and Developmental Disorders, 43*(2), 445-457. doi: 10.1007/s10803-012-1589-6
- Rainey, L., Van Nispen, R., Van der Zee, C., & Van Rens, G. (2014). Measurement properties of

References

questionnaires assessing participation in children and adolescents with a disability: A systematic review. *Quality of Life Research*, 23(10), 2793-2808. doi: 10.1007/s11136-014-0743-3

Reynolds, S., Bendixen, R. M., Lawrence, T., & Lane, S. J. (2011). A pilot study examining activity participation, sensory responsiveness, and competence in children with high functioning autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 41(11), 1496-1506. doi: 10.1007/s10803-010-1173-x

Santillan, L., Frederick, L., Gillmore, S., & Locke, J. (2019). Brief report: Examining the association between classroom social network inclusion and playground peer engagement among children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 34(2), 91-96. doi: 10.1177/1088357619838275

Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R. (2010). *The childhood autism rating scale (CARS): For diaognostic screening and classification of autism* (2nd ed.). Los Angeles, Calif.: Western Psychological Services.

Simpson, K., Adams, D., Bruck, S., & Keen, D. (2019). Investigating the participation of children on the autism spectrum across home, school and community: A longitudinal study. *Child Care Health and Development*, 45(1), 681-687. doi: 10.1111/cch.12679

Simpson, K., Keen, D., Adams, D., Alston-Knox, C., & Roberts, J. (2018). Participation of children on the autism spectrum in home, school, and community. *Child: Care, Health and Development*, 44(1), 99-107. doi:10.1111/cch.12483

Sood, D., LaVesser, P., & Schranz, C. (2014). Influence of home environment on participation in home activities of children with an autism spectrum disorder. *The Open Journal of Occupational Therapy*, 2(3), 2. doi:10.15453/2168-6408.1082

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2006). *Vineland adaptive behaviour scales* (2nd ed.). Bloomington, Minn.: AGS Assessments.

References

- World Bank Group. (2020). High income - World Bank open data. retrieved 3 January 2020 from: <https://da.worldbank.org/income-level/high-incomeat>
- World Health Organization. (2001). *International classification of functioning, disability, and health*. Geneva, Switzerland: World Health Organization.
- World Health Organization. (2007). *International classification of functioning, disability and health for children and youth (ICF-CY)*. Geneva, Switzerland: World Health Organization.
- World Population Review. (2020). *United Arab Emirates population 2020*. Retrieved 3 January 2020 from <http://worldpopulationreview.com/countries/united-arab-emirates-population/>
- Yee, T., Magill-Evans, J., Zwaigenbaum, L., Sacrey, L. A. R., Askari, S., & Anaby, D. (2017). Participation measures for preschool children with autism spectrum disorder: A scoping review. *Review Journal of Autism and Developmental Disorders*, 4(2), 132-141. doi:10.1007/s40489-017-0102-8
- Zingerevich, C., & LaVesser, P. D. (2009). The contribution of executive functions to participation in school activities of children with high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, 3(2), 429-437. doi: 10.1016/j.rasd.2008.09.002

Appendix A

APPENDICES

**Appendix A: Approval letter provided by Research Ethics
Committee, University of Pretoria**

Appendix A



10 December 2019

Dear Mrs LM Rooi

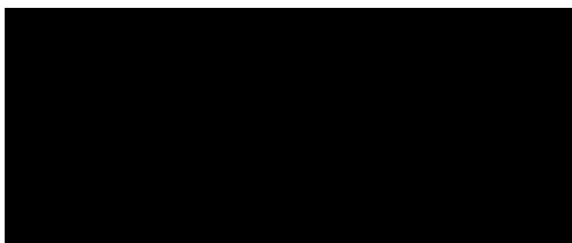
Project Title: Exploring the patterns of participation and participation restrictions in school-aged children with mild to moderate autism in the United Arab Emirates
Researcher: [REDACTED]
Supervisor: [REDACTED]
Department: CAAC
Reference number: 19381345 (HUM027/1019)
Degree: Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 10 December 2019. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely



Fakulteit Geesteswetenskappe
Lefapha la Bomotheo



Appendix B

Appendix B: Permission letter: School CEO/ Principal

Appendix B



October 2019

PERMISSION LETTER TO SCHOOL CEO/PRINCIPAL

Dear Chief Executive Officer/Principal

REQUEST TO CONDUCT RESEARCH AT YOUR INSTITUTION

My name is Lizé Rooi and I am a master's student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa. As part of fulfilling requirements of this degree, I am conducting a research project entitled "Exploring the patterns of participation and participation restrictions in school-aged children with mild to moderate autism in the United Arab Emirates." This project is being completed under the supervision of Prof Shakila Dada.

Rationale for the study

Children with autism participate in activities less often and with less variety than typically developing children. The participation of children in a variety of contexts is important for their health and well-being. Participation in activities such as helping with chores and playing sports promotes development and learning.

Aims of the study

The study aims to describe the patterns of participation of school-aged children with autism as well as to describe the restrictions, which may hamper their participation.

What will be expected of you and your institution?

Upon approval of this request, you grant the researcher, Lizé Rooi, permission to conduct the study at your institution. For this research approximately 30 children with mild to moderate autism between the ages of 10; 0 and 17;11 years will be required. A quiet, suitable venue, in which the study can be

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Lefapha la Bomotho

Appendix B

conducted, would need to be provided. A table and three chairs in the venue should also be available for the duration of the study. You would grant the researcher permission to withdraw the learners, at agreed upon times, from class to complete this study. Furthermore, you would be granting the researcher permission to audio-record the interviews with the children. You would also be required to introduce the researcher to teachers of children 10; 0 to 17; 11 years, with mild to moderate autism.

What will be expected of the teachers?

Informed consent will be obtained from the teachers. Once their consent is obtained the teachers will be required to:

- a. Fill out a learner screening tool to identify possible participants
- b. Distribute and collect parental informed consent forms and questionnaires to and from the parents of possible participants that match the selection criteria
- c. Assist the researcher in identifying the participants

What will be expected of the children?

Assent will be obtained from the child. He/she will be assessed using the CARS (Childhood Autism Rating Scale), by observation in class as well as the teachers report. Upon a second occasion, the children will be taken, one at a time, to a quiet venue for 45-60 minutes each. A structured interview will be administered with each child, using the Short Participation questionnaire and visual supports.

What will happen to the data?

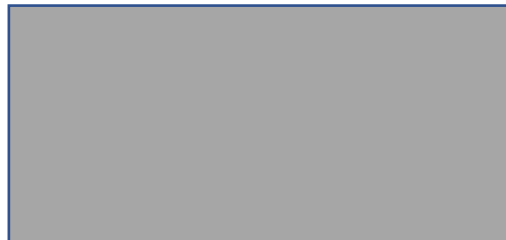
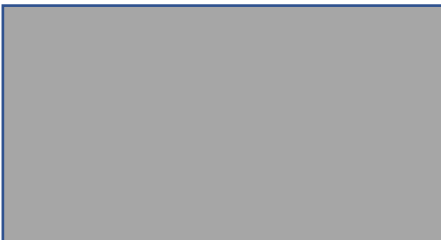
The results will be sent to you following the completion of the research in the form of an electronic mini thesis and may be shared in a scientific paper in article format and as an academic conference presentation. The audio recordings will be treated as strictly confidential and will be stored in password protected electronic files. The letters and questionnaires will be stored using participant numbers to ensure confidentiality of the data. These will be stored both as soft and hard copy at the CAAC at University of Pretoria (South Africa) for 15 years. The data may be re-analyzed in the future for future studies.

Who can be contacted if you have further questions?

Should you require any further information, kindly contact the researcher or her supervisor on the details provided below.

I trust that this letter has provided you with enough information. Please complete the attached reply slip as proof of permission.

Regards,



Appendix B



Permission to conduct the study of the proposed research at this institution

Project title: *Exploring the patterns of participation and participation restrictions in school aged children with mild to moderate autism in the United Arab Emirates*

I do consent to participate in the study and that

1. We have received and read the request to conduct research at this institution from Lizé Rooi.
2. We understand that requirements for the completion of the study.
3. We agree to allow Lizé Rooi to conduct the study at (School name) _____, in accordance with the requirements stipulated in the request.

I _____, Chief Executive officer/Principal of _____ grant permission to Lizé Rooi to conduct the study as outlined in the informed consent letter.

Signed at _____ on the _____ day of _____ 2019.

CEO Signature

Researcher Signature

SCHOOL STAMP

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Appendix C

**Appendix C: Permission Letter: Graduate Studies Department of
School**

Appendix C



October 2019

PERMISSION LETTER TO GRADUATE STUDIES DEPARTMENT

Graduate Studies Department

Dear Sir/madam

REQUEST TO CONDUCT RESEARCH AT YOUR INSTITUTION

My name is Lizé Rooi and I am a master's student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa. As part of fulfilling requirements of this degree, I am conducting a research project entitled "Exploring the patterns of participation and participation restrictions in school-aged children with mild to moderate autism in the United Arab Emirates." This project is being completed under the supervision of Prof. Shakila Dada.

Rationale for the study

Children with autism participate in activities less often and with less variety than typically developing children. The participation of children in a variety of contexts is important for their health and well-being. Participation in activities such as helping with chores and playing sports promotes development and learning.

Aims of the study

The study aims to describe the patterns of participation of school-aged children with autism as well as describe the restrictions, which may hamper their participation.

What will be expected of you and your institution?

Upon approval of this request, you grant the researcher, Lizé Rooi, permission to conduct the study at your institution. For this research approximately 30 children with mild to moderate autism between the ages of 10; 0 and 17; 11 years will be required. A quiet, suitable venue, in which the study can be conducted, would need to be provided. A table and three chairs in the venue should also be available

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Appendix C

for the duration of the study. You would grant the researcher permission to withdraw the learners, at agreed upon times, from class to complete this study. Furthermore, you would be granting the researcher permission to audio-record the interviews with the children. You would also be required to introduce the researcher to teachers of children 10; 0 to 17; 11 years, with mild to moderate autism.

What will be expected of the teachers?

Informed consent will be obtained from the teachers. Once their consent is obtained, the teachers will be required to:

- a. Fill out a learner screening tool to identify possible participants
- b. Distribute and collect informed consent forms and questionnaires to and from the parents of possible participants that match the selection criteria
- c. Assist the researcher in locating the participants

What will be expected of the children?

Assent will be obtained from the child. He/she will be assessed using the CARS(Childhood Autism Rating Scale), by observation in class as well as the teachers report. Upon a second occasion, the children will be taken, one at a time, to a quiet venue for 45-60 minutes each. A structured interview will be administered with each child, using the Short Participation questionnaire and visual supports.

What will happen to the data?

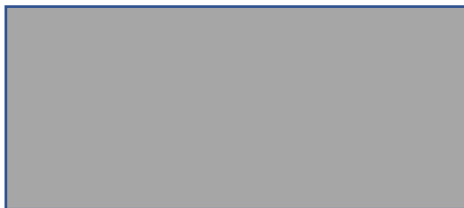
The results will be sent to you following the completion of the research in the form of an electronic mini thesis and may be shared in a scientific paper in article format and as an academic conference presentation. The audio recordings will be treated as strictly confidential and will be stored in password protected electronic files. The letters and questionnaires will be stored using participant numbers to ensure confidentiality of the data. These will be stored both as soft and hard copy at the CAAC University of Pretoria (South Africa) for 15 years. The data may be re-analyzed in the future for future studies.

