Social Participation and its Classification for Preschool Children with Autism Spectrum Disorder

by

Tamara Hoffman Germani

A thesis submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

MEDICAL SCIENCES - PAEDIATRICS

Department of Pediatrics
University of Alberta

Abstract

Background. Social participation is considered the ultimate aim of rehabilitation, particularly for preschool children with Autism Spectrum Disorder (ASD). Given the inherent social difficulties of preschool children with ASD, social participation is a relevant and meaningful construct to explore and target as part of a multidisciplinary team. However, the construct of social participation has not yet been refined for preschool children with ASD by stakeholders to ensure its measurement is meaningful and relevant. There are also no available measures exclusively focused on social participation for preschool children with ASD, which may be imperative to the inclusion of these children in community activities with peers.

Objectives. To *(i)* complete a scoping review on participation measures available for preschool children with ASD, *(ii)* understand stakeholders' perspectives, including parents, professionals and educators, on social participation for preschool children with ASD, and *(iii)* develop and establish content validity for a social participation classification system.

Methods. The International Classification of Functioning, Disability and Health – Child and Youth (ICF-CY) version, was selected to support the theoretical framework of this thesis. First, a *scoping review* was completed using a broad and comprehensive search strategy across several electronic databases with hand searching of reference lists. Second, a *mixed methods web-based survey* of stakeholders, including parents and professionals, was developed to support the refinement of social participation using frequency and content analysis. Third, a *multiple methods study* used a modified nominal group technique and experts developed the *Autism Social Participation Classification*

System (ASPCS) using the refined construct of social participation from the web-based survey. The Delphi model of consensus was then used to generate agreement on content validity of levels over three rounds of a web-based survey by stakeholders from across Canada.

Results. Seven measures of participation were identified in the *scoping review* for possible use with preschool children. Five measures had standardization samples that included preschool children with ASD and three provided both validity and reliability data. For the *mixed methods study,* responses of 74 stakeholders demonstrated that the essential components of social participation were: *(i)* behaviour management, *(ii)* social interactions and *(iii)* various types of play. Additional analysis revealed that stakeholders used intrinsic motivation strategies and contingency management to facilitate social participation. In the *multiple methods study,* an expert group of clinicians and a parent developed the ASPCS over five focus groups and 12 follow-up interviews. Content validity was established with >80% consensus that each of the five levels in three domains, *Behaviour, Social Desire and Activities & Environment,* in the ASPCS were clinically meaningful and distinct.

Conclusions. There were few standardized participation measures for preschool children with ASD and none were exclusively focused on social participation. A new measure was needed. With the refinement of social participation by stakeholders, and using the taxonomy of the ICF-CY, the ASPCS was developed and validated for preschool children with ASD. Evaluation of additional psychometric properties and investigation into its clinical application are needed.

Preface

This thesis is an original work by Tamara H Germani. Ethics approval from the University of Alberta Health Research Ethics Board (Panel B) was received for the following projects: (i) Pro00048032: The Refinement of Social Participation as a Construct for Preschool Children with Autism Spectrum Disorder on September 25, 2014; (ii) Pro00052079: Development of Autism Social Participation Classification System for Preschool Children with Autism Spectrum Disorder on December 22, 2014; and (iii) Pro00053300: Content Validity of the Autism Social Participation Classification System for Preschool Children with Autism Spectrum Disorder on August 20, 2015.

Chapter 3 of this thesis is under review as T. Germani, J. Magill-Evans, L. Zwaigenbaum, L.A.R. Sacrey, S. Askari and D. Anaby "Participation Measures for Preschool Children with Autism Spectrum Disorder: A Scoping Review" *Review Journal of Autism and Developmental Disabilities*. With the support and guidance of Drs. Magill-Evans and Zwaigenbaum, I was responsible for reviewing, coordination of reviewers and co-authors, analyses, and composition of the manuscript.

Chapter 4 of this thesis is in press as T. Germani, L. Zwaigenbaum, J. Magill-Evans, S. Hodgetts, and G.D.C. Ball "Stakeholder Perspectives' on Social Participation in Preschool Children with Autism Spectrum Disorder" *Developmental Neurorehabilitation*. With the support and guidance of Drs. Magill-Evans and Zwaigenbaum, I was responsible for development of research question and design, data collection, analyses, and composition of the manuscript.

Chapter 5 of thesis is under review as T. Germani, L. Zwaigenbaum, S. Hodgetts, J. Magill-Evans, J. Hildebrandt, M. Stolte, S. Mitchell, K. Wennerstorm, & C.A

Hapchyn. “Development and Content Validity of the Autism Social Participation Classification System for Preschool Children with Autism Spectrum Disorder” *BMC Pediatrics.* With the support and guidance of Drs. Magill-Evans and Zwaigenbaum, I was responsible for development of research question and design, data collection, analyses, and composition of the manuscript.

Acknowledgements

I would like to thank my supervisors, Drs. Lonnie Zwaigenbaum and Joyce Magill-Evans, and my committee members, Drs. Geoff Ball and Sandra Hodgetts for their infinite wisdom, time and ongoing mentorship. A special thank-you to the individuals with Autism Spectrum Disorder, their families, and the many professionals I have worked with over the last four years. You are proof that the best lessons occur outside of the classroom.

I am grateful for the following funding and financial support in completing my doctoral degree: (i) Doctoral Recruitment Scholarship (Faculty of Graduate Studies and Research, University of Alberta), (ii) Canadian Institute for Health Research (CIHR) Strategic Training Fellow in Autism (CIHR, Sinneave Family Foundation and McGill University), (iii) Graduate Student Pilot Grant (Autism Society of Edmonton and Area and Autism Research Centre), (iv) Graduate Studentship (Women and Children's Research Institute), (v) Clinical Seed Grant (Glenrose Rehabilitation Hospital Foundation), (vi) Clinician Fellowship (Alberta Innovates – Health Solutions), and (vii) Career Enhance Program Award (Canadian Child Health Clinician Scientist Program).

Table of Contents

List of Tables

List of Figures

Glossary of Terms

ASD	Autism Spectrum Disorder
ACSF:SC	Autism Classification System of Functioning: Social Communication
ASPCS	Autism Social Participation Classification System
CIHR	Canadian Institute of Health Research
CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification System
ICF-CY	International Classification of Functioning, Disability and Health – Child and Youth Version
REDCap	Research Electronic Data Capture
WHO	World Health Organization

Chapter 1: Introduction

The central focus of this thesis is social participation and its measurement. For preschool children with Autism Spectrum Disorder (ASD), it is often the social elements and difficulties such as repetitive behaviours and restricted interests, and sensory sensitivities linked directly to their diagnosis that limit activity involvement and participation (Little, Ausderau, Sideris, & Baranek, 2015). Thus, social participation is a key construct for preschool children with ASD, given the importance of playing or doing with others in social activities as part of healthy development. The term social participation has been frequently used as synonymous with play or group interactions with preschool children (Parten, 1932; Wolfberg, DeWitt, Young, & Nguyen, 2014). In this thesis, the definition used to describe social participation is *involvement in life situations, typically opportunities that focus on peer-to-peer social interactions within the community*.

Challenges exist in the measurement of social participation given its wide breadth and potentially subjective nature. Thus, there is a need to consult and collaborate with stakeholders, such as parents, clinicians, and educators, in the research process (Morris, Shilling, McHugh, & Wyatt, 2011). By involving stakeholders at multiple stages, the applicability of the findings or outcomes such as the development of a social participation classification system, are more likely to be useful and readily translated to practice (Morris et al., 2011). In order to create opportunities for successful social participation, there must first be an understanding of what social participation means for frontline stakeholders and how it is experienced in their day-to-day lives.

1.1. Preschool Children with Autism Spectrum Disorder.

ASD is a neurodevelopmental disability that is characterized by social communication difficulties, and repetitive and restrictive behaviours (American Psychiatric Association, 2014). These challenges create functional restrictions and occupational restrictions in every day life that may limit a child's social development. As preschool children with ASD are a socially vulnerable group, it was hypothesized that there may be unique facilitators and barriers to social participation compared to other children with disabilities that parents and professionals encounter. Present estimates of the rate of ASD is 1 in 68 among 8 year olds, with a boy: girl ratio of 4:1 (Centre for Disease Control, 2014). Although 80% of children demonstrate behavioural signs of ASD by two years of age, the average age of diagnosis remains at 4 years of age (Centre for Disease Control, 2014). Given that early intervention starts soon after diagnosis, examining the social participation of preschool-aged children is prudent to ensure community membership and involvement.

The 'preschool age,' typically considered to be ages three to five years old, is a dynamic period of development. For the purpose of this thesis, children who are of preschool age (i.e., 3 to 5 years old) will be referred to as preschool children, regardless of whether or not they attend preschool. This is a formative period of learning about one's role in groups as well as acquiring social skills and subsequently, having opportunities to practice them (Parten, 1932). For preschool children with ASD, it is important to provide opportunities to participate in social groups at home and in the community. A sample of Canadian preschool children with ASD demonstrated heterogeneous developmental trajectories of adaptive functioning with approximately 20% demonstrating improvement in functioning at six years of age, with interventions being provided shortly after diagnosis depending on geographical region (Szatmari

et al., 2015). However, symptom severity remained relatively stable from diagnosis until six years of age, despite intervention services (Szatmari et al., 2015). This demonstrates that the majority of preschool children diagnosed with ASD will have difficulties with social communication as well as restricted and repetitive behaviours throughout childhood. The cumulative effect of social communication and restricted and repetitive behaviours can have a functional impact on a preschool child's ability to socially participate with peers and activities in their community.

1.2. The Construct of Social Participation.

In the original study of social participation in preschool children by Parten (1932), *social participation* was characterized as different types of 'play behavior' such as: *unoccupied, onlooker, solitary, parallel, associative play*, and *organized supplementary* or *cooperative play*. Parten's study and those that came after largely used a direct observational coding methodology to understand and describe peer-to-peer engagement and relationships. Observations have typically focused on: (i) *extensity*: the number of social contacts the child has with his or her peers and (ii) *intensity*: the types of groups that the child participates in, subdivided by the extent to which they are integrated (such as what is their duty/job/role) and the status of child in the group (e.g., a leadership role, help to plan/shape the group goals) (Parten, 1932). There are also factors specific to the child (i.e., intrinsic factors) and their environment (i.e., extrinsic factors) that can limit or facilitate social participation. *Intrinsic factors* include gender, ethnicity, cognitive abilities, communication skills and behavioural challenges while *extrinsic factors* include socioeconomic status, family location, and availability of community transportation (Myers, Davis, Stobbe, & Bjornson, 2015). These factors, regardless of ability, play an important

role in the intersection of the individual with their activities, opportunity to participate socially with peers, and involvement in their environments, including those outside of the home.

The construct of *social participation* has been applied broadly across pediatric neurodevelopmental disabilities (Bossaert, de Boer, Frostad, Pijl, & Petry, 2015; Goldingay et al., 2013; Koster, Pijl, Nakken, & Van Houten, 2010; Koster, Timmerman, Nakken, Pijl, & van Houten, 2009). It has also been explored within specific disability groups, including but not limited to persons with sensory processing disorders (Cosbey, Johnston, & Dunn, 2010), traumatic brain injury (Dumont, Gervais, Fougeyrollas, & Bertrand, 2004), or developmental coordination disorder (Sylvestre, Nadeau, Charron, Larose, & Lepage, 2013). These groups may have overlapping challenges with ASD, providing insights into some of the facilitators of and barriers to social participation and its classification. There have also been studies with adolescents, young adults, and adults with ASD (Goldingay et al., 2013; Myers et al., 2015; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Shattuck, Orsmond, Wagner, & Cooper, 2011; Tobin, Drager, & Richardson, 2014).

With a focus on students with special needs and their peers, Koster, Nakken, Pijl, and van Houten (2009) described *social participation* as "the presence of positive social contact/ interaction between pupils and their classmates, acceptance of pupils by their classmates, social relationships/ friendships between pupils and their classmates and the pupils' perception that they are accepted by their classmates" (p. 135). This description is consistent with but also expands on Parten's (1932) definition of social participation, to include acceptance and perception of peers as part of the paradigm. For preschool children with disabilities, social participation with peers has benefits including development of social, play and communication skills (Tsao et al., 2008). Their peers, usually typically developing children, also benefit with

increased acceptance of children with special needs when such children are included in their program and social engagements are positive (Tsao et al., 2008).

Preschool children with ASD may spend a significant amount of time within their home environments, especially with the shift in community interventions to occur within naturalistic settings. Early intervention programs focusing on skill acquisition, behaviour management, or functioning often occur in the home and utilize a train-the-trainer model of coaching parents and siblings as mediators. When children with disabilities participate in community programs, such as inclusive preschools or recreational programs, they demonstrate more positive behaviour (e.g., sharing, requesting) when engaged in a blended program (compared to a segregated program) of typically developing preschool children and those with special needs, including ASD (Tsao et al., 2008). Thus, location is relevant to consider when assessing social participation as it influences opportunities to connect with peers, practice social skills and build peer-to-peer relationships. Social participation opportunities taking place within the larger community are important as they allow for peer-to-peer interactions and play. Based on an examination of the existing literature on social participation in preschool or community settings, there has been a focus on the acceptance of children with special needs within the community as well as the opportunities to develop peer relationships.

The majority of the literature on social participation for individuals with ASD has focused on adolescents and adults with ASD. As adolescents transition to adulthood, some elements of social participation remained stable if case management by professionals was present and the individual had higher cognitive functioning; however involvement in community participation was reduced (Myers et al., 2015). There is an increased risk of isolation if the individual with ASD has an increase in challenging behaviours and poor communication abilities

(Myers et al., 2015). For young adults with ASD, social participation is heavily influenced by social functioning that can create support through relationships and natural support networks (Tobin et al., 2014). Social skills groups and membership in various community networks can provide these natural opportunities to develop relationships and supports (Tobin et al., 2014). These social participation opportunities are also facilitated by the individual's informal support systems, usually family members, who provide encouragement and locate or advocate for these groups within the community.

What is presently lacking in the literature on social participation is the perspectives and lived experiences of families, educators, and professionals (herein referred to as stakeholders) of children, including preschool children, with ASD. Given that there are various stakeholders, each need to be included in order to accurately represent and respect their unique needs and perspectives (Elsabbagh et al., 2014). The 'real life' or clinical application of research programs needs to be addressed not just at the end of a study (when time and money have likely run out), but also at the start if findings are to be impactful and translational (Szatmari, Charman, & Constantino, 2012). Thus, researchers and graduate students need to engage with the individuals and their families who may benefit from the research program, to ensure that it is used and useful to practice and daily life (Elsabbagh et al., 2014).

A recent systematic review of interventions to improve social participation for children with ASD included social skills groups, Picture Exchange Communication System, joint attention focused interventions, and parent mediated coaching (Tanner, Hand, O'Toole, & Lane, 2015). There were no 'specific' social participation interventions reported, although each of the studies addressed at least one element of social participation. The majority of interventions focused on social communication and relationships; however, there was less evidence to support

interventions for reducing repetitive and restrictive behaviours, which limit a child's engagement and participation (Tanner et al., 2015). No one measure existed to describe, classify, or evaluate an individual's social participation. Rather, an inconsistent battery of assessments was administered across groups in order to draw conclusions about social participation. Assessments typically evaluated social skills, behaviours, isolation, communication and emotion reading; but none measured social participation. Thus, little research exists on social participation in preschool children with ASD; what is available tends to focus on specific components or contributors rather than social participation as a single, integrated construct.