Who can be contacted if you have further questions?

Should you require any further information, kindly contact the researcher or her supervisor on the details provided below.

I trust that this letter has provided you with enough information. Please complete the attached reply slip as proof of permission.

Regards,



Appendix C

REPLY SLIP

PERMISSION TO CONDUCT THE STUDY OF THE PROPOSED RESEARCH AT THIS INSTITUTION


TOPIC:

Exploring the patterns of and restrictions to participation in school-aged children with mild to moderate autism in the United Arab Emirates

Place tick where appropriate:

I do consent to participate in the study and that

- We have received and read the request to conduct research at this institution from Lizé Rooi.
- We understand that requirements for the completion of the study.
- We agree to allow Lizé Rooi to conduct the study at (School name) MRC-NECC, in accordance with the requirements stipulated in the request.

 _____, Graduate Studies officer of MRC-NECC grant permission to Lizé Rooi to conduct the study as outlined in the informed consent letter.

Signed at 1:08pm on the 8th day of June 2020.

 _____
Graduate studies Signature

 _____
Researcher Signature



Appendix D

Appendix D: Teacher Consent Letter

Appendix D



February 2020

TEACHER CONSENT LETTER

Dear Teacher

REQUEST FOR ASSISTANCE IN CONDUCTING RESEARCH AT YOUR INSTITUTION

My name is Lizé Rooi and I am a master's student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa. As part of fulfilling requirements of this degree, I am conducting a research project entitled "Exploring the patterns of participation and participation restrictions in school-aged children with mild to moderate autism in the United Arab Emirates." This project is being completed under the supervision of Prof. Shakila Dada.

I hereby wish to inform you that I have requested permission to conduct a research project to investigate the patterns of and restrictions to participation in school-aged children with mild to moderate autism.

Rationale of the study

Children with autism participate in activities less often and with less variety than typically developing children. The participation of children in a variety of contexts is important for their health and well-being. Participation in activities such as helping with chores and playing sports promotes development and learning.

The aims of the study

The study aims to describe the patterns of participation of school-aged children with autism, as well as describe the restrictions, which may hamper their participation.

What will be required of you as a teacher?

You will be asked to assist in the following ways:

- Completion of a checklist (Learner Screening Tool by Educators) to help the researcher determine which children in your class meet the selection criteria. Approximately 30 participants aged 10;0 to 17;11 years and have mild to moderate autism.
- Distribution and collection of parental consent forms from potential participants
- Assisting the researcher in locating the children on the day(s) that the research will be conducted. Each child will spend approximately 45-60 minutes on one to one time with the researcher.

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Appendix D

Voluntary participation

Your participation is voluntary, and you may withdraw from the study at any time without consequence.

Procedural integrity

Audio recording will take place to ensure that the researcher follows the same process with each child. The collected data will be kept for data analysis. Information recorded will be kept confidential and only used for data capturing for the purposes of this study.

Risks and benefits

There is no risk to you in this study. Please be aware that no direct benefit will be received from participating in this study, but information will be used to help better understand children in this population.

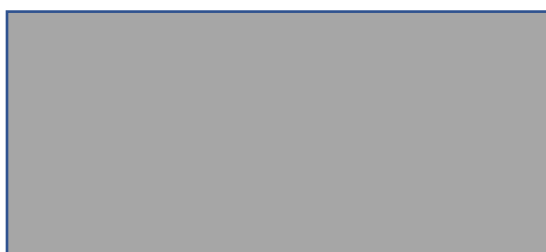
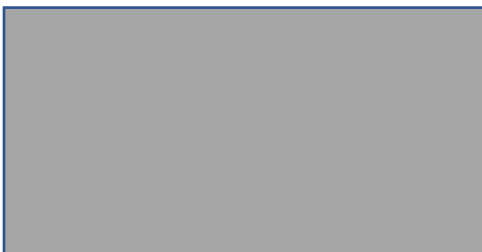
Data storage

This data will be kept at the CAAC, University of Pretoria (South Africa) for a period of 15 years for archive purposes and for possible re-analysis in the future. The audio recordings will be stored in password protected electronic files. Data collected may be used for scientific papers and possible academic conferences.

Who should you contact if you have any further questions?

If you need any further information, please contact the researcher on the details below.

Regards,



Appendix D



REPLY SLIP

Consent to assist in the research process

Project title: *Exploring the patterns of participation and participation restrictions in school aged children with mild to moderate autism in the United Arab Emirates*

I _____, a _____ at _____
hereby confirm that:

1. I have received and read the request form from Lizé Rooi (researcher) to conduct research at this institution.
2. I understand the requirements for the completion of the study.
3. I agree to assist with identification of potential participants for this study at _____ in accordance with the requirements that are stipulated in the letter of request.

Signed at _____ on the _____ day of _____ 2020.

Teacher Name

Teacher Signature

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Appendix E

Appendix E: Questionnaire Reviewer Consent letter

Appendix E



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA



October 2019

QUESTIONNAIRE REVIEWER CONSENT LETTER

Dear Sir/Madam

REQUEST FOR ASSISTANCE IN CONDUCTING RESEARCH

My name is Lizé Rooi and I am a master's student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa. As part of fulfilling requirements of this degree, I am conducting a research project entitled "Exploring the patterns of participation and participation restrictions in school-aged children with mild to moderate autism in the United Arab Emirates." This project is being completed under the supervision of Prof Shakila Dada.

Rationale of the study

Children with autism participate in activities less often and with less variety than typically developing children. The participation of children in a variety of contexts is important for their health and well-being. Participation in activities such as helping with chores and playing sports promotes development and learning.

The aims of the study

The study aims to describe the patterns of participation of school-aged children with autism, as well as describe the restrictions, which may hamper their participation.

What will be required of you as a reviewer?

You will be asked to assist in the following way:

- Complete Questionnaire Appropriateness form: The Short Participation questionnaire has been developed in Sweden and will be used for this study in the United Arab Emirates. You will be required to review the questions and pictures and report on appropriateness for use with children in the United Arab Emirates.

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Appendix E

Who should you contact if you have any further questions?

If you need any further information, please contact the researcher on the details below.

Regards,



Appendix E



REPLY SLIP

Consent to assist in the research process

Project title: *Exploring the patterns of participation and participation restrictions in school aged children with mild to moderate autism in the United Arab Emirates*

I _____, a _____ at _____

hereby confirm that:

1. I have received and read the request form from Lizé Rooi (researcher) to conduct research at this institution.
2. I understand the requirements for the completion of the study.
3. I agree to assist with the review of the Short Participation questionnaire by completing the Questionnaire appropriateness form.

Signed at _____ on the _____ day of _____ 2019.

Name

Signature

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Appendix F1

Appendix F1: Parent Informed Consent letter (English)

Appendix F1



February 2020

PARENT CONSENT LETTER

Dear parent

REQUEST FOR YOUR CHILD'S PARTICIPATION IN A RESEARCH PROJECT

My name is Lizé Rooi and I am a master's student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa. As part of fulfilling requirements of this degree, I am conducting a research project entitled "Exploring the patterns of and restrictions to participation in school-aged children with mild to moderate autism in the United Arab Emirates." This project is being completed under the supervision of Prof Shakila Dada.

Rationale for the study

Children with autism participate in activities less often and with less variety than typically developing children. The participation of children in a variety of contexts is important for their health and well-being. Participation in activities such as helping with chores and playing sports promotes development and learning.

Aims of the study

The study aims to describe the patterns of participation of school-aged children with autism as well as describe the restrictions, which may hamper their participation.

What will be required of your child as a participant?

Participation in the study is voluntary and you may withdraw your child at any point in time from the study. If you choose your child to participate, please fill out the attached form and return to your child's class teacher as soon as possible.

- a. Consent form
- b. Parent questionnaire

What will be required of your child?

The researcher will ask each child to provide assent to participate in the study. Participation of your child is voluntary, and they may withdraw at any time without consequence to them. A stop sign will be visible

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Appendix F1

for your child throughout the session. If your child points to this sign during the course of the session, they may leave and return to their classroom immediately.

Your child will be observed in the classroom for 45 minutes while doing regular schoolwork. Upon a second occasion, he/she will be asked if they would like to participate in the activity. Your child will be asked questions about their daily activities such as leisure activities and school. Picture supports will be used to aid understanding and responses. This means that your child will be shown pictures of all the questions asked. Each child will be asked 30 questions in total. They may respond by answering verbally or by pointing at the options of pictures provided.

A suitable time to interview your child will be found in consultation with the teacher, so as not to interfere with academic time. It is anticipated that 45 minutes one on one time will be required with each child.

Procedural integrity

Audio recording of your child will take place to ensure that the researcher follows the same process with each child. The collected data will be kept for data analysis. Information recorded will be kept confidential and only used for data capturing for the purposes of this study.

Risks and benefits

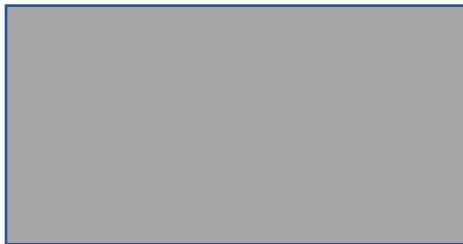
There is no risk to you or your child in this study. Please be aware that no direct benefit will be received from participating in this study, but information will be used to help better understand children in this population.

Data storage

This data will be kept at the CAAC, University of Pretoria (South Africa) for a period of 15 years for archive purposes and for possible re-analysis in the future. The audio recordings will be stored in password protected electronic files. Data collected may be used for scientific papers and possible academic conferences.

If you need any further information, please contact the researcher on the details below.

Regards,



Appendix F1



REPLY SLIP

Parent informed consent to participate in the study

Project title: *Exploring the patterns of participation and participation restrictions in school aged children with mild to moderate autism in the United Arab Emirates*

Name of parent: _____

Name of child: _____

Please tick the appropriate box:

I hereby consent for my child to participate in the research study outlined in the information letter.

I hereby do not consent for my child to participate in the research study outlined in the information letter

Signed at _____ on the _____ day of _____ 2020.

Parent Name

Signature

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Appendix F2

Appendix F2: Parent Informed Consent letter (Arabic)

Appendix F2



فبر خطاب موافقة ولي الأمر

طلب مشاركة طفلك في مشروع بحثي

تحية طيبة وبعد..

بشرفني أن أعرّفكم بنفسي.

أنا / ليزا روي، طالبة ماجستير في مركز الاتصال التزاوي والبدلي في جامعة بريتوريا، جنوب إفريقيا. كجزء من تلبية متطلبات هذه الدرجة، أقوم بإجراء مشروع بحثي بعنوان "استكشاف أنماط وقيود مشاركة الأطفال في سن المدرسة المصابين بالتوحد الخفيف إلى المتوسط في دولة الإمارات العربية المتحدة." حيث يتم استكمال هذا البحث تحت إشراف البروفيسور شاكيلدا دادا.

أسباب الدراسة

عادة يشارك الأطفال الذين يعانون من مرض التوحد في أنشطة أقل ويأقل تنوعاً من الأطفال النامين. تعد مشاركة الأطفال في مجموعة متنوعة من السياقات مهمة لصحتهم ورفاهيتهم. حيث أن المشاركة في أنشطة مثل المساعدة في الأعمال المنزلية وممارسة الرياضة تعزز النمو والتعلم.

أهداف الدراسة

تهدف الدراسة إلى وصف أنماط مشاركة الأطفال في سن المدرسة المصابين بالتوحد وكذلك وصف القيود التي قد تعيق مشاركتهم.

ما الذي سوف يكون مطلوباً من طفلك بصفته مشاركاً؟

تعد المشاركة في الدراسة طوعية ويمكنك سحب طفلك في أي وقت من الدراسة. إذا اخترت مشاركة طفلك، الرجاء ملء النموذج المرفق وإعادته إلى معلم صف طفلك في أسرع وقت ممكن.

- أ. نموذج الموافقة
ب. استبيان الوالدين

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Appendix F2

ماذا الذي سوف يكون مطلوب من طفلك؟

سوف يطلب الباحث من كل طفل الاستجابة للمشاركة في الدراسة. وتعد مشاركة طفلك طوعية، ويجوز له الانسحاب في أي وقت دون أن يترتب على ذلك أي عواقب. سوف تكون علامة التوقف مرئية لطفلك طوال الجلسة. إذا أشار طفلك إلى تلك العلامة أثناء الجلسة، يجوز له المغادرة والعودة إلى الفصل على الفور.

سوف يتم سؤال طفلك عما إذا كان يرغب في المشاركة في النشاط. سوف يتم طرح أسئلة على طفلك حول أنشطته اليومية مثل الأنشطة الترفيهية والمدرسية. وسوف يتم استخدام الصورة للمساعدة في الفهم والاستجابات. هذا يعني أنه سوف يتم عرض صور على طفلك لجميع الأسئلة التي يتم طرحها. وسوف يتم طرح 30 سؤالاً إجمالاً لكل طالب. ويجوز لهم الرد شفهيًا أو بالإشارة إلى خيارات الصور المعروضة.

سوف يتم تحديد الوقت المناسب لمقابلة طفلك بالتشاور مع المعلم، بحيث لا يتعارض مع الوقت الأكاديمي. من المتوقع أن نحتاج 45 دقيقة في المرة الواحدة مع كل طفل.

السلامة الإجرائية

سوف يتم إجراء تسجيل صوتي لطفلك لضمان اتباع الباحث نفس العملية مع كل طفل. سوف تخضع البيانات التي يتم جمعها لعملية تحليل البيانات. علماً بأن كافة المعلومات المسجلة سوف تبقى سرية وتستخدم فقط للحصول على البيانات لأغراض هذه الدراسة.

المخاطر والفوائد

لا يوجد أي مخاطر عليك أو على طفلك جراء هذه الدراسة. يرجى العلم أنه لن يتم تلقي أي مكافأة مباشرة من المشاركة في هذه الدراسة، إلا أنه سوف يتم استخدام المعلومات الناتجة للمساعدة في فهم الأطفال من هذه الفئة بشكل أفضل.

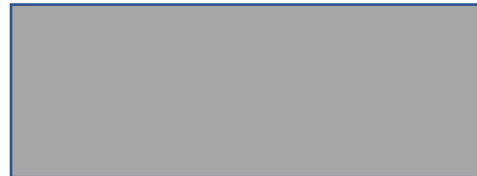
تخزين البيانات

سيتم الاحتفاظ بهذه البيانات في مركز الاتصال التزاويدي والبيدي، في جامعة بريوريا (جنوب إفريقيا) لمدة 15 عاماً لأغراض الأرشيف وإمكانية إعادة التحليل في المستقبل. سيتم تخزين التسجيلات الصوتية في الملفات الإلكترونية المحمية بكلمة مرور. وقد يتم استخدام البيانات التي يتم جمعها للأوراق العلمية والمؤتمرات الأكاديمية المحتملة.

إذا كنت ترغب في الحصول على المزيد من المعلومات، يرجى الاتصال بالباحث على تفاصيل الاتصال الواردة أدناه.

مع خالص التحيات والتقدير،

// توقيع //



Appendix F2



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ورقة الرد

موافقة ولي الأمر المبنية على المعرفة بشأن المشاركة في الدراسة

عنوان المشروع: استكشاف أنماط وقيود مشاركة الأطفال في سن المدرسة المصابين بالتوحد الخفيف إلى المتوسط في دولة الإمارات العربية المتحدة.

اسم ولي الأمر: _____

اسم الطفل: _____

الرجاء اختيار الخانة المناسبة:

أوافق بموجبه على مشاركة طفلي في الدراسة البحثية الموضحة في خطاب المعلومات.

لا أوافق على مشاركة طفلي في الدراسة البحثية الموضحة في خطاب المعلومات.

تم التوقيع في _____ بتاريخ _____ 2020.

التوقيع

اسم ولي الأمر

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Appendix G

Appendix G: Participant Assent letter

Appendix G



CHILD PARTICIPANT ASSENT LETTER

Hello (name), my name is Lizé.

I would like to work with you today.

I will show you some pictures and ask you questions about different things in the pictures.

I want you to answer the questions and point at the pictures.

There is no right or wrong answer and I am not going to tell anybody what you have answered.

I will make a recording while we talk.

As soon as we have finished then you can go.

You can stop at any time, if you don't want to answer any more questions.






You just let me know or point to the stop sign.

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Appendix G

ASSENT QUESTIONS

1		<p>Did you understand the letter I just read to you?</p>
2		<p>Do you know that you can choose to help me or not?</p>
3		<p>Do you understand that you can stop at any time?</p>
4		<p>Is it okay if I make an audio recording while we work?</p>
5		<p>Do you want to ask me anything?</p>

Appendix G

6		Would you like to work with me today?
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Appendix H

Appendix H: Childhood Autism Rating Scale-Edition 2

Appendix H

Childhood Autism Rating Scale, Second Edition

Eric Schopler, Ph.D., Mary E. Van Bourgondien, Ph.D.,
G. Janette Wellman, Ph.D., and Steven R. Love, Ph.D.



Test with Confidence

CARS2-HF

High-Functioning
Version
Rating Booklet

Name: _____ Case ID Number: _____ Test date: _____

Gender: _____ Ethnic background: _____ Rater's name: _____ Date of birth: _____

Based on information from: _____ Age: _____ years _____ months

DIRECTIONS: After rating the 15 items, transfer the ratings from the inside pages to the corresponding spaces below. Sum the ratings to obtain the Total raw score, and indicate the corresponding Severity Group. Circle the Total raw score value in the table. The number printed to the left of the value you have circled is the T-score.

SUMMARY

CATEGORY RATINGS

1. **Social-Emotional Understanding** _____
median = 2.5
2. **Emotional Expression and Regulation of Emotions** _____
median = 2.5
3. **Relating to People** _____
median = 2.5
4. **Body Use** _____
median = 2.0
5. **Object Use in Play** _____
median = 2.0
6. **Adaptation to Change/Restricted Interests** _____
median = 2.5
7. **Visual Response** _____
median = 2.0
8. **Listening Response** _____
median = 2.0
9. **Taste, Smell, and Touch Response and Use** _____
median = 2.0
10. **Fear or Anxiety** _____
median = 2.0
11. **Verbal Communication** _____
median = 2.5
12. **Nonverbal Communication** _____
median = 2.0
13. **Thinking/Cognitive Integration Skills** _____
median = 2.0
14. **Level and Consistency of Intellectual Response** _____
median = 2.0
15. **General Impressions** _____
median = 2.5

Total raw score =

Note. SEM = 0.73.

SEVERITY GROUP

- Minimal-to-No Symptoms of Autism Spectrum Disorder**
(15–27.5)
- Mild-to-Moderate Symptoms of Autism Spectrum Disorder**
(28–33.5)
- Severe Symptoms of Autism Spectrum Disorder**
(34 and higher)

Symptom Level Compared to Individuals With Autism Spectrum Diagnoses

Percentile	T-score	Raw score
>97	>70	>47
97	70	47
96	69	46.5
95	68	46
94	67	45.5
93	66	45
92	65	44–44.5
91	64	43.5
90	63	42.5–43
89	62	41.5–42
88	61	41
87	60	40.5
86	59	39.5–40
85	58	38.5–39
84	57	38
83	56	37.5
82	55	37
81	54	36–36.5
80	53	35.5
79	52	35
78	51	34–34.5
77	50	33–33.5
76	49	32.5
75	48	32
74	47	31.5
73	46	30.5–31
72	45	30
71	44	29.5
70	43	28.5–29
69	42	28
68	41	27.5
67	40	27
66	39	26.5
65	38	26
64	37	25–25.5
63	36	24.5
62	35	24
61	34	23.5
60	33	23
59	32	22–22.5
58	31	21.5
57	30	21
56	29	20.5
55	28	20
54	27	19.5
53	26	19
52	25	18.5
51	24	18
50	23	17.5
49	22	17
48	21	16.5
47	20	16
46	19	15.5
45	18	15
44	17	14.5
43	16	14
42	15	13.5
41	14	13
40	13	12.5
39	12	12
38	11	11.5
37	10	11
36	9	10.5
35	8	10
34	7	9.5
33	6	9
32	5	8.5
31	4	8
30	3	7.5
29	2	7
28	1	6.5
27	<1	6
26		5.5
25		5
24		4.5
23		4
22		3.5
21		3
20		2.5
19		2
18		1.5
17		1
16		0.5
15		0
14		<0
13		<-1
12		<-2
11		<-3
10		<-4
9		<-5
8		<-6
7		<-7
6		<-8
5		<-9
4		<-10
3		<-11
2		<-12
1		<-13
<1		<-14

Note. SEM = 2.8T.

Appendix H

DIRECTIONS

For each category, use the space provided in the *Observations* section for taking notes concerning the behaviors relevant to that item. After you have finished observing the individual, rate the behaviors relevant to each item by circling the number that corresponds to the statement that best describes the individual. You may indicate that the individual's behavior falls between two descriptions by using ratings of 1.5, 2.5, or 3.5. Abbreviated rating criteria are presented for each item. See chapter 3 of the Manual for detailed rating criteria.

1. Social-Emotional Understanding

Social-emotional understanding addresses a person's *cognitive* understanding of others' communication, behaviors, and differing perspectives. The dimensions of social understanding that are included in this item are the ability to read the nonverbal cues of others and the ability to take another person's perspective. This item does not reflect whether someone has friends or is in a relationship. Rather, it deals with a person's ability to perceive and articulate how another person may feel or what his or her perspective may be on a given situation.

- 1** **Age-appropriate social-emotional understanding.** Clearly understands facial expressions, gestures, tone of voice, and body language of others. Able to understand that others may have a different perspective and what that perspective may be.
- 1.5
- 2** **Mildly impaired social-emotional understanding.** Responsive to most facial expressions and expressions of emotion in others' gestures and body language, but these cues may need to be slightly exaggerated. More subtle expressions such as mild sarcasm, doubt, or ambiguity are sometimes not understood. The ability to take another's perspective is inconsistent.
- 2.5
- 3** **Moderately impaired social-emotional understanding.** Shows an understanding of facial expressions, tone of voice, and body language only when these cues are exaggerated. Is likely to ignore or misunderstand expression or perspective of others.
- 3.5
- 4** **Severely impaired social-emotional understanding.** Demonstrates virtually no ability to understand appropriate facial expressions, gestures, tone of voice, or body language. Unable to recognize that the perspective, understanding, or expression of others might differ.