Nevertheless, the concept of *social participation* is frequently used in health research and policy as a goal or ideal outcome for all persons, regardless of ability (Piškur, 2013; Piškur et al., 2013). Social participation plays an essential role in how children learn about their world (and community) and develop social skills essential for interacting with peers (Bedell & Dumas, 2004; Law, 2002). Social participation is also linked to improvements in health and well-being, and a reduction in caregiver burden (Tanner et al., 2015). Individuals with ASD are at risk for poor psychosocial outcomes, which influences their overall health and quality of life (Myers et al., 2015; Tobin et al., 2014). Although these studies broadly characterize social participation as *attending* community activities, there was no report on the intensity or extensity of the individual's social participation in the activity. Thus, there is a need to refine the construct of social participation and measure it in greater depth for individuals with ASD.

1.3. Theoretical Framework of Thesis

The theoretical framework of this thesis is based on the *International Classification of Function, Disability and Health – Child and Youth version* (ICF-CY) that includes a biopsychosocial framework and taxonomy to holistically describe the abilities and issues

children and youth encounter within their communities (World Health Organization, 2007). The international taxonomy is used for describing functional abilities, and is part of a larger conceptual framework to consider the intersecting elements (such as Health Condition, Body Functions and Structures, Activities, Environmental Factors and Personal Factors) that promote or restrict a child's participation in life events, as depicted in Figure 1.1. Notable limitations of the ICF-CY include the underlying assumption that there is 'normal' and 'abnormal' functioning; and that all normal functioning is an universal truth or quest (Whalley Hammell, 2004). Although the ICF(-CY) is intended to be holistic in capturing many dimensions of participation and restriction, for persons with disabilities it arguably can also be marginalizing and create a division of privilege and power (Whalley Hammell, 2004). Healthcare professionals who aim to make 'objective' measurements of the person's functional abilities must strive to be person-centered in the process of using the ICF-CY (Whalley Hammell, 2004).

Ultimately, this framework was utilized to support the refinement of the construct of social participation, and to develop the classification system. In the ICF-CY, participation is broadly defined as "the involvement in a life situation" (World Health Organization, 2007, p. xvi). To date, no clear definition exists of social participation nor is it differentiated from the concept of participation (Piškur et al., 2013). Suggestions have been made to modify the ICF-CY's definition of participation to focus only on an individual's social roles, eliminating the need to differentiate between social participation and participation (Piškur et al., 2013). However, this position has not been widely adopted or endorsed, leading to different types of participation typically by 'environmental type', such as social, community, home and school participation. A lack of consensus on the differentiation of participation from social participation

provided an opportunity in this thesis to refine the construct of social participation from stakeholders' perspectives within the population of interest.

To support the utility of the biopsychosocial framework for clinical practice, there is an international research program creating a 'short list' of ICF-CY categories (known as core sets) in order to describe essential functional abilities and restrictions for individuals with ASD (Bolte et al., 2014). These ASD-specific core sets will form a taxonomy of functioning for use in outcome-based clinical research seeking to provide a 'good quality of life' (Bolte et al., 2014). However, these validated core sets were unavailable at the start of the thesis project; thus, the entire ICF-CY taxonomy was initially considered to support refinement of social participation. The ICF-CY taxonomy was narrowed based on the available reviews for broadly defined participation and children with disabilities, to provide some focus and direction when engaging with stakeholders. Several phases of the international research program described above were published during the data collection and analysis of this thesis, and the implications of these results in relationship to the thesis results are discussed in Chapter 6.

1.4. Classification for Preschool Children with ASD.

This thesis focuses on social participation and its classification for preschool children with ASD. The decision to develop a classification system for social participation stemmed from the scoping review completed on broad participation measures available for use with preschool children with ASD as detailed in Chapter 3. Several clinical tools were identified. They were descriptive, evaluative, semi-structured, questionnaire/parent-reported, or observation-based by a trained health care professional. No tools were identified that focused exclusively on social elements of participation, thus the focus of the scoping review was on social elements as well as behaviours that may restrict participation.

Classification of individuals, including preschool children with ASD, is not a novel endeavor. Previous research has focused on classifying children with ASD by the quality of their social interaction as reflected in four behavioural subtypes: (1) *social aloofness*, (2) *passive interaction*, (3) *active, but odd interaction* and (4) *appropriate interaction* (Wing & Gould, 1979). However, further research suggested that ASD subgroups reflected a continuum, rather than a strict cut-off between ability 'types' (Waterhouse et al., 1996). It was postulated that any classification system useful to the clinical or research community must consider the entire range (or spectrum) or abilities, even those with the most profound intellectual disabilities (Wing & Gould, 1979).

To further validate Wing and Gould's (1979) classification system, Castelloe and Dawson (1993) explored agreements between expert and novice clinical psychologists and between clinician observations and parent completed questionnaires. They reported that the Wing and Gould (1979) classification system had been adopted in clinical practice, guiding Individual Education Plans and treatments for children with ASD. Thus, its validation was important. Findings supported the external validity of the classification subtypes and agreement between clinician raters was acceptable with good agreement between parent and clinician raters.

Subsequently, the DSM-IV also used classifications by diagnosis (e.g., Asperger's Disorder, Pervasive Developmental Disorder- Not otherwise specified) to parse the heterogeneity of ASD (American Psychiatric Association, 2000). Currently, the DSM-5 classifies individuals with ASD (difficulties in social communication with restrictive and repetitive behaviours) as "Level 3 – Requiring very substantial support, Level 2- requiring substantial support, Level 1 – Requiring support," (American Psychiatric Association, 2014). These classifications do not account for the functional abilities an individual may have nor do they provide a full description

on the amount of support needed in day-to-day life. Additionally, there are a limited number of levels for distinguishing a very broad range of abilities that exist in ASD.

A classification system focused on an individual's functional abilities based on observations from families and clinicians in day-to-day life may be more meaningful in describing what child can do with a particular level of support. Focusing on functional abilities, such as 'doing with' someone, and partaking in a community activity, may be more representative and congruent with the lived experience. As well, such a classification system would represent a broad, snapshot of a child's ability and supports needed to succeed in social participation. This snapshot may be useful for new care or service providers in a community or recreational program.

Classification systems have been clinically useful for Cerebral Palsy (CP) by describing and classifying functional abilities based on every day observations (Rosenbaum, Eliasson, Hidecker, & Palisano, 2014). The primary purpose of classification systems such as the Gross Motor Functional Classification System (Palisano et al., 1997) or the Manual Ability Classification System (Eliasson et al., 2006) is to meaningfully discriminate levels of functional abilities of gross and fine motor (respectively) across a heterogeneous condition, CP (Rosenbaum et al., 2014). The need for these two classification systems stemmed from the lack of valid and reliable terms to describe children with CP (Rosenbaum et al., 2014), and the terms being used did not represent a person-centered approach. Value-laden and ill-defined terms such as mild, moderate, or severe were used to describe motor abilities, just as common descriptors today in ASD refer to an individual as low or high functioning (Rosenbaum et al., 2014). All current classification systems developed for children with CP have been framed within the ICF-CY, which promotes the interaction of *Body Structures,* and *Activities & Participation* within a

given *Environment* (Rosenbaum et al., 2014). Thus, the ICF-CY is useful for the classification system developed in this thesis and provides valid terms to describe children with ASD. Although previous classification systems parse abilities within a single dimension (i.e., gross motor for GMFCS), this may not be possible for a multidimensional construct, such as social participation. However, the GMFCS demonstrated a rigorous process of engaging with stakeholders (i.e., parents, clinicians) and experts (i.e., those with over seven years working with this population) for measure development. The GMFCS provides a clear example of the power of brevity and clarity in describing abilities matched with supports to create success as defined within population-based standards. When assessing the clinical utility of such classification systems, there is a need to consider the risks of labeling or stigmatizing children by focusing solely on their level of ability. Recognizing this, users are encouraged to refer to children by description rather than by level when using classification systems. This key principle applies to the classification systems described above, as well as the classification system developed within this research program.

1.5. Objectives and Rationale of Thesis.

There were three objectives of this thesis which were addressed sequentially: 1) review available participation measures for preschool children with ASD, 2) refine the construct of *social participation* for preschool children with ASD from the perspective of stakeholders, and 3) develop, refine and demonstrate content validity of the *Autism Social Participation Classification System* (ASPCS).

Rationale for objective 1 (Chapter 3): There is a gap in the literature with limited reviews of available participation measures for preschool children, and none for those with ASD. Although several reviews have spanned ages birth to 18 years old, there were few preschool measures

available and none focused on application of the measures to children with ASD. Thus, a scoping review, which is a broad search of the literature, was appropriate to determine what was currently available for use and what gaps existed to inform future programs of research on participation in preschool children with ASD.

Rationale for objective 2 (Chapter 4): Based on the scoping review completed in objective 1, no participation measures existed that were solely designed for children with ASD. Previous work highlighted potentially unique barriers and facilitators to participation, particularly with respect to social elements of participation. Thus, social participation was identified as a construct lacking measurement tools particularly relevant to preschool children with ASD who by definition have challenges in social functioning. By refining the construct of social participation specific to this particular population with a defined age group and utilizing stakeholder perspectives, the likelihood of end-user applicability and acceptability was increased. In order to create a feasible focus, the population was limited to preschool children with ASD. Preschool children with ASD, defined as between the third and fifth birthdays, have a range of developmental characteristics, activities and environments, and strong support/ integration within their family unit.

Rationale for objective 3 (Chapter 5): To date, no measure of social participation exists for preschool children with ASD, and given the core difficulties of ASD are social communication and repetitive and restricted behaviours that intersect to create functional challenges and restrict participation in every day life, such a measure was seen as important for describing abilities and placing supports in community programs. Given the lack of utilization of standard assessments in clinical and community programs, an alternative approach to measurement, such as classification systems, was sought. As well, content validity for a measurement tool remains central to ensure comprehensive depth and breadth on the construct of concern. As previously described, a

classification system was sought to describe the abilities of preschool children with ASD to 'do or partake with' in community activities matched with a particular level of support. This stratification of functional abilities and support in community and recreational programs can assist in providing care or service providers with some expectations for level of support to reasonably be provided for social participation to occur. Classification systems also consider a preschool child's average performance while often utilizing observations from an expert on the child (i.e., parent) that can be more representative than a child's performance at one particular moment in time (i.e., in a structured clinical assessment).

At all stages of the project, including funding acquisition, project development and implementation, families of preschool children with ASD and professionals who work with this population were consulted for feedback. This aligns with the Canadian Institute of Health Research (CIHR)'s 'Strategy for Patient-Oriented Research' (SPOR) (Canadian Institute for Health Research [CIHR], 2014) and lays a basis for clinical applicability to future research (Graham, 2012). The focus on the preschool age coincides with an age when integration into the community, such as preschool or recreation programs, begins and regular opportunities for social interactions and relationships with peers occur. By involving stakeholders throughout the project, especially in identifying priories, designing and undertaking the research project, there is a greater likelihood of translation and uptake of the findings into clinical practice (CIHR, 2014; Graham, 2012). In addition, patients may have an improved experience in the healthcare system and subsequently, improved outcomes (CIHR, 2014; Graham, 2012). Thus, a shared sense of purpose was sought throughout this project by including stakeholders as active and informed partners, to drive the clinical applicability of the end results.

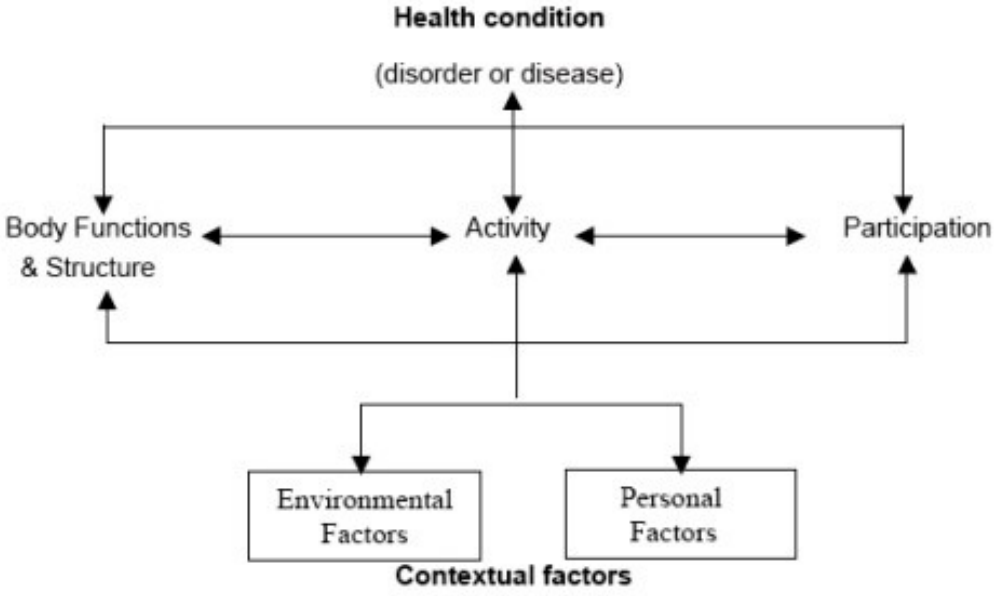
The thesis has six chapters, comprised of three studies: 1) A scoping review of participation measures for preschool children with Autism Spectrum Disorder (Chapter 3; Germani et al., under review), 2) A mixed methods analysis of stakeholders' perspectives on social participation for preschool children with Autism Spectrum Disorder (Chapter 4; Germani, Zwaigenbaum, Magill-Evans, Hodgetts, & Ball, in press), and 3) Development and content validity of the Autism Social Participation Classification System for preschool children with Autism Spectrum Disorder (Chapter 5; Germani et al., under review).

Previous participation reviews focused on school-aged children or those with neuromotor disabilities. It was not possible to complete a review on social participation measures for preschool children with ASD, as none existed. However, the scoping review focused on many of the social elements of participation, which may present unique challenges for those with ASD. The findings from the review supported an exclusive focus of the thesis project on examination and refinement of social participation. This is an emerging area of research with direct implications for preschool children with ASD due to the vulnerability that exists in their social development inherent to an ASD diagnosis. Engaging national stakeholders in the refinement process of social participation for preschool children with ASD was an important step to ensure that this construct would be meaningful to end-users. Utilizing the data collected from the national stakeholder survey on social participation, themes were drawn and presented to a group of experts for further refinement. Thus, through an iterative nominal group process, the construct was refined into distinct elements and essential domains emerged for item generation within the *Autism Social Participation Classification System* (ASPCS). To refine the measure and address the content validity of three domains and five levels that existed within each domain by establishing that they were clinically distinct and clear, the ASPCS then went through several

Delphi rounds. The final outcome of this phase and research project was a developed, refined and partially validated (i.e., content validity) ASPCS.

The progression of this thesis project has evolved based on findings from the scoping review of available participation measure for preschool children with ASD to develop a national stakeholder survey to refine the construct of social participation. This in turn informed the development and refinement of a new tool, the *Autism Social Participation Classification System*, to support the inclusion of preschool children by describing their abilities and supports required to promote their successful social participation.

Figure 1.1. International Classification of Function, Disability and Health – Child and Youth version[1]



[1] Reprinted with permission from International Classification of Functioning, Disability and Health: Child & Youth version: ICF-CY, World Health Organization, Model of Functioning and Disability, p.17, Copyright (2007).