Observations

2. Emotional Expression and Regulation of Emotions

This item refers to the capacity to express feelings and regulate one's emotions. This item is based on both direct observation and the reports of others who have witnessed this person's behavior in other settings.'

- 1** **Age-appropriate and situation-appropriate emotional response.** Shows appropriate type and degree of emotional response, both by word and behavior, including emotional variation such as happy, sad, proud, angry, scared, anxious, and related internal states.
- 1.5
- 2** **Mildly abnormal emotional response.** Emotional expressions are relatively flat, distorted, or slightly exaggerated. Nonverbal expression of emotions does not always match verbal content. Able to describe several emotions in self but limited compared to developmental level. May have intermittent emotional regulation problems.
- 2.5
- 3** **Moderately abnormal emotional response.** Expression of emotions is flat, excessive, or frequently inconsistent with situation or content of verbalized topic. May display greater emotion than expected about special interest or idiosyncratic concerns. Ability to describe or understand emotional states in self is limited. Serious problems with emotional regulation that occur frequently in at least one setting.
- 3.5
- 4** **Severely abnormal emotional response.** Extreme problems with emotional regulation that occur in more than one setting. Responses are extreme or seldom appropriate to situation or content of discussion. Shows extreme mood shifts that are difficult to change. Expresses only a few emotions in their exaggerated form, or perseverates on a particular emotion without understanding.

Observations

Appendix H

3. Relating to People

This item is related to the first two items, which also rate aspects of social relationships. This item differs in that it is confined to dimensions related to direct interpersonal interactions and the person's expression and reaction to another person. The two dimensions that are rated in this item are the person's initiation of interactions and the reciprocal nature of the interactions.

- 1** **No evidence of difficulty or abnormality in relating to people.** Age-appropriate *initiation of interactions* to get help, to have needs met, and for purely social purposes. Interactions with others are fluid and show a *reciprocal, back-and-forth* pattern.
- 1.5
- 2** **Mildly abnormal relationships.** Initiates interactions only to get obvious needs met or around special interests. Some give-and-take noted in interactions, but lacks consistency or fluidity or appropriateness. Aware of other people of same age and interested in interactions, but may have difficulty initiating or managing interactions. Minimal initiation for purely social purposes that does not involve special interests.
- 2.5
- 3** **Moderately abnormal relationships.** Initiates interactions almost totally around his or her special interests, with little attempt to engage others in these interests. Responds to overtures from others, but lacks social give-and-take or responds in ways that are unusual and not always related to original overtures. Unable to maintain an interaction beyond initial overtures.
- 3.5
- 4** **Severely abnormal relationships.** Does not initiate any directed interactions and shows minimal response to overtures from others. Only the most persistent attempts to get the person to engage have any effect.

Observations

4. Body Use

This item represents grossly deviant body movements and also subtler forms of fine motor and coordination problems. Any obvious current deviant behaviors—including posturing, spinning, rocking, toe-walking, and self-directed aggression—automatically merit a rating of 3 or higher, depending on the persistence of the behavior. Difficulties with handwriting and tying shoes are rated on this item, with higher ratings given for problems that are so severe that the person actively resists these tasks. While this item can be scored using another's report, it is best to base your rating on current behavior. Directly observed behaviors should be given more weight than those from another's report.

- 1** **Age-appropriate body use.** Moves with the same ease, agility, and coordination as a typical person of the same age.
- 1.5
- 2** **Mildly abnormal body use.** Some minor peculiarities may be present, such as clumsiness, repetitive movements, poor coordination, or poor balance. May have fine motor difficulties, such as problems with handwriting or tying shoes, compared to others at the same developmental level.
- 2.5
- 3** **Moderately abnormal body use.** Currently displays *any* unusual body posture or stance, hand or finger mannerism, flapping, self-directed aggression, picking at body, rocking, spinning, or toe-walking. Fine motor difficulties or obvious handwriting difficulties are present, which may result in resistance to writing tasks.
- 3.5
- 4** **Severely abnormal body use.** Intense or frequent movements of the type listed above are signs of severely abnormal body use.

Observations

Appendix H

5. Object Use in Play

This rating includes the person's interest in and use of objects. In addition to the traditional issues related to repetitive play with parts of objects, the focus of this item also includes the degree to which the person engages in imaginative symbolic play and the degree to which toy figures are used as agents. For older persons, the rating may need to be based on the parent interview. Any obvious inappropriate or repetitive use of objects or obvious interest in parts of objects as opposed to the whole should be rated 3 or higher, depending on the persistence.

- 1 Appropriate interest in, and creative use of, toys and other objects.**
Able to spontaneously use toys in age-appropriate imaginative symbolic play and able to use objects to represent something else. He or she shows interest in a variety of toys and leisure materials.
- 1.5
- 2 Mildly inappropriate interest in, or use of, toys and other objects.**
Play or imaginative themes tend to be repetitive or appear to reflect things seen in movies or on TV. Some use of toy people as agents, for example, has an action figure or doll use other play materials. Some make-believe play or use of objects to represent something else. Responds to others' attempts to engage him or her in pretend play, but limited spontaneous initiation of imaginative play. Interests may be unusual in intensity or inappropriate for age. No obvious repetitive or inappropriate use of objects, such as twirling or spinning, or interest in parts of objects at this level.
- 2.5
- 3 Moderately inappropriate interest in, or use of, toys and other objects.** Limited imaginative creative play, either spontaneously or in response to others. People typically not used as agents, and limited use of objects to represent other things. No original themes in play. May show some repetitive, inappropriate use of objects or interest in parts of objects. Interest in play or novelty materials restricted to a few items and may be inappropriate for age or of an unusual intensity.
- 3.5
- 4 Severely inappropriate interest in, or use of, toys and other objects.**
No creative play. Toys or other novelty items are used in repetitive or inappropriate manner.

Observations

6. Adaptation to Change/Restricted Interests

This item includes difficulty coping with change, ritualistic behaviors, and restricted special interests. The rating is based on the most severe level of difficulty in any one specific area.

- 1 Age-appropriate response to change/variety of interests.** May notice or comment on changes in routines, but accepts these changes without undue stress. Shows a wide variety of interests, with no single interest or theme predominating.
- 1.5
- 2 Mildly abnormal adaptation to change/variety of interests.** Unusually quick to develop new routine or, when others try to change task, the person may continue the same activity or use the same materials, though he or she can be directed to change if needed. *OR*, person shows preference for specific activities or toys or topics of conversation, though can be directed to other topics.
- 2.5
- 3 Moderately abnormal adaptation to change/variety of interests.** Has definite special interests or preferences for specific activities, toys, objects, or topics. Adult needs to actively work to engage him or her in other topics or activities. Shows displeasure and may resist change or try to maintain routine. May become distressed by attempts to interrupt or change topic or activity. May have rituals or routines that have to be done in a particular way. May report subjective feelings of distress about change or interruptions, or may become overly fixed on schedule, checklist, or timing of events.
- 3.5
- 4 Severely abnormal adaptation to change/variety of interests.** Has definite special interests or preferences, or has severe reaction to change. Reacts with extreme anxiety, anger, or resistance to attempts to change activity or topic or routine.

Observations

Appendix H

7. Visual Response

This item covers use of vision in three areas: visual fascinations, the ease with which the person can shift visual attention, and the degree to which the person's eye contact is integrated with actions and communication.

- 1** **Age-appropriate visual response.** Visual behavior is normal and appropriate for his or her age. Eye contact is good and integrated with verbal and nonverbal communication skills. Easily shifts visual attention.
- 1.5
- 2** **Mildly abnormal visual response.** May stare inappropriately at others. Eye contact is not consistently integrated with verbalizations. Included at this level is any inconsistency in eye contact, regardless of the proportion of time he or she makes eye contact. May show more interest than is typical in describing small details in room or in looking at specific objects, such as moving parts, lights, or mirrors.
- 2.5
- 3** **Moderately abnormal visual response.** Eye contact is not integrated with verbalizations. Obvious visual fascination with objects, lights, mirrors, spinning toys, and so on. May use peripheral vision to look at things. Obvious difficulty shifting visual attention from high-interest items.
- 3.5
- 4** **Severely abnormal visual response.** Persistent avoidance of eye contact. Excessive interest in looking at specific objects or in looking at objects in a peculiar way.

Observations

8. Listening Response

This rating is based on the person's response to sounds and how the listening response is coordinated with the use of other senses. The person's response to his or her own name is scored on this item. Emphasis is placed on unusual over- or underinterest in sounds, as opposed to distractibility. Older individuals should be asked directly about this item.

- 1** **Age-appropriate listening response.** Listening behavior is normal and appropriate for his or her age. Listening is used together with other senses; for example, child looks toward person who is speaking. Person responds to name.
- 1.5
- 2** **Mildly abnormal listening response.** Some difficulty responding to verbalizations when background noise present. Responds to name after repeated attempts to get attention. There may be some lack of response or mild overreaction to certain sounds. Atypical listening responses are apparent either in direct observation or by report from outside witness, but not both.
- 2.5
- 3** **Moderately abnormal listening response.** Responses to sounds or verbalizations are inconsistent. May show marked reaction to some sounds or complete disregard for others. Seldom responds to name as a means of getting attention. Unusual responses are obvious across settings, based on some combination of direct report of person, witness report, and direct observation.
- 3.5
- 4** **Severely abnormal listening response.** Overreacts or underreacts to sounds to an extremely marked degree. Is noticeably less responsive to verbalizations than to noises made by objects. Does not respond to repeated attempts to get his or her attention by calling his or her name. Unusual responses are evident across settings.

Observations

Appendix H

9. Taste, Smell, and Touch Response and Use

This item addresses the person's response to stimulation of the near receptors of taste, smell, touch, and pain. Subtler aspects of the stimulation of these senses include responses to the texture of clothing or food such that the person wears a limited variety of clothes or eats a limited variety of foods. Self-report of issues in this area should be considered, especially for adults.

1 Normal use of, and response to, taste, smell, and touch. Explores new objects in age-appropriate way, generally by looking and feeling. Responds appropriately to pain or touch from others. Reacts to minor pains or illnesses by showing appropriate discomfort, but does not overreact. Wears a variety of textures of clothing and eats a wide variety of foods.

1.5 Mildly abnormal use of, and response to, taste, smell, and touch. May occasionally explore things by subtle attempts to smell or taste the object, or rub the object against part of his or her face or body. May show a mild over- or underreaction to touch or pain. May have obvious clothing or food preferences, but is easily encouraged to try new things. Unusual sensory responses are apparent in direct observation or by report from outside witness, but not both.

2.5 Moderately abnormal use of, and response to, taste, smell, and touch. Obviously explores objects by smelling or tasting them, or rubbing the object against part of his or her face or body. Over- or underreacts or stiffens to touch or pain to a moderate degree. *OR*, the person has limited clothing he or she will wear or food he or she will eat. Limitations in sensory areas such as clothing and/or food preferences are obvious across settings, and the person reports these difficulties or they are obvious on direct observation. Sensory issues are difficult to modify and create stress or require adaptations in the everyday environment.

3.5 Severely abnormal use of, and response to, taste, smell, and touch. Has extreme limits on the foods he or she eats or clothing he or she wears. *OR*, extreme reactions or underreactions to touch or pain. *OR*, he or she shows persistent preoccupation with smelling, touching, or tasting things. Near-receptor issues are a source of extreme stress for person, who puts stress on the environment to find ways to cope with these difficulties. Unusual responses are evident across settings.

Observations

10. Fear or Anxiety

This item focuses on the degree to which the person has unusual fear or anxiety compared to what is appropriate for the situation or context.

1 Normal fear or anxiety. Behavior is appropriate both to the situation and for his or her age.

1.5 Mildly abnormal fear or anxiety. Occasionally shows too much or too little fear or anxiety compared to the reaction of a typical person of the same age in a similar situation. The abnormal response is only evident in one setting—for example, either on direct observation or based on report from witness in another setting, but not both.

2.5 Moderately abnormal fear or anxiety. Shows either quite a bit more or quite a bit less fear or anxiety than is typical even for a younger person in a similar situation. The abnormal response is apparent across more than one setting, and the person either reports these difficulties or they are obvious on direct observation.

3.5 Severely abnormal fear or anxiety. Fear or anxiety is pervasive across all settings and persists even after repeated explanations or experiences with harmless events or objects. It is extremely difficult to calm or comfort the person. Conversely, may show persistent and pervasive disregard for hazards that others of same age avoid.

Observations

Appendix H

11. Verbal Communication

This is a rating of two facets of the person's speech and language skills, and is best evaluated by a direct interaction with the person. This item includes verbal oddities—such as formal language, unusual tone or inflection, and repetitive or made-up phrases—and the ability to carry on a reciprocal conversation.

- 1 Normal verbal communication, age and situation appropriate.** Able to carry on an age-appropriate conversation with another person, he or she is able to respond to others' overtures while also adding additional information in at least a four-element sequence. No evidence of unusual speech inflection, volume, or tone. No evidence of made-up words or repetitive or rote phrases.
- 1.5
- 2 Mildly abnormal verbal communication.** Conversation exchanges are more limited than expected for this age. Occasional use of made-up words or repetitive, rote phrases. At times may display unusual vocal intonation or rate of speech. Ratings at this level indicate that the person has problems with conversation or verbal oddities, but not both.
- 2.5
- 3 Moderately abnormal verbal communication.** Minimal initiations of conversation during direct interaction. Verbalizations include overly formal language or repetitive phrases. Little reciprocal conversation; may talk on own topic but little sense of interaction. Vocal intonation or rate of speech often unusual. Some use of unusual words or repetitive speech. Some apparent difficulties in carrying on a reciprocal conversation and displays some type of verbal oddity.
- 3.5
- 4 Severely abnormal verbal communication.** Inability to have a conversation with another person. May respond to specific questions, but does not engage in a to-and-fro conversation. Does not initiate communication. Language may be overly formal or pedantic. Marked abnormal speech inflection or tone. Frequently uses made-up words or repetitive phrases. Significant difficulties in both areas of expressive communication—reciprocal conversation and verbal oddities.

Observations

12. Nonverbal Communication

This item rates all forms of nonverbal communication. While both use of and response to nonverbal cues are considered, greater emphasis is placed on their use. Attention is given to the use of gaze to regulate and understand interactions and the use of facial expressions and gestures in combination with verbalizations for a variety of communication functions—instrumental, descriptive, and emphatic.

- 1 Normal use of nonverbal communication, age and situation appropriate.** Uses a variety of facial expressions and instrumental, descriptive, and emphatic gestures that are well integrated with verbalizations. Responds to facial expressions and gestures from others. Gaze is used to regulate interactions with others.
- 1.5
- 2 Mildly abnormal use of nonverbal communication.** Uses instrumental gestures such as pointing or reaching to indicate wants. Descriptive gestures are used infrequently and are not well coordinated with verbalizations. Responds to very obvious facial expressions or gestures from others. May show too little or exaggerated facial expressions at times, though generally shows appropriate expressions. Inconsistent in use of gaze to regulate interaction with others.
- 2.5
- 3 Moderately abnormal use of nonverbal communication.** Facial expressions are often flat or exaggerated. Uses limited instrumental gestures, and these gestures are not well integrated with verbalizations. Rarely uses descriptive or emphatic gestures. Shows limited response to nonverbal communication from others. Joint attention is rare, as the person seldom uses or responds to gaze or gesture as a means of sharing attention to an object or activity.
- 3.5
- 4 Severely abnormal use of nonverbal communication.** Facial expressions are either flat or exaggerated. Does not use instrumental, descriptive, or emphatic gestures and shows no awareness of nonverbal communication from others. No evidence of using gaze to regulate activities with others.

Observations

Appendix H

13. Thinking/Cognitive Integration Skills

This is a rating of the person's ability to understand the meaning of larger concepts and the ability of the person to integrate relevant details into a meaningful overview (central coherence). Part of this process involves the person's ability to discriminate between relevant and irrelevant details.

- 1** **Age-appropriate thinking/cognitive integration skills.** Able to understand meaning of information presented either pictorially, in writing, or verbally. He or she demonstrates central coherence, that is, the ability to attend to relevant versus irrelevant details and integrate this information into a meaningful overview.
- 1.5
- 2** **Mildly impaired in specific thinking/cognitive integration skills.** Delayed thinking compared to persons of same age. Difficulties may be seen in distinguishing relevant from irrelevant cues for conceptualizing or person can verbalize an overall understanding but is unable to articulate how meaning was derived. At times supportive presence of another person helps with comprehension.
- 2.5
- 3** **Moderately impaired in specific thinking/cognitive integration skills.** Notable difficulties comprehending meaning and integrating information into overall conceptualization, but shows great attention to specific things and concrete details. Frequently requires specific prompts from others to attend to relevant details or grasp the larger conceptualization.
- 3.5
- 4** **Severe delay in specific thinking/cognitive integration skills.** Shows repeated and consistent difficulty distinguishing relevant from irrelevant details. Even with persistent efforts from another, may not be able to conceptualize the overall meaning of information.

Observations

14. Level and Consistency of Intellectual Response

THE RATER MUST read the complete description in the Manual before rating this item. This rating is concerned with the discrepancies in and consistency of the individual's skills across different areas, as well as the person's general level of intellectual functioning. By definition, this instrument is appropriate only for individuals whose overall IQ score is above 80, so the descriptors make this assumption. *Unless the individual has a savant skill, which always receives a rating of 4, all individuals whose adaptive skills are appropriate for their age and intellectual abilities should receive a rating of 1, regardless of intellectual level or variability in skills.*

- 1** **Intelligence is at least normal and reasonably consistent across various areas.** Has at least average Intellectual abilities and does not have any unusual intellectual skills or problems. IQ score is average or higher (≥ 85) with limited discrepancies. Adaptive skills are appropriate for age and intellectual abilities.
- 1.5 *IQ score is 90 or above, with limited variability across areas. Adaptive skills are less than expected for cognitive level.*
- 2** **Mildly abnormal intellectual functioning.** Not as smart as typical person of same age; skills appear evenly delayed across all areas. IQ score in the low-average range (80 to 90) with limited discrepancies. Adaptive skills are less than expected for level of intelligence.
- The individual's overall cognitive skills are near the low-average range (IQ score between 80 and 90), but there is significant variability in skills. Adaptive skills are less than expected for level of intelligence.*
- 2.5
- 3** **Moderately abnormal intellectual functioning.** In general, overall functioning is within the normal range, but shows significant discrepancy across skill areas. Adaptive skills are less than expected for level of intelligence.
- The individual's overall intellectual functioning is above average (IQ score >115), and he or she shows significant variability in skills. Adaptive skills are less than expected for level of intelligence.*
- 3.5
- 4** **Severely abnormal intellectual functioning.** Has a skill that is significantly better than expected for his or her level of intelligence and better than that exhibited by typical peers (savant skill). At least low-average intelligence (≥ 80). Adaptive skills are typically less than expected for level of intelligence, but in rare instances may be appropriate for cognitive level.

Observations

Appendix H

15. General Impressions

This is intended to be an overall rating of autism based on your subjective impression of the degree to which the person has autism as defined by the other 14 items. This rating should be made without recourse to averaging the other ratings. As with the other items, this rating should be made by taking into account all available data from such sources as the case history, test results, parent and other interviews, or past records.

1 **No autism spectrum disorder.** Shows none of the symptoms characteristic of an autism spectrum disorder.

1.5

2 **Mild autism spectrum disorder.** Shows only a few symptoms or only a mild degree of an autism spectrum disorder—mild interference with daily functioning.

2.5

3 **Moderate autism spectrum disorder.** Shows a number of symptoms or a moderate degree of an autism spectrum disorder—moderate interference with daily functioning.

3.5

4 **Severe autism spectrum disorder.** Shows many symptoms or an extreme degree of an autism spectrum disorder—extreme interference with daily functioning.

Observations

Appendix II

Appendix I1: Ten Questions Screen (English)

Appendix II



Parent Questionnaire

Section A.

Dear Parent

Thank you for allowing your child to participate in this study.

Please answer the following questions:

Date of birth of your child: DAY/MONTH/YEAR

Since when has your child attended school? DAY/MONTH/YEAR

Your child's diagnosis:

Does your child have brothers or sisters?

Yes No

If yes, how many?

Number of brothers: _____ Number of sister: _____

Which language does your child speak? (Tick the box/es that apply to your child):

<input type="checkbox"/>	English only
<input type="checkbox"/>	Arabic only
<input type="checkbox"/>	English and Arabic
<input type="checkbox"/>	Other language. Specify:

Does your child use a device (iPad/book) to communicate?

Yes No

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Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Appendix II

Section B.

PLEASE MARK "YES" OR "NO" WITH AN X IN RELATION TO YOUR CHILD

	YES	NO
Compared with other children, did the child have any serious delay in sitting, standing or walking?		
Compared with other children, does the child have difficulty in seeing, either in the daytime or at night?		
Does the child appear to have difficulty in hearing?		
When you tell the child to do something, does he/she seem to understand what you are saying?		
Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?		
Does the child sometimes have fits, become rigid, or lose consciousness?		
Does the child learn to do things like other children of his/her age?		
Does the child speak at all (can he/she make himself/herself understood in words; can he/she say some recognizable words)?		
Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?		
Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow?		

Thank you for completing this questionnaire

Appendix I2

Appendix I2: Ten Questions Screen (Arabic)

Appendix I2



استبيان ولي الأمر

القسم أ.

تحية طيبة وبعد..