Chapter 1 References.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders, fourth edition (4th ed., text rev.)*. Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2014). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5)*. Washington, DC: American Psychiatric Association.

Bedell, G. M., & Dumas, H. M. (2004). Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. *Brain Injury, 18*(1), 65-82.

Bolte, S., de Schipper, E., Robison, J. E., Wong, V. C., Selb, M., Singhal, N., . . . Zwaigenbaum, L. (2014). Classification of functioning and impairment: the development of ICF core sets for autism spectrum disorder. *Autism Research, 7*(1), 167-172. doi:10.1002/aur.1335

Bossaert, G., de Boer, A. A., Frostad, P., Pijl, S. J., & Petry, K. (2015). Social participation of students with special educational needs in different educational systems. *Irish Educational Studies, 34*(1), 1-12.

Canadian Insitute for Health Research. (2014). Strategy for Patient-Oriented Research Patient Engagement-Framework. *Canadian Institute for Health Research.* Accessed online June 22, 2016.

Castelloe, P., & Dawson, G. (1993). Subclassification of children with autism and pervasive developmental disorder: A questionnaire based on Wing's subgrouping scheme. *Journal of Autism and Developmental Disorders, 23*(2), 229-241.

Centre for Disease Control. (2014). Prevalence of Autism Spectrum Disorder among children aged 8 years. *Morbidity and Mortality Weekly Report, 63*(SS02), 1-21.

Cosbey, J., Johnston, S. S., & Dunn, M. L. (2010). Sensory processing disorders and social participation. *American Journal of Occupational Therapy, 64*(3), 462-473.

Dumont, C., Gervais, M., Fougeyrollas, P., & Bertrand, R. (2004). Toward an explanatory model of social participation for adults with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 19*(6), 431-444.

Eliasson, A.-C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A.-M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology, 48*(07), 549-554.

Elsabbagh, M., Yusuf, A., Prasanna, S., Shikako-Thomas, K., Ruff, C. A., & Fehlings, M. G. (2014). Community engagement and knowledge translation: progress and challenge in autism research. *Autism, 18*(7), 771-781. doi:10.1177/1362361314546561

Germani, T., Magill-Evans, J., Zwaigenbaum, L., Sacrey, L. . R., Askari, S., & Anaby, D. (under review). Participation measures for preschool children with Autism Spectrum Disorder: A scoping review. *Review Journal of Autism and Developmental Disabilities*.

Germani, T., Zwaigenbaum, L., Magill-Evans, J., Hodgetts, S., & Ball, G. D. (in press). Stakeholder perspectives' on social participation in preschool children with ASD. *Developmental Neurorehabilitation.*

Germani, T., Zwaigenbaum, L., Magill-Evans, J., Hodgetts, S., Hildebrandt, J., Stolte, M., Mitchell, S., Wennerstorm, K., & Hapchyn, C.A. (under review). Development and content validity of the Autism Social Participation Classification System for preschool children with Autism Spectrum Disorder. *BMC Pediatrics.*

Goldingay, S., Stagnitti, K., Sheppard, L., McGillivray, J., McLean, B., & Pepin, G. (2013). An intervention to improve social participation for adolescents with autism spectrum disorder: Pilot study. *Developmental Neurorehabilation*, *18*(2), 122-130.

Graham, I. D. (2012). Knowledge synthesis and the Canadian Institutes of Health Research. *Systematic Review, 1*(6).

Koster, M., Nakken, H., Pijl, S. J., & van Houten, E. (2009). Being part of the peer group: A literature study focusing on the social dimension of inclusion in education. *International Journal of Inclusive Education, 13*(2), 117-140.

Koster, M., Pijl, S. J., Nakken, H., & Van Houten, E. (2010). Social participation of students with special needs in regular primary education in the Netherlands. *International Journal of Disability, Development and Education, 57*(1), 59-75.

Koster, M., Timmerman, M. E., Nakken, H., Pijl, S. J., & van Houten, E. J. (2009). Evaluating social participation of pupils with special needs in regular primary schools. *European Journal of Psychological Assessment, 25*(4), 213-222.

Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy, 56*(6), 640-649.

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.

Morris, C., Shilling, V., McHugh, C., & Wyatt, K. (2011). Why is it crucial to involve families in all stages of childhood disability research. *Developmental Medicine & Child Neurology, 53,* 769-771.

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with Autism Spectrum Disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders*, 1-9.

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710-2719. doi:10.1007/s10803-013-1833-8

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*(4), 214-223.

Parten, M. B. (1932). Social participation among pre-school children. *Journal of Abnormal and Social Psychology, 27*(3), 243.

Piškur, B. (2013). Social participation: Redesign of education, research, and practice in occupational therapy. *Scandinavian Journal of Occupational Therapy, 20*(1), 2-8.

Piškur, B., Daniëls, R., Jongmans, M. J., Ketelaar, M., Smeets, R. J., Norton, M., & Beurskens, A. J. (2013). Participation and social participation: are they distinct concepts? *Clinical Rehabilitation*, 0269215513499029.

Rosenbaum, P., Eliasson, A.-C., Hidecker, M. J. C., & Palisano, R. J. (2014). Classification in childhood disability Focusing on function in the 21st century. *Journal of Child Neurology, 29(*8), 1036-1045.

Shattuck, P. T., Orsmond, G. I., Wagner, M., & Cooper, B. P. (2011). Participation in social activities among adolescents with an autism spectrum disorder. *PLoS One, 6*(11), e27176. doi:10.1371/journal.pone.0027176

Shikako-Thomas, K., & Law, M. (2015). Policies supporting participation in leisure activities for children and youth with disabilities in Canada: from policy to play. *Disability & Society*, *30*(3), 381-400.

Sylvestre, A., Nadeau, L., Charron, L., Larose, N., & Lepage, C. (2013). Social participation by children with developmental coordination disorder compared to their peers. *Disability & Rehabilitation, 35*(21), 1814-1820.

Szatmari, P., Charman, T., & Constantino, J. N. (2012). Into, and out, of the "Valley of Death": research in autism spectrum disorders. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(11), 1108-1112.

Szatmari, P., Georgiades, S., Duku, E., Bennett, T. A., Bryson, S., Fombonne, E., . . . Thompson, A. (2015). Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with autism spectrum disorder. *JAMA Psychiatry, 72*(3), 276-283.

Tanner, K., Hand, B. N., O'Toole, G., & Lane, A. E. (2015). Effectiveness of interventions to improve social participation, play, leisure, and restricted and repetitive behaviors in people with autism spectrum disorder: A systematic review. *American Journal of Occupational Therapy, 69*(5), pg 69051800101-690518001012. doi: 10.5014/ajot.2015.017806.

Tobin, M. C., Drager, K. D., & Richardson, L. F. (2014). A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders, 8*(3), 214-229.

Tsao, L.-L., Odom, S. L., Buysse, V., Skinner, M., West, T., & Vitztum-Komanecki, J. (2008). Social participation of children with disabilities in inclusive preschool programs: Program typology and ecological features. *Exceptionality, 16*(3), 125-140.

Waterhouse, L., Morris, R., Allen, D., Dunn, M., Fein, D., Feinstein, C., . . . Wing, L. (1996). Diagnosis and classification in autism. *Journal of Autism and Developmental Disorders, 26*(1), 59-86.

Whalley Hammell, K. (2004). Deviating from the norm: A sceptical interrogation of the classificatory practices of the ICF. *British Journal of Occupational Therapy, 67*(9), 408-411.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*(1), 11-29.

Wolfberg, P., DeWitt, M., Young, G. S., & Nguyen, T. (2014). Integrated play groups: Promoting symbolic play and social engagement with typical peers in children with ASD across settings. *Journal of Autism and Developmental Disorders, 45*(3), 830-845.

World Health Organization. (2007). *International Classification of Functioning, Disability and Health - Child and Youth Version*. Geneva, Switzerland: WHO Press.

Chapter 2: Overview of Methods

The methods of this thesis are: 1) a scoping review (Chapter 3); 2) a mixed methods study (Chapter 4); and 3) a multiple methods study (Chapter 5). This chapter presents details of the methodology of the three studies (Chapters 3 – 5) that could not be included within the word limitations of the respective journals. To fully understand the methods of each study, the journal article and the additional details presented below need to be considered together.

The Scoping Review

The scoping review presented in Chapter 3 was a broad search of the published and unpublished literature for participation measures available for use with preschool-aged children with Autism Spectrum Disorder (ASD). The reasons for choosing the scoping review methodology, the steps involved in a scoping review, and limitations of the methodology are included in Chapter 3. Scoping reviews are used to convey the breadth and depth of a particular area of inquiry that may not (yet) be amenable to a more rigorous or systematic review (Levac, Colquhoun, & O'Brien, 2010). They are often the most appropriate review methodology for an emerging area of research, for which little is known or previously reviewed on the topic. Scoping reviews are subject to bias, although two or three reviewers are often employed to help these mitigate biases. However, scoping reviews are still beneficial as they promote the rapid collection of data that can be synthesized into relevant and practical conclusions for stakeholders (Davis, Drey, & Gould, 2009).

Missing from Chapter 3 are details of the search and selection process. It was anticipated that the majority of the assessments would be found in published literature. However, in keeping with scoping practice methodology, a search of grey literature (publications of professional networks, conference abstracts) was included to identify measures in the early stages of

development or those that were less psychometrically rigorous but being used within clinical practice.

Original review terms included “autism”+ “participation” with “measures” or “assessments” or “tools;” however, this yielded zero search results. The term “autism” or “ASD” or “Asperger’s” or “autism spectrum disorder*” when combined with “participation” and “pre*school” search terms also yielded zero search results. This was likely due to a paucity of literature on ASD, participation and measurement. The final search terms used are included in Chapter 3.

Related to the selection process, several phone meetings were held between the reviewers, Tamara Germani (TG) and Sorayya Askari (SA), to discuss inclusion and exclusion criteria as well as develop a review data extraction form. Decisions made during phone meetings were documented by TG. These meetings were part of the iterative process of developing, reviewing and testing the data extraction form to ensure that it was sensitive, comprehensive and appropriate for the review question. Further details of the selection process are in Chapter 3. A data extraction form is in Appendix A.

The Mixed Methods Online Survey

The mixed methods study presented in Chapter 4 used a convergent, parallel design (Creswell and Piano Clark, 2011), including both qualitative and quantitative data. This design promotes the collection and analysis of two independent strands of data at the same time, and with equal consideration. The findings of the qualitative and quantitative data are used to obtain a better, more complete understanding of a phenomenon or construct. Both types of data are equally important to address the study purpose. In addition, qualitative and quantitative data can be compared to better explore convergence, divergence, conflict or the relationships that exist

between these two types of data in the analysis phase. It can be challenging to understand why conflict or divergence can occur between two types of data in the same pool of participants. Triangulation or participant checks on preliminary data analysis may provide insights regarding why these differences exist, or to help understand the relationships between these types of data.

This design was chosen because of the two purposes of the study. Qualitative data was needed to better understand and refine the construct of social participation from professionals' and parents' perspectives (Mayan, 2009). The qualitative data were elicited through a series of open-ended questions. Quantitative measurement was better suited for comparing perspectives between stakeholder groups and was obtained using rating scales for items. Both types of data were collected in parallel then analyzed separately. The results of each analysis were then integrated (Creswell and Piano Clark, 2011). This integration is well illustrated in Chapter 4, in which themes from the qualitative analysis are related to the highest rankings of items.

Purposeful sampling was appropriate for this type of design because it ensured a diversity of professional designations (e.g., psychology, education; n=49) and family member participants (n=25). Diversity of professional backgrounds, and a strong representation of family participants were important to ensure that the whole range of perspectives was included, and to help maximize the applicability of the construct under development (Mayan, 2009). To recruit for this study, a list of clinicians and researchers was generated for whom assessment of 'participation' was assumed to be integral to their professional work. This included organizations that address participation (e.g., CanChild), and several that connect Canadian pediatric and allied health professionals (e.g., Canadian Pediatric Society, Canadian Association of Occupational Therapists). Families were recruited through service providers (e.g., Geneva Centre for Autism) and not-for-profit ASD advocacy groups (e.g., Autism Society Alberta, Autism Ontario).

A web-based survey was used for rapid access to numerous respondents while providing anonymity and a reduced cost compared with paper-based mail surveys (Rhodes et al., 2003). Two surveys were developed and tailored to either a family member or professional. These surveys are in Appendix B. The survey was circulated through a secure system, Research Electronic Data Capture (REDCap; Harris et al., 2009), a platform hosted through the University of Alberta that complies with federal privacy and health information laws.

An unexpected challenge associated with the online methodology arose during response screening to ensure that all data included in the study was valid. A research assistant was employed as an unbiased third-party to screen all 220 responses for nonsense responses prior to being included in data analysis. In total, 146 nonsense responses were identified and excluded from data analysis. Reasons for identification as a nonsense response included, but was not limited to: (1) empty survey responses, (2) incomplete or early closure of survey, (3) multiple entries from the same respondent, (4) did not meet inclusion criteria, or (5) redundant responses, such as copying and pasting the question into the answer descriptive textboxes. When possible, participants who were identified as providing nonsense responses were contacted by the research assistant, told they were not eligible for participation in the study and were given the contact information of the Research Ethics Office at the University of Alberta if they had any concerns. A total of 42 participants were contacted by email, by retroactively linking responses to contact information across two independent surveys. Further discussion about the challenges and strategies used in the provision of financial incentives are included in Chapter 6.

The Multiple Methods Study

For the multiple methods study, presented in Chapter 5, there were two distinct phases: Phase 1 focused on the development of the Autism Social Participation Classification System

(ASPCS) utilizing expert focus groups, and Phase 2 focused on the refinement and initial validation of the ASPCS.

A multiple methods study combines the sequential collection and analysis of qualitative and quantitative data over several phases of a research program (Creswell and Piano Clark, 2011). This is a common methodology for development-focused research programs related to measurement or intervention. A mix of types of research methodologies can be utilized at the design level, and then data collection and analysis can be integrated to achieve an overarching aim. There is equal emphasis placed on each phase, although commonly, one will inform the development of another sequentially. The strength of the multiple methods study is that it leverages the strengths of different types of methodologies to answer a multifaceted research question. However, the management, collection and analysis of the various types of data at several different time points can be a bit overwhelming to manage pragmatically, integrate coherently or replicate. By utilizing trailing for decision-making as well as systematically documenting processes in each phase, confidence in the ability to replicate the study and transparency can be achieved. In addition, the use of platforms (i.e. REDCap) or data registry (i.e., Google Drive) can assist in the organization of data across phases.

The two related phases leveraged the methodological strengths of the other in developing and refining the ASPCS. Phase 1 primarily utilized a qualitative content analysis to guide the development of the ASPCS, although experts did occasionally participate in quantitative ranking or clarity assessments. Phase 2 primarily utilized a quantitative frequency analysis to demonstrate agreement on clarity and distinctiveness of the levels, although stakeholders could (and occasionally did) provide qualitative comments for suggested improvements. Although both studies could be characterized as ‘mixed methods’ (Phase 1: QUALITATIVE-quantitative; Phase

2: QUANTITATIVE-qualitative [Creswell and Piano Clark, 2011]), they may be more accurately characterized as 'multiple methods' as different recruitment methods, data collection processes and analysis were conducted to achieve the overarching aim of the research.