شكراً لك على السماح لطفلك بالمشاركة في هذه الدراسة.
الرجاء الإجابة على الأسئلة التالية:

تاريخ ولادة طفلك: اليوم/الشهر/السنة: _____
منذ متى التحق طفلك بالمدرسة؟ اليوم/الشهر/السنة: _____

تشخيص حالة طفلك:

هل لدى طفلك إخوة أو أخوات؟

نعم لا

إذا كانت الإجابة نعم:

كم عدد الإخوة: _____ كم عدد الأخوات: _____

اي لغة يتحدث طفلك؟ (ضع إشارة في المربعات التي تنطبق على طفلك):

الإنجليزية فقط	<input type="checkbox"/>
العربية فقط	<input type="checkbox"/>
الإنجليزية والعربية	<input type="checkbox"/>
لغة أخرى. الرجاء التحديد:	<input type="checkbox"/>

هل يستخدم طفلك أجهزة مثل (أي باد/الكمبيوتر اللوحي) للتواصل؟

لا نعم

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Appendix I2

القسم ب

تحت "نعم" أو "لا" فيما يتعلق بطفلك. يرجى وضع علامة

لا	نعم
	مقارنة مع الأطفال الآخرين، هل يجد الطفل صعوبة في الرؤية، سواء في النهار أو في الليل؟
	هل يبدو أن الطفل يعاني من صعوبة في السمع؟
	عندما تطلب من الطفل فعل شيء ما، هل يبدو أنه يفهم ما تقوله؟
	هل يواجه الطفل صعوبة في المشي أو تحريك ذراعيه أو هل يعاني من ضعف و/أو تصلب في الذراعين أو الساقين؟
	هل يصاب الطفل في بعض الأحيان بنوبات، أو يصبح جامداً، أو يفقد وعيه؟
	هل يتعلم الطفل فعل أشياء مثل الأطفال الآخرين في سنه؟
	هل يتكلم الطفل على الإطلاق (هل يستطيع أن يعبر عن نفسه بالكلمات، هل يستطيع التحدث بكلمات مفهومة)؟
	هل تختلف طريقة حديث الطفل بأي حال من الأحوال عن طريقة الحديث العادية (كأن تكون غير واضحة بما يكفي بأن تصبح مفهومة من قبل أشخاص آخرين غير أفراد أسرته/أسرتها المباشرين)؟
	بالمقارنة مع الأطفال الآخرين في سنه، هل يظهر الطفل بأي شكل من الأشكال متأخر عقلياً أو ثقيل أو بطيء الفهم؟

شكراً لاستكمال هذه الأسئلة

Appendix J

Appendix J: Teacher Questionnaire: Learner Screening Tool by Educators

Appendix J

LEARNER SCREENING TOOL BY EDUCATORS (LeSTE)

Learner Name: _____

Participant number:

--	--

Date of Birth: _____

Age: ____ years ____ month/s

Gender: ____

Primary Diagnosis: _____

For each of the following questions, please indicate (✓) this learner's ability in each of the areas listed.

AREAS YES NO

Areas	YES	NO	Admin Use
Vision	1. Are you aware of any visual problems that affect this learner's ability to learn?	<input type="checkbox"/>	<input type="checkbox"/>
	2. Does the learner wear glasses or contact lenses?	<input type="checkbox"/>	<input type="checkbox"/>
Hearing	3. Are you aware of any hearing problems that affect this learner's ability to learn?	<input type="checkbox"/>	<input type="checkbox"/>
	4. Does the learner wear a hearing aid?	<input type="checkbox"/>	<input type="checkbox"/>
	5. Does the learner respond when called by a person not facing him/her?	<input type="checkbox"/>	<input type="checkbox"/>
Motor Skills	6. Does the learner have any physical disabilities that affect his/her ability to use his/her hands?	<input type="checkbox"/>	<input type="checkbox"/>
	7. Can the learner hold a piece of paper or cardboard in his/her hands?	<input type="checkbox"/>	<input type="checkbox"/>
	8. Can the learner pick up small objects the size of a 5c coin with one or both hands?	<input type="checkbox"/>	<input type="checkbox"/>
	9. Can the learner control a pencil / crayon to write?	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive	10. Can the learner identify visual objects (e.g. pictures) in the front of the classroom from his/her desk?	<input type="checkbox"/>	<input type="checkbox"/>
	11. Can the learner identify pictures, symbols or words in a book s/he is holding?	<input type="checkbox"/>	<input type="checkbox"/>
	12. Can the learner follow instructions?	<input type="checkbox"/>	<input type="checkbox"/>
	13. Can the learner listen to an explanation without interrupting?	<input type="checkbox"/>	<input type="checkbox"/>
	14. Can the learner concentrate on a task for 20 minutes?	<input type="checkbox"/>	<input type="checkbox"/>
LoLT	15. Does the learner understand English as the Language of Learning and Teaching?	<input type="checkbox"/>	<input type="checkbox"/>
	16. Can the learner use English as the Language of Learning and Teaching to communicate?	<input type="checkbox"/>	<input type="checkbox"/>
PCS	17. Has the learner been exposed to Picture Communication Symbols (Boardmaker) at school?	<input type="checkbox"/>	<input type="checkbox"/>
	18. Can the learner recognize any Picture Communication Symbols used in lessons?	<input type="checkbox"/>	<input type="checkbox"/>

Learner Screening Tool by Educators completed by: _____

Appendix K

Appendix K: Questionnaire Appropriateness Form

Appendix K



QUESTIONNAIRE APPROPRIATENESS FORM

Please review the Participation short questionnaire and complete the form below. Answer the questions about the short Participation questionnaire in relation to English/Arabic speaking children in the United Arab Emirates. The questionnaire consists of 30 questions and 30 pictures. Please list the items on the questionnaire which need to be revised and comment in the space provided.

Name:

Profession:

Number of years of experience working with children:

Date:

No	Criteria	Agree 1	Somewhat agree 2	Disagree 3
1.	The questions are written in simple language			
2.	The questions are not ambiguous			
3.	The questions are clear			
4.	The questions are specific (not too general)			
5.	There are no technical terms or jargon used			
6.	The questions are relevant to the target audience			
7.	There are no leading questions			
8.	The pictures match their corresponding questions			
9.	The pictures are clear			

Comments/ suggestions to improve the questionnaire:

Thank you for completing this form

Appendix L

Appendix L: Participation Questionnaire 30 item Scoring Booklet

Appendix L

Participation Questionnaire-Short 6-16 version
(PQ-short 6-16) 190920

Participation Questionnaire – Rating and scoring form

For research use (for the researcher to fill in)

Survey Number: _____

Researcher Number: _____

Participant ID: _____

Date distributed: _____

Information about the child

Name _____

Age _____ Date of birth _____ Gender _____













What language(s) is/are spoken at home? _____

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Appendix L

Participation Questionnaire-Short 6-16 version
(PQ-short 6-16) 190920



















Participation Questionnaire

1. Do you read magazines, newspapers or books?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		
2. Do you write, with a pencil or a computer?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		
3. Do you wake up in the morning at the time that you want to?	Yes: Often 		Is it important for you to be better on this? (Is this a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		
4. Do you get to your school in time (or other important things)?	Yes: Often 		Is it important for you to be better on this? (Is this a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		
5. Do you go to bed at the time you want to?	Yes: Often 		Is it important for you to be better on this? (Is this a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		
6. If you get stressed, are you able to handle it in a good way?	Yes: Often 		Is it important for you to be better on this? (Is this a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		

(Arvidsson, 2019)

Appendix L













Participation Questionnaire-Short 6-16 version
(PQ-short 6-16) 190920

7. Do you understand the text in a book or a newspaper?	Yes: Often 	
	Yes: Sometimes 	Is it important for you to be better on this? (Is this a problem for you?)
	No: Seldom/never 	It's not a problem for you
8. Do you understand the TV news? (p310)	Yes: Often 	
	Yes: Sometimes 	Is it important for you to be better on this? (Is this a problem for you?)
	No: Seldom/never 	It's not a problem for you
9. Do you take part in a discussion?	Yes: Often 	
	Yes: Sometimes 	Is it important for you to do this more? (Is this a problem for you?)
	No: Seldom/never 	Do you think it's just as enough often as it is? (It's not a problem for you)
10. Do you use e-mail/text message (sms/WhatsApp)?	Yes: Often 	
	Yes: Sometimes 	Is it important for you to do this more? (Is this a problem for you?)
	No: Seldom/never 	Do you think it's just as enough often as it is? (It's not a problem for you)
11. Do you go by car, as passenger?	Yes: Often 	
	Yes: Sometimes 	Is it important for you to do this more? (Is this a problem for you?)
	No: Seldom/never 	Do you think it's just as enough often as it is? (It's not a problem for you)
12. Do you go by bus or taxi?	Yes: Often 	
	Yes: Sometimes 	Is it important for you to do this more? (Is this a problem for you?)
	No: Seldom/never 	Do you think it's just as enough often as it is? (It's not a problem for you)

(Arvidsson, 2019)

Appendix L













Participation Questionnaire-Short 6-16 version
(PQ-short 6-16) 190920

13. Do you take a shower or wash your body as often as you think is needed?	Yes: Often 		Is it important for you to do this more? (Is it a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		
14. Do you brush your teeth as often as you think is needed?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		
15. Do you (roughly) know what you should eat to feel good?	Yes: Often 		Is it important for you to be better on this? (Is this a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		
16. Do you (roughly) know how to take care of yourself to keep healthy? (p5702)	Yes: Often 		Is it important for you to be better on this? (Is this a problem for you?)
	Yes: Sometimes		It's actually not a problem for you
	No: Seldom/never		
17. Do you buy/shop things that you want to buy?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		
18. Do you prepare/cook some of your own food?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		

(Arvidsson, 2019)

Appendix L



















Participation Questionnaire-Short 6-16 version
(PQ-short 6-16) 190920

19. Do you clean parts of your home by yourself?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		
20. Do you hang out with friends/meet friends?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		
21. Do you make new friends?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		
22. Do you know how to make contact with someone new that you would like to know better?	Yes: Often 		Is it important for you to be better on this? (Is it a problem for you?)
	Yes: Sometimes		It's not a problem for you
	No: Seldom/never		
23. Do you go to school?	Yes: Often 		Is this a problem for you?
	Yes: Sometimes		It's actually not a problem for you
	No: Seldom/never		
24. Do handle your own money?	Yes: Often 		Is it important for you to do this more? (Is this a problem for you?)
	Yes: Sometimes		Do you think it's just as enough often as it is? (It's not a problem for you)
	No: Seldom/never		

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Appendix L

Participation Questionnaire-Short 6-16 version
(PQ-short 6-16) 190920

25. Do you participate in any sports activity?	Yes: Often		Is it important for you to do this more? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes		
	No: Seldom/never		
26. Do you participate in any cultural activity (e.g. theater, playing music)?	Yes: Often		Is it important for you to do this more? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes		
	No: Seldom/never		
27. Do you go to restaurants or cafés?	Yes: Often		Is it important for you to do this more? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes		
	No: Seldom/never		
28. Do you go to the movies?	Yes: Often		Is it important for you to do this more? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes		
	No: Seldom/never		
29. Do you do any activities in the countryside, like hiking, picking fruit or fishing?	Yes: Often		Is it important for you to do this more? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes		
	No: Seldom/never		
30. Do you go on holiday?	Yes: Often		Is it important for you to do this more? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes		
	No: Seldom/never		

(Arvidsson, 2019)

Appendix L

Participation Questionnaire-Short 6-16 version
 (PQ-short 6-16) 190920

Scoring Sheet – participation (frequency and importance)

Survey Number: _____	Researcher Number: _____
Participant ID: _____	

Item – Activity	Frequency			Importance	
	Often	Some-times	Seldom /never	Import-ant	Not import-ant
1. Do you read magazines, newspapers or books?	3	2	1	2	1
2. Do you write, with a pencil or a computer?	3	2	1	2	1
3. Do you wake up in the morning at the time that you want to?	3	2	1	2	1
4. Do you get to your school in time (or other important things)?	3	2	1	2	1
5. Do you go to bed at the time you want to?	3	2	1	2	1
6. If you get stressed, are you able to handle it in a good way?	3	2	1	2	1
7. Do you understand the text in a newspaper?	3	2	1	2	1
8. Do you understand the TV news?	3	2	1	2	1
9. Do you take part in a discussion?	3	2	1	2	1
10. Do you use e-mail/text message (sms/WhatsApp)?	3	2	1	2	1
11. Do you go by car, as passenger?	3	2	1	2	1
12. Do you go by bus or taxi?	3	2	1	2	1
13. Do you take a shower or wash your body as often as you think is needed?	3	2	1	2	1
14. Do you brush your teeth as often as you think is needed?	3	2	1	2	1
15. Do you (roughly) know what you should eat to feel good?	3	2	1	2	1
16. Do you (roughly) know how to take care of yourself to keep healthy?	3	2	1	2	1
17. Do you buy/shop things that you want to buy?	3	2	1	2	1
18. Do you prepare/cook some of your own food?	3	2	1	2	1
19. Do you clean parts of your home by yourself?	3	2	1	2	1
20. Do you hang out with friends/meet friends?	3	2	1	2	1
21. Do you make new friends?	3	2	1	2	1
22. Do you know how to make contact with someone new that you would like to know better?	3	2	1	2	1
23. Do you go to school?	3	2	1	2	1
24. Do you handle your own money?	3	2	1	2	1
25. Do you participate in any sports activity?	3	2	1	2	1
26. Do you participate in any cultural activity (e.g. theater, playing music)?	3	2	1	2	1
27. Do you go to restaurants or cafés?	3	2	1	2	1
28. Do you go to the movies?	3	2	1	2	1
29. Do you do any activities in the countryside, like walking, hiking, picking fruit or fishing?	3	2	1	2	1
30. Do you go on holiday?	3	2	1	2	1
Summary (numbers of scores)					

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Appendix M

Appendix M: Procedural Checklist

Appendix M

Procedural Checklist

Participant no:	
--------------------	--

Step	Description	Task completed	
		Yes	No
1.	Introduce self to child		
2.	Proceed with child to a quiet room		
3.	Conduct assent procedure		
	3.1 Explain the purpose of the study using the wording detailed in the Short Participation questionnaire		
	3.2 Ask if child has any questions		
	3.3 Ask assent from child participant		
	3.4 If child assents continue with procedures below		
	3.5 If child does not assent, walk child back to their classroom		
4.	Administer CARS		
	4.1 Take the child back to their classroom		
	4.2 Observe them in the classroom while completing the CARS form		
	4.3 Consult with teacher for additional information		
	4.3 Score the CARS form		
5.	Conduct assent procedure		
	5.1 Fetch the child from class and introduce self to child again		
	5.2 Proceed with child to a quiet room		

Appendix M

	5.3 Explain the purpose of the study using the wording detailed in the Short Participation questionnaire 5.4 Ask if child has any questions 5.5 Ask assent from child participant 5.6 If child assents continue with procedures below 5.7 If child does not assent, walk child back to their classroom		
6.	Short Participation questionnaire instrument procedure:		
	6.1 Explain to the child that you are going to show them some drawings of people participating in various activities and that you would like to know if they also participate in the activities. 6.2 Place the frequency template in front of the child and explain the levels of frequency using clear, plain and appropriate language. 6.3 Administer Trial items of the questionnaire 6.4 Frequency: Administer the frequency procedure 6.5 Administer importance-rating procedure 6.6 Document on scoring sheet for each item		
7.	Thank the child for participating, provide token and walk him/her to class		

Appendix N

Appendix N: Participation Questionnaire 30 item Interview Schedule

Appendix N

Participation Questionnaire – short version (PQ-short) – Instructions (Arvidsson, 2019)

The main purpose of the questionnaire is to identify what activity items the child perceives as restricted or problematic in terms of participation.

The assessment is conducted as a structured interview/oral survey where the children rate their participation based on the present situation regarding 30 items of everyday activities.

The activities that the child rates that he/she not perform often but rates important to do more often can be considered as restricted (as a possible problem that can be focus for an intervention). Participation restriction = the combination Does sometimes or seldom/never and perceived as important to do more often.

Each of the 30 activity item is rated in three steps:

1. Picture choice: The child chooses a picture representing the activity
2. Frequency rating: The child rates if he/she performs the activity or not and how often (Often, sometimes or never/seldom)
3. Importance ratings: If the child rates that he/she not does the activity often, he/she rates if it would be important to do the activity more often (i.e. if it is a perceived problem that he/she doesn't perform the activity as often as wanted)

Material

Participation Questionnaire – Rating and scoring form
Pictures for choosing what is representing the activity
Visual support for rating the frequency

Appendix N

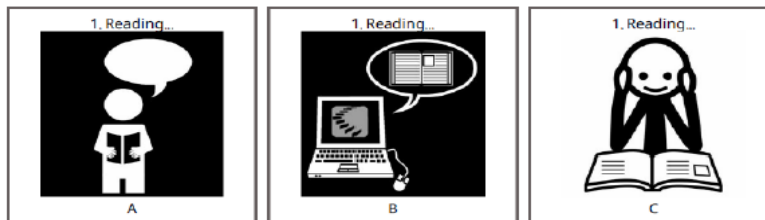
Introducing the questionnaire

Ask the questions about the child (at the front of the questionnaire). Explain that you will ask questions about different things/activities you can do in everyday life. Say that you will ask questions about how often he/she does the activity, and if he/she thinks the activity might be important to do more often.

1. Choosing picture representing the activity (picture choice)

Start with the first question (see question 1 below).

Show the child the three pictures representing this item and ask: "Which one of the pictures, A, B and C, do you think shows reading?"



The child can say the letter (A, B or C), point or use something (whatever is available) to choose a picture. If the child chooses picture C, you mark that like:

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B X No choice: O	Yes: Often STOP	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes No: Seldom/never	

If the child chooses more than one picture you ask, once: "But if you had to choose one picture, which one would it be?" If the child still chooses more than one, mark all the choices.

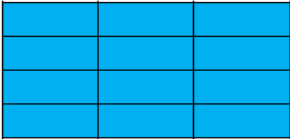
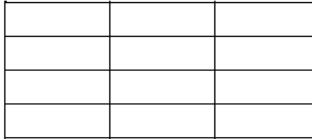
If the child doesn't choose any picture you ask, once: "You don't think any of the pictures shows reading?" (or the activity for the item). If the child still doesn't make any choice, you mark "No choice":

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: X	Yes: Often STOP	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes No: Seldom/never	

Appendix N




2. Asking about how often the activity is performed (frequency)

The purpose is that the child should answer how often the activity is performed and for these ratings a visual support is provided:

Often	Sometimes	Seldom/never
		

Show the child the visual support and say that this may be helpful for them when answering. Point each box and say "This show if you maybe do something *often* (point), maybe *sometimes* (point) or maybe *seldom or never* (point).




Then you ask the child: "Do you read magazines, newspapers or books?"

<p>1. Do you read magazines, newspapers or books?</p> <p>Picture(s) chosen: A B C No choice: O</p>	<p>Yes: Often </p> <p>Yes: Sometimes </p> <p>No: Seldom/never </p>	<p>Is it important for you to do this more often? (Is this a problem for you?)</p> <p>Do you think it's just as enough often as it is? (It's not a problem for you)</p>
--	---	---




The child can answer a frequency directly, then just tick/mark the answer.

The child may also answer just "yes" or "no":

If the child answers "yes", ask a question about if it's *often* (point) or *sometimes* (point). If the child answers "*often*", no follow-up question about importance will be asked (that why it says STOP). Just tick over the answer (see below) and move on to the next question.

<p>1. Do you read magazines, newspapers or books?</p> <p>Picture(s) chosen: A B C No choice: O</p>	<p>Yes: Often </p> <p>Yes: Sometimes </p> <p>No: Seldom/never </p>	<p>Is it important for you to do this more often? (Is this a problem for you?)</p> <p>Do you think it's just as enough often as it is? (It's not a problem for you)</p>
--	--	---

If the child answers "*sometimes*" and tick the answer:

<p>1. Do you read magazines, newspapers or books?</p> <p>Picture(s) chosen: A B C No choice: O</p>	<p>Yes: Often </p> <p>Yes: Sometimes </p> <p>No: Seldom/never </p>	<p>Is it important for you to do this more often? (Is this a problem for you?)</p> <p>Do you think it's just as enough often as it is? (It's not a problem for you)</p>
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


If the child answers "Yes: sometimes" or "No: Seldom/Never", the follow-up question about the perceived importance of the activity is asked.

Appendix N





3. Asking about the how important it would be to do the activity more often (importance)

If the child has answered "Yes: sometimes" or "No: Seldom/Never", the question about the perceived importance of the activity is asked: "Is it important for you to do this more often? Is this a problem for you (that you not perform the activity often)?" or "Do you think it's just as enough often as it is? It's not a problem for you?"

For example. The child answered that he/she reads newspaper sometimes and then that it is important to read newspaper more often (i.e. it's perceived as a problem). Then tick:

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Yes: Often 	Is it important for you to do this more often? (Is this a problem for you?)  Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes  No: Seldom/never 	

If the child answered that it is not important to read newspapers more often (i.e. not think it's a problem). Then tick as below, and continue to the next question.

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Yes: Often 	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you) 
	Yes: Sometimes  No: Seldom/never 	




Comment: Both the activity in itself as well as the scale of "how often" is not always easy to understand for the child so sometimes some further explanations may be needed. Therefore you sometimes have to re-formulate the question and give some examples, however without changing the content of the activity item.

Appendix N

Scoring instructions

Scoring – picture choice

Score by marking the letter of the chosen picture(s). See example below:




	Frequency	Importance
1. Do you read magazines, newspapers or books? Picture(s) chosen: X B C No choice: O	Yes: Often = 3 	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes = 2 	
	No: Seldom/never = 1 	

In the scoring sheet it will be:

Item – Activity	Picture chosen			No choice
	A	B	C	
1. Do you read magazines, newspapers or books?	X	B	C	
2. Do you write, with a pencil or a computer?	A	B	C	

The child is allowed to choose more than one picture (then you mark them all).

If the child doesn't make any choice:

	Frequency	Importance
1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: X	Yes: Often = 3 	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)
	Yes: Sometimes = 2 	
	No: Seldom/never = 1 	

Item – Activity	Picture chosen			No choice
	A	B	C	
1. Do you read magazines, newspapers or books?	A	B	C	
2. Do you write, with a pencil or a computer?	A	B	C	X

Appendix N

Scoring – participation (Frequency and Importance)

For each activity item, the scoring is made separately for Frequency (the question about how often) and Importance (the question about if important and/or a problem or not).