In Phase 1, investigator networks were utilized to identify experts appropriate for inclusion similar to previous classification system recruitment methods (Palisano et al., 1997; Wood & Rosenbaum, 2000). The expert group was comprised of individuals from at least four different professional backgrounds (n=7), in addition to a parent expert with multiple children with ASD. All professional experts had over seven years of clinical experience with preschool children with ASD and the parent expert had at least one preschool child at the time of the study.

A modified nominal group technique was used to develop distinguishable levels within the ASPCS, similar to the development process followed by other classification systems (DiRezze et al., in press; Rosenbaum et al., 2008). By structuring groups using a modified nominal group technique, each expert had the opportunity to have their perspective considered equally in shared decision-making in reoccurring focus groups. For example, by asking "*What strengths separate children from Level 1 to Level 3 when participating in activities*," participants first responded in a brief serial fashion (i.e., no longer than one sentence). Next, meanings of each response were clarified in a serial fashion, until all experts were in agreement with the distilled descriptions of levels provided. This process is considered modified, as there was flexibility provided to experts who could not attend all focus group meetings due to conflicting clinical or urgent personal commitments. Thus, the implementation of follow-up interviews modified the nominal group technique but provided an opportunity for experts to share their perspectives and stay up-to-date on the ASPCS development process despite their demanding schedules.

The doctoral student facilitated the expert groups with the assistance of a research assistant. All meetings were audio recorded. Data were collected over four expert group meetings, allowing for a four-month break for the Delphi survey to be circulated. Following the Delphi results from round one, the expert group met an additional time to review broad stakeholder feedback and validate changes suggested (thus, there were five meetings in total). Expert group meetings were transcribed by a reputable transcription company and coded, with documentation of each change made based upon the group's consensus description, similar to the process of the Autism Classification System of Functioning: Social Communication (ACSF:SC; DiRezze et al., in press). A research assistant checked transcriptions against audio-recordings for errors or missed comments due to participants talking over each other to ensure transcription completeness. Facilitator guides for each focus group are in Appendix C.

In Phase 2, maximum variation sampling was used to ensure that information and perspectives gathered identified common patterns that cut across variation (Patton, 1990). This approach ensured the representativeness of stakeholders in providing a broad and general consensus that is independent of the stakeholders' background or personal experiences. Tracking participant designation throughout recruitment and data collection helped to ensure a variety of backgrounds (e.g., occupational therapist, speech-language pathologist, parent) and balanced representation of perspectives. Recruiting a variety of professional backgrounds, particularly in allied health professionals, was relatively quick and easily accessed. In contrast, representation of parents was considerably more difficult, and a variety of direct, and ongoing recruitment strategies were used to increase representation of parent participants.

The Delphi Model is a consensus technique used with stakeholders with expertise in a particular area over three rounds of questioning (Hsu and Sandford, 2007). This provided

anonymity for respondents, controlled the feedback process, and allowed for data collection through qualitative and quantitative methods. The Delphi survey was circulated over three rounds through the Research Electronic Data Capture (REDCap) platform (Harris et al., 2009).

In the first Delphi round, there was low family participation (n=5) compared to professionals (n=33). In subsequent rounds, efforts were made to ensure that more family participants were recruited. For each subsequent round, the Dillman method was used to recruit responses by sending reminders with a date of the upcoming draw to encourage participation (Wortman et al., 1998). The surveys circulated via REDCap for rounds 1, 2, and 3 are available in Appendix D.

Details of methodology have been included in this chapter in order for the reader to better understand the rationale for their selection and appreciate their limitations. The inclusion of this chapter provides a more detailed description than is possible in a journal articles, and lays the basis for replication or research that builds on the work described in this thesis. I now present the journal articles that include key details of the methodology and fit within word limits of the specific journal.

Chapter 2 References.

Chien, C.W., Rodger, S., Copley, J., & Skorka, K. (2014). Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health–Children and Youth. *Archives of Physical Medicine and Rehabilitation, 95*(1), 141-152.

Creswell, J.M. and Piano Clark,V.L. (2011). *Designing and Conducting Mixed Methods Research,* Thousand Oaks, CA: SAGE.

Davis, K., Drey, N. & Gould, D. (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies, 46*(10), 1386-1400.

DiRezze, B., Rosenbaum, P., Zwaigenbaum, L., Cooley-Hidecker, M.J., Stratford, P., Cousins, M., Camden, C., Law, M. (in press). Developing a classification system of social communication functioning of preschool children with autism spectrum disorder. *Developmental Medicine and Child Neurology.*

Emde, M. and Fuchs, M. (2013). Using interactive feedback to enhance responses quality in Web surveys: The case of open-ended questions. *General Online Research Conference.*

Harris, P.A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J.G. (2009). Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377-381.

Hsu, C.C., and Sandford, B.A. (2007). The Delphi technique: making sense of consensus. *Practical assessment, Research & Evaluation, 12*, 1-8.

Krosnick, J.A. and Fabrigar, L.R. (1997). Chapter 6: Designing rating scales for effective measurement in surveys. In L. E. Lyberg, P. Biemer, M. Collins, et al. (Eds.) *Survey Measurement and Process Quality.* New York, NY: John Wiley & Sons.

Levac, D., Colquhoun, H., & O'Brien, K. (2010). Scoping studies: Advancing the methodology. *Implementation Science, 5*(1), 1-9.

Mayan, M. (2009). *Essentials of Qualitative Inquiry*, Walnut Creek, CA: Left Coast Press.

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*(4), 214-223.

Patton, M.Q. (1990) *Qualitative Evaluation and Research Methods,* Thousand Oaks, CA: Sage Publications.

Rhodes, S., Bowie, D., & Hergenrather, K. (2003). Collecting behavioural data using the world wide web: considerations for researchers. *Journal of Epidemiology and Community Health, 57,* 68-73.

Rosenbaum, P., Palisano, R., Bartlett, D., Galuppi, B., & Russell, D. (2008). Development of the Gross Motor Function Classification System for cerebral palsy. *Developmental Medicine and Child Neurology, 50*(4), 249-253.

Wood, E., & Rosenbaum, P. (2000). The Gross Motor Function Classification System for cerebral palsy: a study of reliability and stability over time. *Developmental Medicine and Child Neurology, 42,* 292-296.

Wortman, P.M., Smyth, J.M., Langenbrunner, J.C.,& Yeaton, W.H. (1998). Consensus among experts and research synthesis: a comparison of methods. *International Journal of Technology Assessment in Health Care, 14*(1), 109-122.

Chapter 3: Scoping Review of Participation Measures for Preschool Children with Autism Spectrum Disorder

This chapter is currently under review at the journal: *Review Journal of Autism and Developmental Disabilities*

Germani, T., Magill-Evans, J., Zwaigenbaum, L., Sacrey, L.A.R., Askari, S., & Anaby, D. 'Participation Measures for Preschool Children with Autism Spectrum Disorder: A Scoping Review.'

Abstract.

The purpose of the scoping review was to identify participation measures for preschool children with Autism Spectrum Disorder (ASD). A comprehensive search strategy was employed across several electronic databases with hand searching of reference lists. Seven measures of participation were identified. Five measures had standardization samples that included preschool children with ASD and three provided both validity and reliability data. Each assessment reported psychometric properties and covered a range of developmentally appropriate activities and environments. Parents and professionals can use the identified participation measures to describe participation challenges that exist. However, professionals may need to elicit additional information regarding the impact of repetitive and restrictive interests, interpersonal abilities, and novel environments on participation to capture the core challenges of ASD.

Keywords: participation, autism spectrum disorder, measurement, scoping review

Children with disabilities may have restrictions that interfere with the frequency of participation, as well as the diversity of their activities. Participation is 'involvement in a life situation' (World Health Organization [WHO], 2007), and can have a positive impact on health and well-being (Law, 2002). Participation in meaningful activities is an essential outcome in clinical practice (Hemmingsson & Jonsson, 2005) and there is a subsequent need for valid and reliable participation measures (Resnik & Plow, 2009) that target children with disabilities. A child's participation in various activities supports the development of their physical, cognitive, and communication skills and creates opportunities to make friendships (Hoogsteen & Woodgate, 2010; Law et al., 2004; Sylvestre, Nadeau, Charron, Larose, & Lepage, 2013). The construct of participation encompasses the larger context of a child's life by using the collective integration of their functional abilities, developed or regained through rehabilitation that fosters community belonging (Coster & Khetani, 2008).

One inherent challenge in measuring participation for children is the ambiguity and complexity of the definition, 'involvement in a life situation' (Coster & Khetani, 2008). Coster and Khetani (2008) champion the inclusion of spatial and temporal dimensions in considering *where* and *when* children are doing the activities that matter to them when assessing participation. The WHO's definition of participation is not developmentally sensitive as young children are deeply embedded in their family's context (Coster & Khetani, 2008). It is impossible to separate the child's participation from their family's participation in activities (Coster & Khetani, 2008). For the purposes of this review, participation was conceptualized as involvement in life situations that consider where and when these meaningful activities take place. This allows for the review to align within the WHO's framework *The International Classification of Functioning, Disability and Health – Children and Youth version* (ICF-CY; WHO, 2007*)*, while

balancing the need for developmentally sensitive activities and supportive environments. The ICF-CY considers the dynamic interaction between the individual's body structure and functions, a health condition (i.e., a disorder), their activities, participation, and contextual factors (i.e., environmental and personal factors) in life situations.

Autism Spectrum Disorder (ASD) involves challenges in social communication and interactions, as well as repetitive behaviours and restricted interests (American Psychiatric Association, 2014). The lifelong difficulties in social communication and interactions include difficulties in social reciprocity, understanding nonverbal communication, as well as developing and maintaining relationships. Repetitive and restricted behaviours, including insistence on sameness, sensory sensitivities, and aversion to change, can impact life participation at home, in educational programs, or the community. A recent scoping review by Askari et al. (2014) highlights participation patterns of children with ASD across the entire spectrum, and the factors that affect these patterns. Of particular importance were factors associated with the core symptoms of ASD (e.g., difficulties with social communication and interpersonal relationships), even for purely physical or recreational activities (Askari et al., 2014). Thus, participation in a variety of meaningful activities at home and in the community is a worthwhile goal for individuals with ASD, including preschool children.

Even though children as young as 24 months old can be reliably diagnosed with ASD (Johnson & Myers, 2007), the average age for diagnoses is between 3 to 4 years in North America (Burstyn, Sithole, & Zwaigenbaum, 2010; Daniels & Mandell, 2013). The prevalence of ASD in four-year old children is 13.4 per 1000 (Christensen et al., 2016). These preschool children are more likely to have an intellectual disability and are more likely to be identified at an earlier age due to significant social and behavioural challenges (Christensen et al., 2016).

Thus, early interventions for preschool children with ASD that target specific tangible improvements (e.g., skill development such as word acquisition, sharing of toys) must be placed within the larger context of participation in life events, which evolve as the child with ASD develops. Measures that support the evaluation of how children with ASD participate in the day-to-day activities of family and community activities within life situations have not yet been identified and reviewed in a systematic way.

Rationale & Aim of Review

The primary goal of current treatments for ASD, particularly early intervention, is to improve participation at home, in the community, or at early education programs. Thus, the selection of participation measures to support the selection of meaningful goals and outcomes for a pre- and post- delivered treatment plan for preschool children with ASD in a variety of activities in real-life settings is important.

Presently, little is known about the measurement of participation of preschool children with ASD who are at a critical time in development for involvement with peers and the community. Previous reviews of participation measurements have focused on Cerebral Palsy (Morris, Kurinczuk, & Fitzpatrick, 2005; Sakzewski et al., 2007), Acquired Brain Injury (Ziviani, Desha, Feeney, & Boyd, 2010), hand-use (Chien, Rodger, Copley, & McLaren, 2013) or disabilities generally (Adolfsson, Malmqvist, Pless, & Granuld, 2011; Chien et al., 2014; Phillips, Olds, Boshoff, & Lane, 2013). None have focused on ASD or preschool children with disabilities but the reviews are useful for identifying the breadth of measures available. The aim of the scoping review was to determine what participation measures are available for use with preschool children with ASD.

Method

Scoping reviews are 'a rapid review' for the purposes of identifying research gaps and providing findings for policy or service provision (Anderson, Allen, Peckham, & Goodwin, 2008; Arksey & O'Malley, 2005). Selection of a scoping review methodology for this study was appropriate to gain insights into a relatively under-studied area (i.e., participation in preschool children with ASD) to inform clinical decision-making. This review followed the methodology proposed by Arksey and O'Malley (2005), with subsequent steps based on recommendations by Levac, Colquhoun, and O'Brien (2010).

Step 1: Identifying the Research Question

We developed the research question: *What participation measures are available for use with preschool children diagnosed with ASD?* Our group wanted to generate a breadth of coverage as recommended by Arksey and O'Malley (2005).

Step 2: Identifying Relevant Studies

Studies were from 1990 to April 30, 2014 as the previously listed participation disability reviews found no literature prior to 1990. Based on Arksey and O'Malley (2005), the following were searched: 1. electronic databases (including CINAHL, Embase, Health and Psychological Instruments [HAPI], and Medline) using search terms "participation" AND "measure OR assessment OR outcome measure" AND "child* OR p*ediatric*" AND "disabilit*"; the selection of these search terms and databases were done with the consultation of a health sciences librarian; 2. reference lists of previous reviews (Adolfsson et al., 2011; Chien et al., 2013; Chien et al., 2014; Morris et al., 2005; Phillips et al., 2013; Sakzewski et al., 2007; Ziviani et al., 2010); 3. key electronic journals (e.g., *Disability & Rehabilitation, Autism);* 4. publications of professional networks (e.g., *American Occupational Therapy Association, International Society of Autism Research)* and relevant organizations (e.g., *CanChild*), and 5. conference

abstracts (e.g., *International Meeting for Autism Research)*. Using the same terms and databases, a search covering May 1, 2014 to April 20, 2016 was run to identify any additional articles addressing participation measures in preschool children with ASD. Four reviews, one new assessment, and five articles further validating previously identified measures were located.

Levac et al. (2010) recommended that the purpose should guide decision-making, including selection of a suitable team and, when possible, to limit scope and justify the reasons. Our team had expertise in ASD, childhood disability, measurement, and participation. The difficulties in conceptualizing and measuring participation have been well documented (Law, 2002); therefore, measures had to report a definition of participation that was consistent with the WHO and developmentally sensitive to preschool children, as recorded by the two reviewers.

Step 3: Study Selection

Inclusion and exclusion criteria were applied to all measures. To be included in the review, the measures had to meet the following criteria: 1) available in English, 2) used with preschool children (5 years old or younger), 3) have a specific focus on children with ASD or a broad focus on children with disabilities including those with ASD or functional/behavioural descriptions consistent with ASD (e.g., sensory sensitivities, social communication challenges, difficulties managing behaviours) and 4) reported at least one psychometric property (e.g., reliability, validity). Articles were excluded if they: 1) focused only on children over five years old (n=39), or 2) focused exclusively on children with physical disabilities (n=4). Abstracts, summaries, and titles were reviewed to determine if the publication might fit the criteria, and merit a review of the whole document. Fifty-seven articles were read in full, covering 35 measures and seven related reviews as part of the scoping review (see Figure 3.1). Any challenges that arose were discussed and resolved by email. After review of the 35 measures, SA

and TG had 94% agreement on the inclusion of six measures. A third blind reviewer, LARS, resolved disagreements over the remaining two measures, resulting in their exclusion. The 2016 search added one additional measure. Previous reviews (including those that exclusively focused on specific neurological or development disabilities) had potential overlap in content areas and were retained for relevance and understanding of the participation measurement field.