Scoring the **frequency**: Yes: Often = 3, Yes: Sometimes = 2, No: Seldom/Never = 1. See example below:

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Frequency	Importance
	Yes: Often = 3	
	Yes: Sometimes = 2 No: Seldom/never = 1	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Frequency	Importance
	Yes: Often = 3 STOP	
	Yes: Sometimes = 2 No: Seldom/never = 1	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Frequency	Importance
	Yes: Often = 3 STOP	
	Yes: Sometimes = 2 No: Seldom/never = 1	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you)

Scoring the **importance**: Is important/ a problem = 2, Is *not* important/ *not* a problem = 1. See example below:

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Frequency	Importance
	Yes: Often STOP	
	Yes: Sometimes No: Seldom/never	Is it important for you to do this more often? (Is this a problem for you?) = 2 Do you think it's just as enough often as it is? (It's not a problem for you)

1. Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Frequency	Importance
	Yes: Often = 3 STOP	
	Yes: Sometimes = 2 No: Seldom/never = 1	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you?) = 1

Appendix N

Three examples of scoring frequency and importance

Example 1

Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Yes: Often STOP	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you?)
	Yes: Sometimes	
	No: Seldom/never	

Item – Activity	Frequency		Importance	
	Often	Seldom /never	Important	Not important
1. Do you read magazines, newspapers or books?	3	1	1	1
2. Do you write, with a pencil or a computer?	3	2	2	1

Example 2

1. Do you read magazines, newspapers or books?	Yes: Often STOP	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you?)
	Yes: Sometimes	
	No: Seldom/never	

Item – Activity	Frequency		Importance	
	Often	Seldom /never	Important	Not important
1. Do you read magazines, newspapers or books?	3	1	2	1
2. Do you write, with a pencil or a computer?	3	2	2	1

Example 3*)

Do you read magazines, newspapers or books? Picture(s) chosen: A B C No choice: O	Yes: Often STOP	Is it important for you to do this more often? (Is this a problem for you?) Do you think it's just as enough often as it is? (It's not a problem for you?)
	Yes: Sometimes	
	No: Seldom/never	

Item – Activity	Frequency		Importance	
	Often	Seldom /never	Important	Not important
1. Do you read magazines, newspapers or books?	3	2	2	1
2. Do you write, with a pencil or a computer?	3	2	2	1

*) Note that for example 3, importance is not scored since no rating is performed.

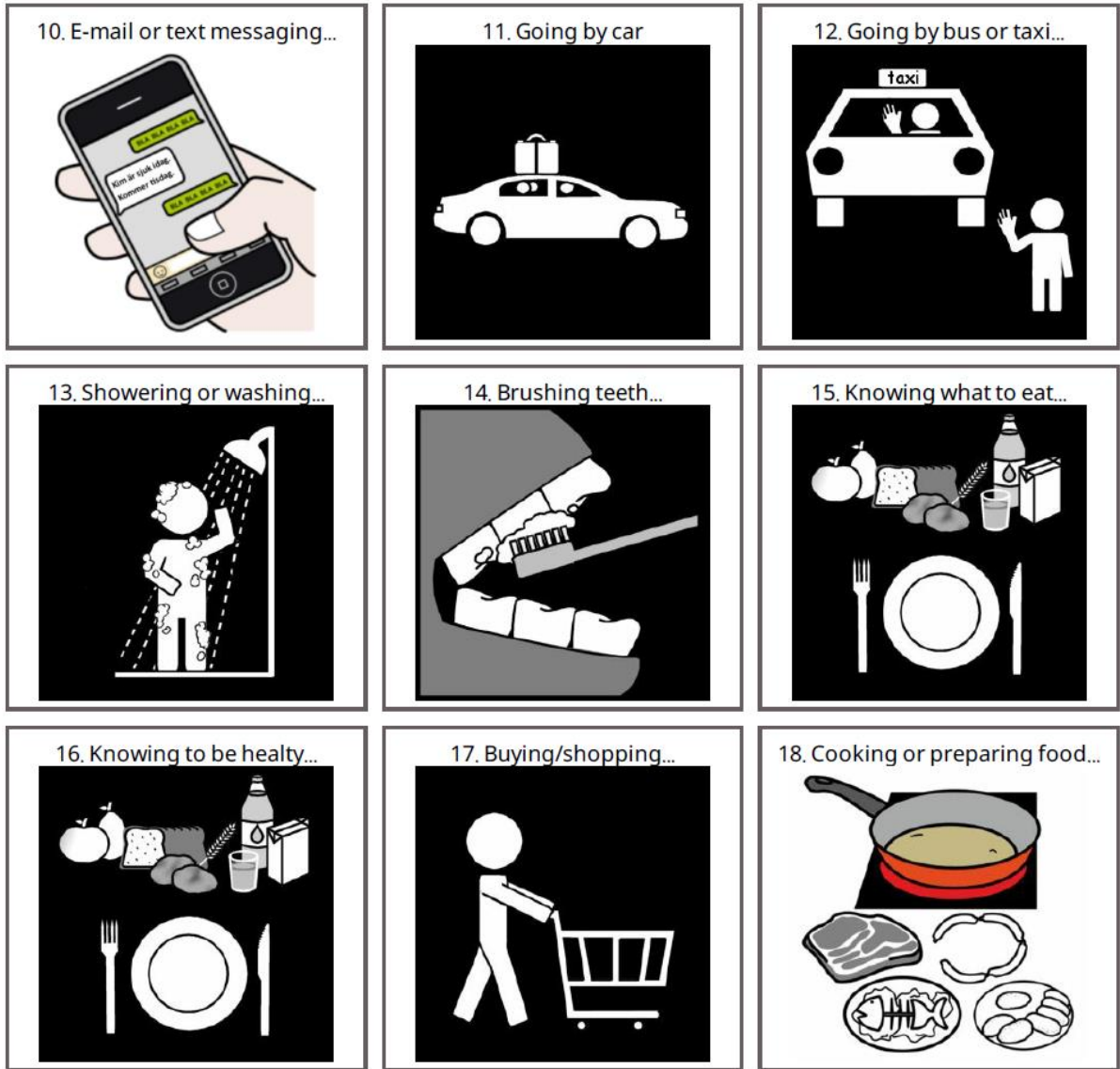
Appendix O

Appendix O: Participation Questionnaire 30 item Picture support

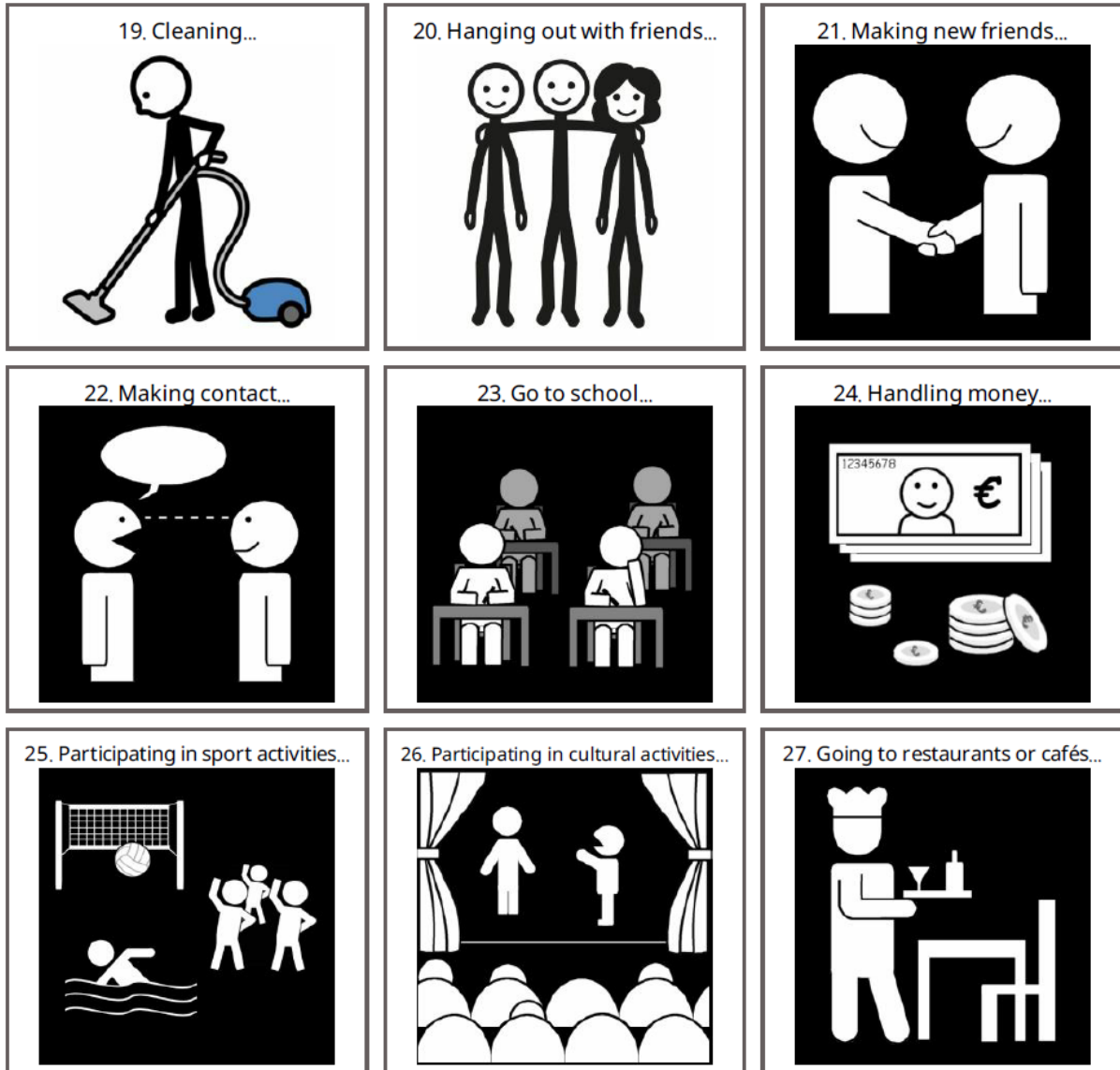
Appendix O



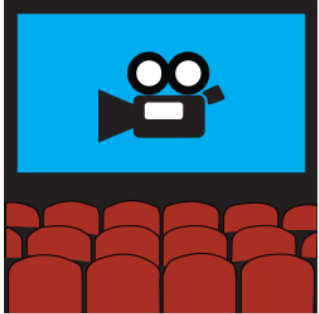
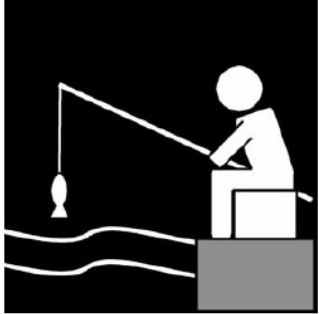

Appendix O



Appendix O



Appendix O

<p>28. Going to the movies...</p> 	<p>29. Doing countryside activities...</p> 	<p>30. Going on holiday...</p> 

Appendix O

Often			Sometimes			Seldom/never		

Appendix P

Appendix P: Declaration of Language Editing

Appendix P



Editing Declaration

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To whom it may concern

6 July 2020

I hereby declare that I am a professional editor and have edited and proofread the following dissertation:

Exploring the patterns of participation and participation restrictions in school-aged children
with mild to moderate autism in the United Arab Emirates

by

Lizé Monique Rooi
Student no.: 19381345

As a professional editor with an English major obtained from the University of Pretoria in 2003, I am also a Full Member of the Professional Editors' Guild and a member of SATI (membership number 1002503).

Yours sincerely

Mrs Lené Kraft