Step 4: Charting the Data

Two reviewers, SA and TG, jointly developed the data extraction form for collecting relevant aspects of each measure across the following areas: behaviour difficulties, sensory challenges, social participation, peer relationships, familiarity of individuals or the setting, use of an aide in the activity, and the structure (i.e., routine) provided in the environment and for transitions. Each measure was reviewed using the structured form (described above) to record the measure's activity type, contextual factors and respondent type. The development of a structured form by reviewers was an iterative process that allowed for flexibility and comprehensiveness in data extraction (Colquhoun et al., 2014). In the form development, the reviewers considered the core diagnostic features of ASD (e.g., restrictive and repetitive behaviours) and the ICF-CY framework (e.g., peer relationships, environmental supports). In addition, the primary author (TG) extracted relevant information regarding reliability and validity, as reported, for each measure.

Step 5: Collection, Summarizing and Reporting the Results

Measures meeting inclusion criteria are summarized in Table 3.1. Information is provided on psychometric properties, utility with the ASD population, and constructs measured considered important for preschool children with ASD.

Results

The scoping review identified seven measures with potential use for preschool children with ASD although the recommended age range varied across measures and often involved children with motor delays or those with an "injury of insult" post-birth. The seven measures were: 1) *Assessment of Preschool Children's Participation* (APCP; Law, King, Petrenchik, Kertoy, & Anaby, 2012), 2) *Child and Adolescent Scale of Participation* (CASP; Bedell, 2004, 2009), 3) *Children's Assessment of Participation with Hands* (CAPH; Chien, Rodger, & Copley, 2015), 4) *Children's Participation Questionnaire* (CPQ; Rosenberg, Jarus, & Bart, 2010), 5) *Matrix for Assessment of Activities and Participation* (MAAP; Castro & Pinto, 2013), 6) *PreSchool Activities Card Sort* (PACS; Berg & LaVesser, 2006; LaVesser & Berg, 2011) and 7) *Young Children's Participation and Environment Measure* (YC-PEM; Khetani, Graham, Davies, Law, & Simeonsson, 2015). Five measures had a sample of children with ASD in their standardization sample (*CPQ, CAPH, MAAP, PACS,* and *YC-PEM)*.

Preschool Children with ASD. Of the five measures that included children with ASD as part of their standardization sample, the *CAPH* had the largest number (n=42, 21%), followed by the *MAAP* (n=22, 33%). The *CAPH* focused on participation in life situations requiring hand-use, which may impact social participation. The *MAAP* provided a distinct profile of participation associated with ASD, and participation was strongly linked to functional abilities. Participation patterns differed significantly from age-matched children with other disabilities or typical development. Two measures (*CPQ*, *YC-PEM*) did not explicitly state the diagnostic groups targeted and included a wide range of functional issues (e.g., learning difficulties, difficulty controlling behaviours) that may fall within the category of ASD. This functional, non-diagnostic specific approach may have implications for capturing participation within a wide range of abilities similar to and including preschool children with ASD. This may include preschool

children with an elevated family-risk of ASD, or some emerging challenges in social skills who are subsequently referred for early intervention without a diagnosis. Based on PACS scores, 103 preschool children with ASD had lower participation compared to 41 typically developing preschool children, including social interactions. Other measures were developed for one particular neurodevelopmental diagnosis such as Acquired Brain Injury (*CASP*), although a portion of the sample had ASD or only had published data for children with a physical disability (including co-morbid conditions, such as a learning disability) which may have implications for preschool children with ASD (*APCP, Dutch Version; Bult et al 2013).*

Activities. As an essential component of the ICF-CY, activity was seen as an important sub-category to explore for preschool children with ASD. All activities in the seven measures were developmentally appropriate for preschool (and in some cases, school-aged) children. All measures covered activities common in everyday life, such as play, active or physical recreation, and social activities with family members or community peers. Given that preschool children require some assistance and supervision, all measures expected some dependence when completing activities. The *CAPH* and *CPQ* explored independence level. The *CAPH, APCP, CPQ* and *YC-PEM* assessed activity diversity and intensity/ frequency based on the relative amount of time spent on an activity and the *CPQ* measured performance skills. Desire for change in activity participation was assessed in *CAPH* and *YC-PEM*.

Context. All measures addressed more than one environment, typically focusing on home and community settings, which is appropriate for preschool children. Only the *YC-PEM* specifically elicited facilitators and barriers across specific settings including home, daycare/ preschool as well as considering specific aspects of each environment such as the physical layout

or sensory qualities. Other measures inquired about the activities a child does and does not participate in and why, which may be related to environmental demands.

Respondent. All measures utilized parent report via interview or questionnaire except the *MAAP*, which utilized professionals' responses, based on child observation in a daycare/preschool setting. The *MAAP* does not elicit family's values or perspectives on participation, which are most important for the child's involvement.

Psychometrics. As summarized in Table 3.1, all measures reported some psychometric properties (either validity *or* reliability). Only the *CAPH, CPQ* and *YC-PEM* reported both. Validity and reliability remain important components in the selection of rigorous measures of participation for all children.

Discussion

This scoping review identified five participation measures that have been used with preschool children with ASD, three of the five with reported validity and reliability, and two others that have potential but have been used with other preschool disability populations. While this is very encouraging for practice, it must be noted that none of the measures explicitly evaluated the impact of restricted and repetitive behaviours, a core symptom of ASD, on participation. For example, a child's fixation on 'spinning wheels' is a repetitive and restricted behaviour that impairs the ability to 'play together' with peers which creates restrictions in non-solitary play activities. This may be best captured however by parent-report under categories such as 'diversity of activities' or as a 'desire for change.' For example, in the *YC-PEM,* families are able to express their desire for the child to participate in more cooperative games or activities in an interactive manner.

The only measure that was developed *exclusively* for preschool children with ASD was the *MAAP.* However, its authors argue that a *functional* approach versus a *diagnostic* approach better serves the developmental needs of preschool children with disabilities in profiling participation abilities. Thus, the *MAAP* has utility also for preschool children without ASD such as preschool children demonstrating developmental delays. The other measure that focused on the need for a functional, not diagnostic specific, profile of preschool children was the *YC-PEM*. The authors reported behavioural difficulties rather than diagnoses. This may reflect the shared challenges of many disabilities (e.g., social difficulties, sensory sensitivities) with ASD.

Our search strategy was validated by overlapping results with prior reviews of participation measures. The prior reviews were primarily for school-aged children or adolescents with disabilities. However, two included children from birth to 18-year-olds (Adolfsson et al., 2011; Phillips et al., 2013), and two focused on 2- to 12-year-olds (Chien et al., 2013; Chien et al., 2014) although results from all four reviews mainly pertained to children over 5 years old. Three of our measures had been previously identified but four were new, likely due to their recent publication dates. These previous reviews helped place our review related to ASD within the broader childhood disability literature. In addition, the reviews also supported the consideration of what participation barriers and facilitators may be elicited that are *unique* to ASD (e.g., restrictive and repetitive behaviours), but also potentially similar to other preschool children with disabilities (e.g., availability of an aide).

When considering activities for measuring participation, preschool children with ASD may have a unique participation profile particularly related to social activities that involve peers. As a preschool child develops, the demands of following social norms and rules increase across self-care, school/work-related, and leisure domains. While playground activities such as running

and climbing for preschool children may be considered physical in nature, there are also many social demands in these activities that can be challenging for preschool children diagnosed with ASD (Little, Sideris, Ausderau, & Baranek, 2014). Early interventionists can utilize the measures identified in our review to gain a holistic participation profile of a child to guide early intervention aimed at improving participation in activities with peers. Understanding a child's abilities at an activity level, and the required integration of different skills (e.g., requesting, turn-taking, and imitation) can highlight goals to work on in a naturalistic setting. It is also relevant to understand the social demand of the activity as well as child's environment such as available support personnel, amount of noise/light, social expectations and peer attitudes that may restrict or facilitate participation – all measured by the *YC-PEM*.

All seven measures considered contexts for participation and one elicited environmental barriers and facilitators (*YC-PEM*). Context was an important consideration when appraising the measures, as there is often a focus on providing targeted interventions within one environment with the goal of generalizing skills across environments. Clinicians on a child's early intervention team can specify, with input from families, the environment they are changing to support increased participation. Others, such as teachers or educational assistants, support inclusive participation tailored to the child. Children with disabilities are vulnerable to participation restrictions due to physical or social elements of the environment (Harding et al., 2009). Significant institutional and social barriers such as attitudes and lack of knowledge exist as reported by parents with children from 3 to 12 years old with physical disabilities (Law et al., 1999). Measuring participation restrictions for preschool children with ASD is important in order to understand the intersecting facets such as social or attitudinal contexts that may limit participation beyond physical barriers. For example, at the beginning of a program or activity the

child may have disruptive or negative behaviours due to difficulties with transitions or a new environment. While the behaviour may resolve with support or familiarity, the initial responses and attitudes of the peers towards the child may be hard to change, resulting in restricted participation in activities with peers.

Familiarity as a contextual factor of participation was not addressed by any of the seven measures. A preschool child with ASD may have all the functional abilities for an activity and can do the activity with a familiar peer or sibling but be unable to do so with a new peer or in a novel environment. Another aspect of context is the competency (or skill-set) and familiarity of the child's aide. None of the measures included formal questions addressing this aspect. A familiar aide may be needed to successfully support participation in familiar activities and then support the child in transferring these skills into a new environment. This may be an important component for future measures specific to participation in preschool children with ASD.

Psychometric properties such as reliability and validity are important considerations when selecting a measure of participation. For example, if measuring changes over time, the assessment needs to have good test-retest reliability to ensure that changes identified are due to interventions and not to poor test-retest reliability. Similarly, a measure should be internally consistent with all items on an assessment measuring the same general construct of participation. Three of the seven measures did not report reliability information and one did not report validity information. No measures reported psychometrics specifically for preschool children with ASD. The *MAAP* provided evidence that unique participation profiles exist for preschool children with ASD (Castro & Pinto, 2013) but psychometrics exclusively for ASD were not reported. The *CAPH, CPQ* and *YC-PEM* reported aspects of validity and reliability and are the closest to being ready for clinicians to use when measuring participation in a variety of settings. Future research

should address the missing psychometric information that is needed in order to ensure the measures are suitable for their stated purpose and to increase confidence in their use.

Participation measures are likely the most appropriate clinical tools to evaluate the combination of interventions across complex, naturalistic settings that are provided to preschool children with ASD. Often early intervention teams use multiple modalities to globally focus on the acquisition of social, physical, emotional, and social skills that are client- and family-centered and focus on participation in activities at home, preschool or community settings. Modalities may include sensory-regulation strategies, behavioural modification, assistive communication technologies, and caregiver mediated training models all with the end goal of enhancing participation and engagement in a variety of activities in real-life settings. For example, understanding how participation goals are achieved is important to support socially valid outcomes for preschool children with ASD, such as being in a community soccer league or attending a birthday party. In the community soccer league scenario, the YC-PEM may elicit several environmental barriers that exist, in addition to several activity-level difficulties in participation with peers. In comparison to the birthday party scenario, a clinician may elicit from a parent specific difficulties with a component of an activity related to hand-use by using the CAPH (e.g., has difficulties with the toys such as blocks) that may create issues with social participation and involvement. Both of these examples demonstrate the use of participation measures in life situations that may be addressed or modified to achieve a child's and family's desired participation in a community event.

Limitations

This scoping review focused on preschool children with ASD and aimed to provide a comprehensive, systematic search of participation measures for these children. Given a scoping

review's methodology, the review is limited in rigour, has the potential for bias, and has no formal quality assessment of the studies (Grant & Booth, 2009). However, scoping reviews provide a preliminary appraisal of the literature and measures, as is appropriate with emerging areas of research, such as participation measurement in preschool children with ASD. Future research could explore the impact of repetitive and restricted behaviours on a child's participation and review measures intended for older children with ASD across environments.

Conclusions

Although participation in a variety of activities is a worthwhile goal for preschool children with ASD, the measurement tools available to determine progress towards this goal remain limited. The findings of this review add to the research currently available on participation measures available to measure socially validated outcomes for preschool children with ASD, as well as explore barriers and facilitators that exist in a child's ability to participate in the community. More in-depth research related to the use, cross-cultural validation and evaluation of participation as a broad primary outcome measure is needed. By identifying and reviewing appropriate participation measures for preschool children with ASD, clinicians can be informed about the validated and reliable measures available in practice to set and monitor client and family centered participation goals.

Figure 3.1. Selection of Articles Describing Measures for Inclusion in Review

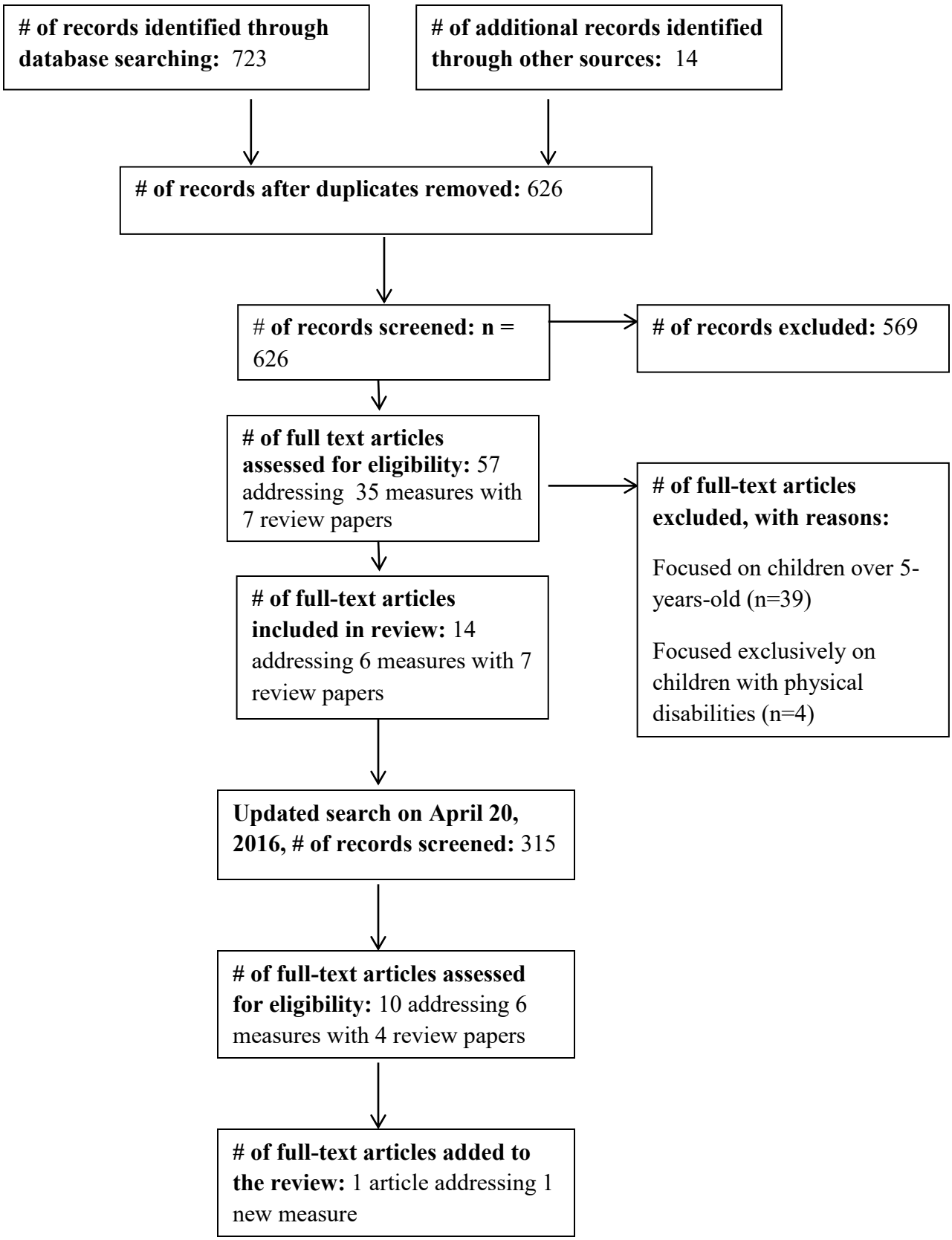


Table 3.1. Summary of Participation Measures for Preschool Children with ASD

	Purpose	Psychometrics	Utility with ASD population	Constructs Measured Considered Important for Preschool Children with ASD
Assessment of Preschool Children's Participation (APCP) (Law et al., 2012)	Ages: 2 to 5-11. Evaluates diversity and intensity of participation in day-to-day activities (play, active/physical recreation, social) Parent report questionnaire.	**Internal Consistency-** diversity, α=0.73 to 0.85; intensity, α=0.52 to 0.70 **Construct Validity-** hypothesis testing against literature. Effect sizes- medium to large **Reliability** not reported (NR)	N = 120 (71 males) All had CP. Several also had: DD- 50.8%, Vision Impairment- 35%, Seizure Disorder- 25%, Learning Disorder- 12.5%	✓ Participation ✓ Peer Relationships ✓ Support from Environment
Child and Adolescent Scale of Participation (CASP) (Bedell, 2004, 2009)	Ages: 3 to 22 (10% < 6) Measures participation in home, school, & community compared to TD children. Parent report questionnaire.	**Construct validity** - Rasch Analysis, a unidimensional construct **Internal consistency-** high (α=0.96) **Reliability-** NR	N = 313 (173 males) TD- 17% Acquired Brain Injury- 56% DD (including ASD)- 19% Learning/Attention/Sensory impairment- 8%	✓ Participation ✓ Peer Relationships ✓ Structure of Environment
Children's Assessment of Participation with Hands (CAPH) (Chien et al., 2015)	Ages: 2 to 12 Measures hand-use participation in self-care, recreational, educational, and domestic & community life domains. Parent reported questionnaire.	**Internal consistency –** .72 to .78 for most scales/domains, except for participation diversity (.34-.64) in all domains, frequency (.31) in self-care domain, & desire for change (.55) in domestic and community life domain. **Reliability:** Test-retest: ICC: -0.69 - .0096.	N= 202 (123 males) TD – 52% Disabilities- 48%; included ASD (n= 42), intellectual/ developmental delays, language/ speech delay, learning disability, Down Syndrome, physical disability, hearing/ visual impairment	✓ Participation ✓ Peer Relationships
Children's Participation Questionnaire (CPQ) (Rosenberg et al., 2010)	Ages: 4 to 6 Measures participation in everyday activities. Activity rated on intensity, independence level, enjoyment,	**Construct validity-** moderate to high correlations **Convergent and divergent validity-** correlations with Vineland Adaptive Behaviour Scales and CPQ	N = 480 (390 males) TD- 52% Disabilities- 48%; included DD, motor delays, visual motor difficulties, sensory sensitivities, attention deficits,	✓ Participation ✓ Peer Relationships ✓ Availability of Aide

	parent's satisfaction. Parent report via questionnaire.	**Reliability:** Cronbach's alpha= .79 to .90. Test-retest: ICC= .84- .90	and learning deficits	
Matrix for Assessment of Activities & Participation (MAAP) (Castro & Pinto, 2013)	Ages: 3 to 6 Examines functional abilities of children with ASD, DD, or TD in different routines. Teacher or regulated health care professional observations.	**Validity** - NR **Internal reliability** - Cronbach's alpha = 0.98	N = 66 (sex not reported) TD- 33% ASD- 33% Other disabilities- 33% Compared to TD children, significant differences in pattern of abilities in most ICF-CY domains	✓ Participation ✓ Peer Relationships
Pre-School Activities Card Sort (PACS) (Berg & LaVesser, 2006; LaVesser & Berg, 2011)	Ages: 3 to 6 Participation in everyday activities. Parent interviewed by using activity photographs - asked if child participates; if not, why.	**Content validity** established **Reliability** NR	N= 68 (32 males), TD Follow-up study: ASD (n=103) vs. TD (n=41). ASD children- fewer activities in self-care, community mobility, vigorous and sedentary leisure, social interactions, chores, education.	✓ Participation ✓ Peer Relationships
Young Children's Participation & Environment Measure (YC-PEM) (Khetani et al., 2015)	Ages: birth to 5 3 participation scales, 1 environment scale. Range of activities & environmental features that support or hinder participation. Parent report via interview or electronic survey	**Internal Consistency-** participation (.68 to .96) environment (.92 to .96) **Construct Validity** - differences by age/disability. Association between participation and function **Test-Retest-** participation, .31 - .93; environment, .91 to .94	N = 395 (222 males) TD- 76% 24% had disability based on deficits in Communication (71.2 – 74.2 %), Controlling Behaviours (57.1 – 62.1%); Managing Emotions (57.1 – 59.1%), Reacting to Sensations (55.2 – 61.2%)	✓ Behaviours (such as insistence on sameness) ✓ Participation ✓ Peer Relationships ✓ Support from Environment ✓ Availability of Aide

ASD: Autism Spectrum Disorder; CP: Cerebral Palsy; DD: Developmental Disabilities; ICC: Intraclass Correlation Coefficient; ID: Intellectual Disability; MD: Muscular Dystrophy; PDD: Pervasive Developmental Delay; LD: Learning Disability; TD: typically developing; ICF-CY: International Classification of Functioning, Health and Disability – Child and Youth version (World Health Organization, 2007); NR: not reported; *parents reported multiple disabilities

Acknowledgments.

TG was supported by the Autism Research Training program, Canadian Child Health Clinician-Scientist Career Enhancement Program, Alberta Innovates Health Solutions Clinician Fellowship Award, Autism Society of Edmonton Area and Autism Research Centre Graduate Student Pilot Grant, and Women and Children's Health Research Institute Graduate Studentship. LARS was supported by the Alberta Innovates Health Solutions Post-Doctoral Fellowship Award. LZ was supported by the Stollery Children's Hospital Foundation Chair in Autism.

Conflicts of Interest.

The authors have no conflicts of interest to report.

Chapter 3 References

Adolfsson, M., Malmqvist, J., Pless, M., & Granuld, M. (2011). Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disability and Rehabilitation, 33*(13-14), 1230-1244.

American Psychiatric Association. (2014). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5)*. Washington, DC: American Psychiatric Association.

Anderson, S., Allen, P., Peckham, S., Goodwin, N. (2008). Asking the right questions: Scoping studies in the commissioning of research on the organization and delievery of health services. *Health Research Policy & Systems, 6*(1),1-12.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32.

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*, 103-114.

Bedell, G. (2004). Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *NeuroRehabilitation, 19*(3), 191-205.

Bedell, G. (2009). Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilation, 12*(5), 342-351.

Berg, C., & LaVesser, P. (2006). The Preschool Activity Card Sort. *OTJR: Occupation, Participation and Health, 26*(4), 143- 151.

Bult, M.K., Verschuren, O., Kertoy, M.K., Lindeman, E., Jongmans, M.J., & Ketelaar, M. (2013). Psychometric evaluation of the Dutch version of the Assessment of Preschool Children's Participation (APCP): Construct validity and test-retest reliability. *Physical & Occupational Therapy in Pediatrics, 33*(4), 372-383.

Burstyn, I., Sithole, F., & Zwaigenbaum, L. (2010). Autism spectrum disorders, maternal characteristics and obstetric complications among singletons born in Alberta, Canada. *Chronic Diseases in Canada, 30*(4), 125-134.

Castro, S., & Pinto, A. (2015). Matrix for Assessment of Activities and Participation: Measuring functioning beyond diagnosis in young children with disabilities. *Developmental Neurorehabilation, 18*(3), 177-189.

Centre for Disease Control. (2014). Prevalence of Autism Spectrum Disorder among children aged 8 years. *Morbidity and Mortality Weekly Report, 63*(SS02), 1-21.

Chien, C.W., Rodger, S., & Copley, J. (2015). Development and psychometric evaluation of a new measure for children's participation in hand-use life situations. *Archives of Physical Medicine & Rehabilitation, 96*(6), 1045-1055.

Chien, C.W., Rodger, S., Copley, J., & McLaren, C. (2013). Measures of participation outcomes related to hand use for 2-to 12-year-old children with disabilities: A systematic review. *Child: Care Health and Development, 40*(4), 458-471.

Chien, C.W., Rodger, S., Copley, J., & Skorka, K. (2014). Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health–Children and Youth. *Archives of Physical Medicine and Rehabilitation, 95(1)*, 141-152.

Christensen, D.L., Bilder, D.A., Zahorodny, W., Pettygrove, S., Durkin, M.S., Fitzgerald, R.T., Rice, C., Kurzius-Spencer, M., Baio, J., & Yeargin-Allsopp, M. (2016). Prevalence and characteristics of Autism Spectrum Disorder among 4-year-old children in the Autism

and Developmental Disabilities Monitoring Network. *Journal of Developmental & Behavioral Pediatrics, 37*(1), 1-8.
Colquhoun, H.L., Levac, D., O'Brien, K.K., Straus, S., Tricco, A.C., Perrier, L., Kastner, M., & Moher, D. (2014). Scoping reviews: Time for clarity in definitions, methods and reporting. *Journal of Clinical Epidemiology, 67*, 1291-1294.
Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability & Rehabilitation, 30*(8), 639-648.
Daniels, A. M., & Mandell, D. S. (2013). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism*, *18*(5), 583-597.
Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal, 26*(2), 91-108.
Harding, J., Harding, K., Jamieson, P., Mullally, M., Politi, C., Wong-Sing, E., . . . Petrenchik, T. M. (2009). Children with disabilities' perceptions of activity participation and environments: A pilot study. *Canadian Journal of Occupational Therapy, 76*(3), 133-144.
Hemmingsson, H., & Jonsson, H. (2005). An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health—some critical remarks. *American Journal of Occupational Therapy, 59*(5), 569-576.
Hoogsteen, L., & Woodgate, R. L. (2010). Can I play? A concept analysis of participation in children with disabilities. *Physical & Occupational Therapy in Pediatrics, 30*(4), 325-339.
Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics, 120*(5), 1183-1215.
Khetani, M. A., Graham, J. E., Davies, P. L., Law, M. C., & Simeonsson, R. J. (2015). Psychometric properties of the Young Children's Participation and Environment Measure. *Archives of Physical Medicine and Rehabilitation, 96*(2), 307-316.
King, G.A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P. (2005) Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development, 33*(1), 28-39.
LaVesser, P., & Berg, C. (2011). Participation patterns in preschool children with an autism spectrum disorder. *OTJR: Occupation, Participation and Health, 31*(1), 33- 39.
Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy, 56*(6), 640-649.
Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., King, G., & Hanna, S. (2004). Participation of children with physical disabilities: Relationships with diagnosis, physical function, and demographic variables. *Scandinavian Journal of Occupational Therapy, 11*(4), 156-162.
Law, M., Haight, M., Milroy, B., Willms, D., Stewart, D., & Rosenbaum, P. (1999). Environmental factors affecting the occupations of children with physical disabilities. *Journal of Occupational Science, 6*(3), 102-110.
Law, M., King, G., Petrenchik, T., Kertoy, M., & Anaby, D. (2012). The Assessment of Preschool Children's Participation: Internal consistency and construct validity. *Physical & Occupational Therapy in Pediatrics, 32*(3), 272-287.
Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science, 5*(1), 1-9.

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.

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480-1486.

Mandich, A.D., Polatajko, H.J., Miller, L.T., & Baum, C. (2004). *Paediatric Activity Card Sort (PACS)*. Ottawa: CAOT Publications ACE.

McConachie, H., Colver, A.F., Forsyth, R.J., Jarvis, S.N., & Parkinson, K.N. (2006). Participation of disabled children: how should it be characterised and measured? *Disability & Rehabilitation, 28*(18), 1157-1164.

Morris, C., Kurinczuk, J., & Fitzpatrick, R. (2005). Child or family assessed measures of activity performance and participation for children with cerebral palsy: a structured review. *Child: Care, Health, and Development, 31*(4), 397-407.

Phillips, R. L., Olds, T., Boshoff, K., & Lane, A. E. (2013). Measuring activity and participation in children and adolescents with disabilities: A literature review of available instruments. *Australian Occupational Therapy Journal, 60*(4), 288-300.

Resnik, L., & Plow, M. A. (2009). Measuring participation as defined by the International Classification of Functioning, Disability and Health: an evaluation of existing measures. *Archives of Physical Medicine and Rehabilitation, 90*(5), 856-866.

Rosenberg, L., Jarus, T., & Bart, O. (2010). Development and initial validation of the Children Participation Questionnaire (CPQ). *Disability & Rehabilitation, 32*(20), 1633-1644.

Sakzewski, L., Boyd, R., & Ziviani, J. (2007). Clinimetric properties of participation measures for 5-to 13-year-old children with cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology, 49*(3), 232-240.

Sylvestre, A., Nadeau, L., Charron, L., Larose, N., & Lepage, C. (2013). Social participation by children with developmental coordination disorder compared to their peers. *Disability & Rehabilitation, 35*(21), 1814-1820.

World Health Organization. (2007). *International Classification of Functioning, Disability and Health - Child and Youth Version*. Geneva, Switzerland: WHO Press.

Young, N. L., Yoshida, K. K., Williams, J. I., Bombardier, C., & Wright, J. G. (1995). The role of children in reporting their physical disability. *Archives of Physical Medicine and Rehabilitation, 76*(10), 913-918.

Ziviani, J., Desha, L., Feeney, R., & Boyd, R. (2010). Measures of participation outcomes and environmental considerations for children with acquired brain injury: A systematic review. *Brain Impairment, 11*(02), 93-11.

Chapter 4: Stakeholders' Perspectives on Social Participation in Preschool Children with Autism Spectrum Disorder

This manuscript is in press in *Developmental Neurorehabilitation:*

Germani, T., Zwaigenbaum, L., Magill-Evans, J., Hodgetts, S., & Ball, G.D.C. 'Stakeholders' Perspectives on Social Participation in Preschool Children with Autism Spectrum Disorder.'

Abstract.

Objective: To determine (*i*) the essential components of *social participation* for preschool children with Autism Spectrum Disorder (ASD) using stakeholders' perspectives and (*ii*) the facilitators and barriers' experienced in promoting social participation.

Method: A mixed methods, web-based survey utilizing the International Classification of Functioning, Disability and Health – Child and Youth version (ICF-CY) taxonomy was circulated across Canada through purposeful snowball sampling.

Results: Frequency analysis of the combined responses of 74 stakeholders revealed the most essential components of social participation were: *(i)* behaviour management, *(ii)* social interactions and *(iii)* various types of play. Further, content analysis revealed that stakeholders used intrinsic motivation strategies and contingency management to facilitate social participation.

Conclusion: Stakeholders reported that the purpose of social participation was to engage the child in fun, enjoyable social activities that developed relationships between the child and peers and created a sense of belonging in the community.

Keywords: Stakeholders' Perspectives, Social Participation, Autism Spectrum Disorder, Preschool Children, International Classification of Functioning, Disability and Health – Child and Youth version

Social participation is a robust indicator of health and well-being [1]. In particular, social participation is important for children with a disability [2] who generally have fewer friends, less interactions with peers in their classroom, and are less likely to be socially accepted than peers without a disability [3]. Social participation has been conceptualized for adults with Autism Spectrum Disorder (ASD) as involvement in social networks, social skills groups and support groups, with an emphasis on meaningful engagement with peers that creates a sense of belonging and community [4]. Indeed, social participation has been linked to improved quality of life and overall functioning for young adults with ASD that provides opportunities to become connected to peers within their community [4, 5]. At this time, there is a lack of understanding of social participation for preschool children with ASD, as most of the previous literature has focused on youth or adults with ASD or more broadly, children with disabilities.

An understanding of social participation is especially important for children diagnosed with ASD given that the diagnosis is characterized by difficulties in social communication, as well as repetitive and restrictive behaviours [6]. A present estimate of the rate of ASD in the United States is 1 in 68 among 8 year olds, with a boy: girl ratio of 4:1 [7]; this estimate is similar for children in Canada. Although 80% of children demonstrate behavioural signs of ASD by two years of age, the average age of diagnosis remains at 4 years of age [7]. A medical doctor and/or interdisciplinary team typically diagnoses ASD between 2 and 4 years of age [7, 8]. Children with ASD are most likely to receive interventions services within the school, home or community settings [9]. By definition, ASD symptoms lead to restrictions in social participation. Previous analyses focusing on children with special needs describe four common themes of social participation: (1) friendship/relationships, (2) interactions, (3) perception of the student with special needs and (4) acceptance by classmates [10]; however, this analysis was not specific

to preschool children with ASD. Thus, an exploration of *social participation* specific to preschool children with ASD is needed.

Preschool children with ASD participate less in social activities, including special events such as birthday parties or family vacations [11] compared to typically developing peers. Participating in fewer social activities reduces the opportunity for preschool children with ASD to develop or practice social skills. Preschool children with ASD are also less likely to be engaged with or within proximity of peers, and demonstrate challenging behaviours during 'free play' compared to typically developing children who are usually engaged in joint activities with peers [12, 13]. At present, the literature suggests the need to consider social skills, the role of peers and availability of activities or special events, and opportunities to practice these skills in an integrated manner when conceptualizing social participation for this age group. Thus, determining the essential components of social participation, particularly from stakeholders' perspectives, would enhance understanding and practical application for professionals and parents who are looking to support social participation for preschool children with ASD.

The purpose of this study is to: 1) understand the essential components of social participation for preschool children with ASD from professionals' including clinicians, educators and therapy or educational assistants, as well as parents' (hereafter, 'stakeholders') perspectives; and 2) understand the facilitators and barriers experienced by stakeholders in promoting social participation. In refining social participation, there is a need to engage multiple stakeholders involved in the research process, which increases the likelihood of end-user applicability [1].. Including stakeholders in this context fits within an *integrated knowledge translation* framework that encourages collaboration of researchers with knowledge users over the entirety of the research process [14, 15]. Recent discussions of stakeholder engagement in ASD have

highlighted the need to develop and maintain these relationships [16] as well as the processes needed to guide this pursuit [17]. This study later informed the development of a classification system about social participation for preschool children with ASD, which stakeholders were integrally involved in the development process.

Methods

Study design and location

The sample was purposefully selected using a snowball technique. A mixed methods approach was selected using a convergent, parallel design [18]. This approach allowed the parallel collection of quantitative and qualitative data, with separate analyses, and then integration of results from each data type [18] while an online platform allowed broad access across the country. Ethical approval for this research was received from University of Alberta Health Research Ethics Board. Data were collected through a web-based survey hosted through a secure online platform called Research Electronic Data Capture (REDCap; [19]) from November 27, 2014 to February 1, 2015.

Recruitment

The survey was electronically circulated to a national list of 98 organizations working with children with ASD, including multidisciplinary professional groups representing each province, service providers, and advocacy/family support groups. Organizations self selected to participate by forwarding the invitation to families, posting on social media platforms, and/or circulating within their workplace. A sample size of 25 professionals and 25 parents was targeted to allow for a rich and diverse understanding of social participation [20]. Professionals and families self-selected to participate by emailing the primary author or clicking a hyperlink posted on their respective organization's website. If participants exited the survey prematurely, this was

viewed as withdrawal of consent and data were removed. Participants were offered a $10 electronic gift card to Apple iTunes or Amazon.ca upon completion of the survey.

To participate, families had to self identify as having at least one child with ASD less than eight years old or be a professional working (for at least two years) with children with ASD less than eight years old. This age was selected to allow a range of parents to participate after completion of the diagnostic process and the start of early intervention services, but still close enough to preschool years to allow accurate recall of events. For professionals, this age range accommodated variability across regions as to when children with ASD started elementary school programs (i.e., from 5 to 7 years).

Survey Development

When we conceived this research, we were not aware of any published literature reviews on social participation for preschool or school-aged children with ASD. As a result, relevant social elements were selected from a recent review of participation measures in preschool children with ASD [21], with a specific focus on social elements unique to ASD, and a content analysis of participation measures utilizing the *International Classification of Functioning, Health and Disability –Child and Youth* (ICF-CY) framework [22]. This provided an initial focus for the selection of ICF-CY constructs for inclusion in the survey. Descriptors for priority constructs were drawn from the nine *Activities & Participation* chapters in the ICF-CY (World Health Organization (WHO, [23]). These essential social constructs have been underrepresented in current participation measures [22] and are essential to activities within social contexts for preschool children with ASD. In total, 18 out of a possible 572 constructs, from nine chapters describing *Activities & Participation*, were identified by the primary author in consultation with the authorship team as relevant for stakeholders to consider and/or related to essential

components of social participation within a biopsychosocial perspective. For the construct to be considered for selection, the ICF-CY description had to include a social element (e.g., play, family or peer interactions) that would be relevant to preschool children with ASD.

The four-part survey included both closed- and open-ended questions, as shown in Figure 4.1. In Part 1, stakeholders were oriented to the purpose of the survey, acknowledged consent, and identified as either professionals or family members. This identification determined the demographic questions in Part 2 that were most appropriate (e.g., clinical designation, years of practice, etc. OR number of children with ASD, total number of children, etc.). Part 3 ascertained perspectives on the most essential components of social participation for preschool children with ASD. Using the taxonomy of the ICF-CY, stakeholders were asked to select the most essential of the 18 constructs, grouped by ICF-CY chapters: *Chapter 2 - General Tasks and Demands*, *Chapter 7 - Interpersonal Interactions and Relationships,* and *Chapter 8 - Major Life Areas*. To determine the essential components of social participation for preschool children with ASD from stakeholders' perspectives, participants ranked the ICF-CY constructs from *most* to *least relevant* for social participation. For example, stakeholders were asked "Please rate how essential the following items [constructs] are for describing a child's social participation: (i) managing behaviour, (ii) accepting novelty, and (iii) responding to demands." In addition, each theme followed up with a series of open-ended questions such as: "When enrolling a client/child in a new activity, what factors do you consider to ensure social participation will be successful?" and "Where does your client(s) have the greatest success participating in social activities?"

Pilot Testing of Survey

Pilot testing the survey provided an opportunity to refine: (1) clarity of questions, (2) usability, (3) design (e.g., "could you somehow show how many remaining questions"), and (4)

sensitivity and appropriateness of questions for this population. Six participants (one parent, two clinicians, two graduate students, and one academic) responded to initial drafts using REDCap [19]. Based on the verbal and written responses to open-ended questions on usability, clarity and design, we made several revisions to the survey. This included rewording open-ended questions, altering alignment of questions on the page, changing font size, and adding visual cues to indicate proportion of survey completed, as well as examples for each brief item requiring agreement from *Strongly Agree* to *Strongly Disagree*. After two rounds of pilot testing, each with one family member, one clinician and one child-health trainee, the survey was finalized over two weeks.

Analytic Approach

To address objective 1, quantitative data were analyzed through frequency counting. The top three constructs deemed to be *most important* between the two groups were identified, as well as a combined stakeholder group. The qualitative data were used to address objective 2, providing participants an opportunity to give examples of facilitators and barriers experienced in promoting social participation. The qualitative data were analyzed using a latent (inductive) content analysis, a systematic, objective means of describing and quantifying phenomena to make replicable and valid inferences [24, 25]. There were three phases: preparation, organizing, and reporting [24]. In the preparation phase, a single unit was reviewed (i.e., one participant's survey response) until the coder (first author) was immersed in that participant's response. In the organizing phase, immersion in the data was completed by re-reading all participant responses to the same question several times. Once immersed, open and free coding occurred, which allowed for responses to be categorized together under higher ordered headings that emerged and consolidated similar categories [24, 26]. The reporting phase highlighted the overarching themes

and described the process used to analyze results (i.e., audit trail). To ensure rigour, strategies included prolonged engagement in the data, participant checks with local stakeholders as part of a larger study on social participation, keeping a personal journal for audit trailing and checking, and confirming and re-considering themes that emerged [27]. Qualitative data was managed utilizing NVivo 9 (QSR International, 2010) and quantitative data was managed utilizing IBM SPSS version 20.0.

Results

In total, 74 individuals participated in this research (see Table 4.1). About one third of all participants were parents (n=25). Occupational therapists (n=17) comprised the largest category of professionals that participated. Parents and professionals from across Canada participated although close to half were from the province of Alberta. Consistent with the sex ratio in ASD of 4 boys to 1 girl [7]. 80% of families of preschool children with ASD parented a male child. Parents and professionals reported a wide range of communication and cognitive abilities through the examples shared although no formal assessment or question specifically asked about functional abilities or severity level of ASD.

Objective 1

Parents and professionals had complementary, but not identical, perspectives on social participation for preschool children with ASD. A combined frequency analysis of the components deemed most essential for social participation is presented in Table 4.2. The highest ranked ICF-CY constructs for stakeholders (‘strongly agree’ or ‘agree’) that were essential components of social participation were: (1) *Regulating behaviours within interactions* (*Chapter 7,* 69.0%); (2) *Responding to demands* (*Chapter 2,* 67.8%); and (3) *Following routines* (*Chapter 2,* 64.7%).

Professionals were more likely to respond with strongly agree/agree and to select more constructs in comparison to parents, who often only selected one or two constructs as essential to social participation (see Table 4.2). The highest ranked ICF-CY constructs for families were: (1) *Following routines* (*Chapter 2,* 64.0%, strongly agree/agree); (2) *Parallel play* (*Chapter 8,* 60.0%); and (3)– *Responding to demands* (*Chapter 2,* 56.0%). The highest ranked constructs for professionals were; (1) *Regulating behaviours within interactions* (*Chapter 7*, 93.9%, strongly agree/agree), (2) *Initiating (and responding to) social interactions* (*Chapter 7,* 91.8%), and (3) *Shared cooperative play* (*Chapter 8,* 87.8%). Although there was some broad overlap in the constructs ranked highly by both families and professionals, discrepancies existed, which likely represents differences in stakeholder priorities and experiences. The constructs that professionals ranked as essential were ranked as a priority by a minority of families (e.g., initiating social interactions). Family members responded that social participation occurred most frequently with family members or with adult facilitators. Professionals described the essential components of social participation as being with a peer or developmentally matched child; however, they also observed that, in reality, social participation occurred largely with adult facilitators.

Objective 2

Based on qualitative analysis, facilitators and barriers to social participation were described by families and professionals as occurring across a variety of environments, including (but not limited to) the child's primary residence, daycare or preschool, and structured or non-structured community activities, as shown in Table 4.2. Further, stakeholders reported a variety of facilitators and barriers that fit within three broad themes of social participation: *Behaviour Management*, *Interactions & Relationships*, and *Play & Activities of Daily Living*. As the ICF-CY was selected as the theoretical framework prior to data collection, unsurprisingly the data

was well aligned with the three chapters of the ICF-CY chapters that constructs were selected from: *Chapter 2 - General Tasks and Demands (such as behaviour management)*, *Chapter 7 - Interpersonal Interactions and Relationships,* and *Chapter 8 - Major Life Areas (such as play).*

Behaviour Management: Stakeholders described using a variety of behaviour management strategies to facilitate social participation prospectively or in the moment. Parents reported using cognitive strategies to ease anxiety and build confidence such as '*I pretend that individuals she knows a little bit are really interested in her and try to build excitement around social situations that are usually anxiety prone for her*.' As expected, many stakeholders reported using behavioural strategies such as positive reinforcement and applied behavioural analysis, which are consistent with best practice in ASD interventions for preschool children to address the child's disruptive and difficult behaviours that may restrict social participation [28]. The child's interests (particularly their restricted and repetitive interests) would sometimes facilitate interactions and relationships, particularly if the child could lead or teach his peers about his or her particular interest, but it also restricted the scope, nature or depth of the social participation. Behavioural rigidity (e.g., '*social participation is you playing the game he says to play*') reportedly narrowed the type and frequency of activities with peers. Also, stakeholders described their role to support emotional and behavioural regulation as more than was expected for similarly developing or age-matched peers.

Interactions & Relationships: Most stakeholders described their preschool child's social participation as most often occurring between themselves and the child, and not with peers. During integrated social programs in the community, relationships with peers were often with a mature peer (possibly one who viewed the child as 'different' and would naturally accommodate) or a younger peer (possibly naïve to the child's delayed social skills or whose

skills better matched the child's). These peers provided naturalistic and in the moment facilitation of social participation for preschool children with ASD, without the reported use of an adult facilitator. As well, these shared experiences between the child and peers had the added benefit of creating joy, fun, and developed a sense of belonging, which was perceived as paramount for social participation by stakeholders. For example, some stakeholders reported challenges in developing relationships because the preschool child with ASD tended to focus on him/herself or a particular toy rather than the peer. Also, stakeholders reported that being familiar with a peer, and perceived acceptance of 'stimming' or repetitive behaviours, allowed the child to feel safe and more likely to enjoy and be successful in the social activity. This behaviour was acceptable by some standards and allowed the child to express him/herself in a non-threatening, fun manner, and connect with peers with the 'just right' amount of structure and support.

Play & Activities of Daily Living: Stakeholders reported balancing activity mastery with social interaction opportunities as a means to facilitate social participation. For example, parents enrolled their child in the same swim class repeatedly to give their child an opportunity to be a swim leader and (hopefully) be more accepted by his peer group with a better opportunity to practice social skills. In this domain, professionals focused on mastering the concrete skill or activity in order for the child to have an opportunity to focus on social interaction and development of a peer-relationship, which mattered more to parents. Also, parents reported that limitations in performing activities of daily living, such as feeding or toileting, restricted social participation opportunities. Families were less likely to enrol their child in community/social programs if they needed more assistance with activities of daily living than the program could provide or if family washrooms were unavailable in community programs.

Discussion

Our results support *(i)* the understanding of the essential components of social participation using stakeholders' perspectives and *(ii)* understanding the facilitators and barriers that exist for preschool children with ASD. The most frequently reported ICF-CY constructs by stakeholders as essential components for social participation were (1) Regulating Behaviours within Interactions (ICF-CY: Chapter 7), (2) Responding to Demands (ICF-CY: Chapter 2), and (3) Following Routines (ICF-CY: Chapter 2). Professionals and families reported the following additional ICF-CY constructs as essential: initiating social interaction and shared cooperative play (professionals), and engagement in parallel play (parents), respectively.

Social participation as described by the stakeholders includes many abilities that may be particularly restricting for preschool children with ASD such as social skills, interpersonal relationships, friendships, behaviour regulation and management, and involvement in activities with others. Adult facilitators, such as parents and professionals, and peers were paramount in overcoming these restrictions in promoting social participation. Our findings suggest that there are challenges in determining components are essential for a construct such as social participation that is more than 'doing' for the sake of 'doing', but taps into community belonging and social involvement that exists even in this young cohort of children. Our findings are consistent with previous literature [3, 10] except for the focus on the management and support provided by adult facilitators for behavioural and emotional regulation to enhance the 'doing' of the activity with others, such as being part of a swim class or social activity. Behavioural regulation as a restriction to social participation *may* be an issue unique to preschool children with ASD due to the combination of communication delays, emotional regulation challenges, and sensory sensitivities that exist within this diagnostic group. Regulation remains are a central

component of social competence as those children with ASD acting out or demonstrating challenging behaviours are more likely to experience isolation or social rejection by peers [29].

Our research aligns with other recent reports, such as a previous study that for parents of youth with severe physical disabilities, previous experiences (either positive or negative) defined the activity selection and the quality of the experience of social participation [30]. Their findings related to the balance of parent and child needs, previous experiences and availability of resources to make social participation possible are relevant to families and children with ASD as well. Only parents in our study reported the need to be more physically involved in the social activities and to scaffold the interactions. This difference may relate to the developmental age of the children in our study relative to those in the previous study [30]. Furthermore, parents in our study reported various emotional and cognitive demands that required them to be "on alert" when participating in community activities. This may be an important consideration for how adults facilitate play and scaffold interactions to be more inclusive of the developmentally-matched peer or classmate to help develop social relationships and broaden the available social participation opportunities.

Social participation provides important opportunities for a child with a disability to develop friendships with peers, enhance their own self-concept, and create meaning in life [31]. For clinical practice, the exploration of social participation encourages rehabilitation therapists to reflect on how they can develop, support and increase participation [2] for clients with ASD in partnership *with* families. In our qualitative data, professionals were more likely than families to describe child factors, rather than family factors or previous experiences, as impacting social participation. As well, professionals placed an emphasis on the skills of social participation (e.g., social skills or doing an activity), while families placed an emphasis on shared experiences with

peers that were fun or joyful. This has implications for the child's direct involvement in these opportunities as well as the role and priorities adult facilitators may have in promoting social participation with peers. For example, if a professional is the adult facilitator, the facilitation of the interaction may focus exclusively on the development of a skill in comparison to a parent who may place an emphasis on positive shared experiences. This reflects the importance of soliciting parents' experiences and priorities (e.g., to have fun and make friends) when targeting participation in the community and the partnerships required across community organizations to facilitate opportunities.

Determining the essential components of social participation from stakeholders' perspectives, including families, will help ensure that measures focus on success that is meaningful to the stakeholders. Additionally, using the biopsychosocial model of the ICF-CY [23] positions future researchers in this area to have a supportive theoretical framework from which to base their outcomes, linking theory to practice. Given that the ICF-CY is broad and diverse, it is well suited to capture the complex and intersecting elements of an activity's demands and the environment on the ability of an individual with ASD to participate in social opportunities [32, 33]. From an integrated knowledge translation perspective, engagement of stakeholder perspectives, including parents, supports meaningfulness and representativeness of the experience in developing measures and programs of research that better meet the experiences of preschool children with ASD and their families. Families reported on aspects of the environment that impacted social participation, such as attitudes of peers and their families, indicating that further studies could focus on the environment's role in influencing social participation.

Strengths and Limitations

This study has several strengths to support the findings. Our survey included a national sample of families and professionals, which provided an opportunity to help understand social participation to be relevant for a variety of stakeholders. Through this process, we demonstrated the importance of multiple stakeholder perspectives as complementary but not identical. A mixed methods approach allowed for a complete account of stakeholders' perspectives, a diversity of views and expanded the breadth of research question [18]. However, there are also limitations. Although the intent of our sampling was to have a rich and diverse sample from across Canada, half of the respondents were from Alberta. This may have reflected the professional connections of the investigator group. As well, we did not collect data on the cognitive, communication, or functional abilities of the preschool children with ASD, which would have offered a more comprehensive background of families' perspectives when describing social participation. Based on responses received, there may have been some ambiguity in the questions addressing the essential components of social participation versus describing the every day lived experiences. Although this occurred in piloting of our survey and modifications were made, based on answers, we postulate this may still have occurred for some respondents. This also added to the difficulty in determining what was an essential component of social participation from the broader discussion of facilitators and supports required. In addition, two professionals did not report the age range of their clients, although they self-identified as having worked with preschool children with ASD by participating in the study. As well, the ethnic and cultural background of the participants is unknown; which may have an influence on the selection and participation of social activities as a family. In addition, there is the paucity of information on the classroom setting of the preschool child with ASD. This may have implications for social participation as preschool children with ASD situated in inclusive settings may have more opportunities for social

participation with peers compared to those in self-contained classrooms. Further, as participants were provided with an electronic gift card upon completion, this may have influenced motivation for participation in the study.

Conclusions

This study used multiple stakeholder perspectives to determine the essential components of social participation for preschool children with ASD. Our findings emphasize social participation as an important construct using the ICF-CY taxonomy and the need to elicit a variety of stakeholders' perspectives when considering social participation goals for preschool children with ASD. Future studies exploring stakeholders' perspectives on social participation for preschool children with ASD could focus on differences that may exist between types of communication and functional abilities, as well as socioeconomic and cultural differences. This construct from professionals' and families' perspectives is important to ensure the applicability of future research and clinical practice interventions targeting social participation to promote health, development and quality of life in preschool children with ASD.

Figure 4.1. Stakeholder Survey Composition

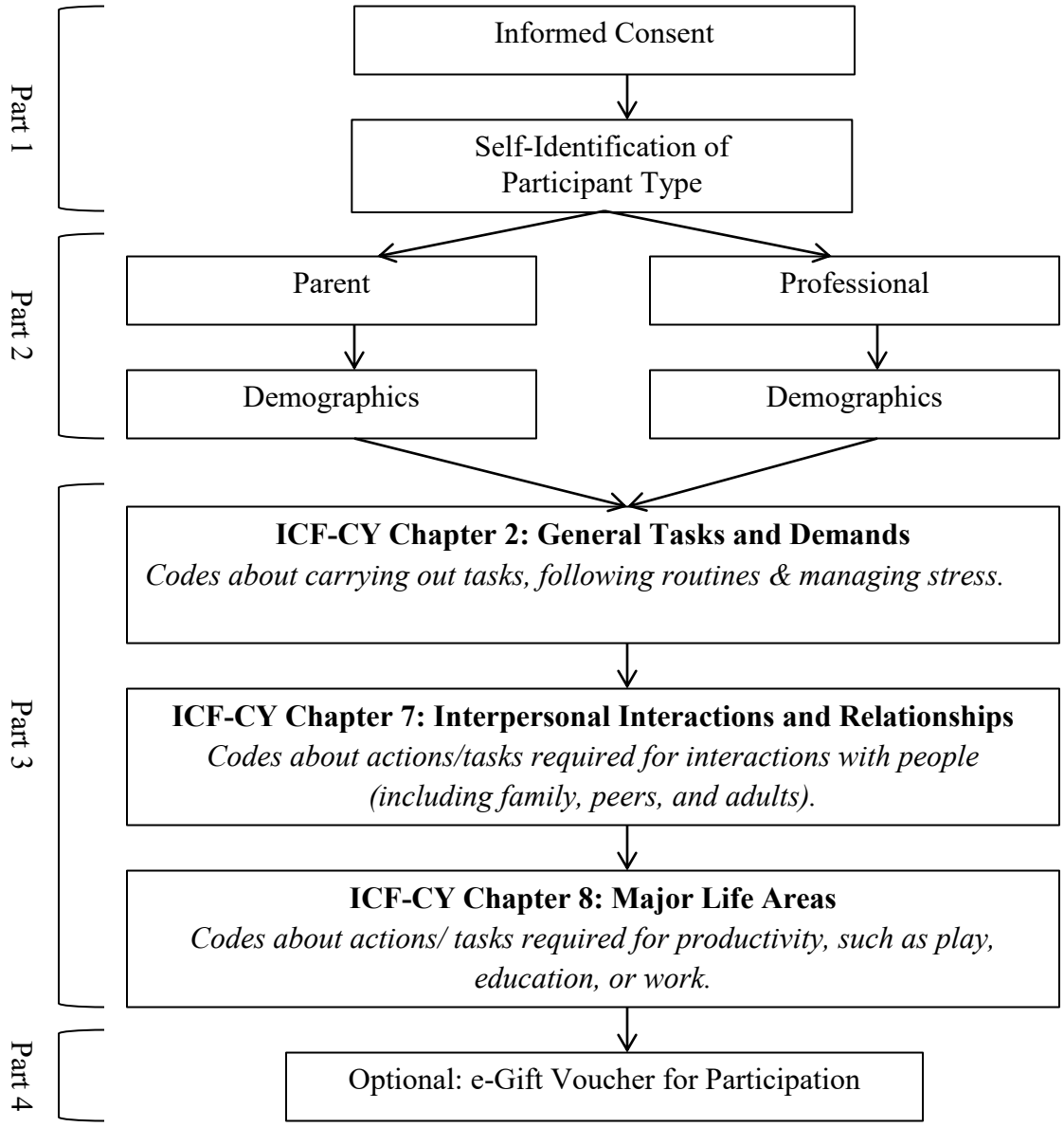
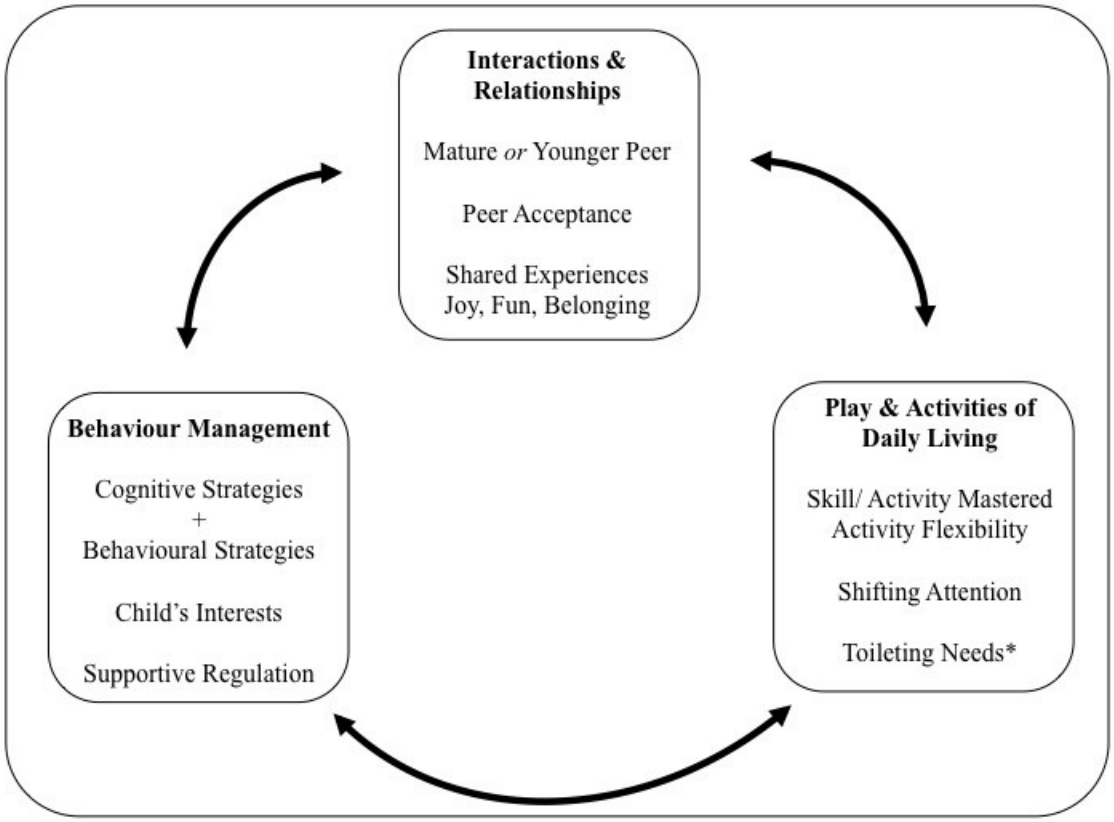


Figure 4.2. Stakeholders' Perspectives on Facilitators and Barriers to Social Participation



*Only families reported *Toileting* as an important aspect

Table 4.1. Characteristics of Stakeholders

Parent Characteristics (n=25)		
Total number of children at home	Mode (range)	2 (1-4)
Age of youngest child with ASD in years	Mean (SD)	4.9 (1.7)
	Range	2.0 – 7.0
Has >1 child with ASD	4 (16.0 %)	
Child with ASD male	20 (80.0 %)	
Professional Characteristics (n=49)		
Years of practice with ASD*	Mean (SD)	9.2 (7.0)
# of current clients with ASD*	Mean (SD)	7.2 (7.6)
Age of current clients with ASD** in years	Mean (SD)	2.8 (1.8)
	Range	0.5 – 8.0
Allied Health Professional[1]	28 (57.1%)	
Educator	5 (10.2%)	
Physician[2]	2 (4.1%)	
Non-Regulated Professional[3]	14 (28.6%)	

[1]Included occupational therapists, psychologists, social workers, & speech language pathologists
[2] Includes pediatrician and developmental pediatrician
[3]Included rehabilitation assistants, interventionists, aides, psychometrists, & behaviour therapists
*one participant did not respond
** two participants did not respond

Table 4.2. Percentage (%) of parents (n= 25) or professionals (n= 49) choosing each response category for items on the International Classification of Functioning, Disability and Health – Child and Youth version

Rated item in terms of how important it was for describing child's social participation or "doing" in activities.	Respondent	Strongly Agree/ Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree/ Disagree
Chapter 2: General Tasks and Demands						
Following routines: Follows guidance of others for basic daily routines, such as getting ready for bed	*Family*	64.0 [1]	24.0	0.0	12.0	0.0
	Professional	65.3	32.7	2.0	0.0	0.0
	Combined	64.7 [3]	28.4	1.0	6.0	0.0
Managing changes in daily routine: Handles changes to usual sequence of activities, such as completing bedtime routine in a different order	*Family*	40.0	24.0	12.0	4.0	20.0
	Professional	75.5	16.3	0.0	6.1	2.0
	Combined	57.8	20.2	6.0	5.1	11.0
Managing one's behaviour: Acting in an appropriate way in response to new situations, people, or experiences, e.g., meeting a new teacher	*Family*	44.0	20.0	4.0	20.0	12.0
	Professional	77.6	12.2	4.1	4.1	2.0
	Combined	60.8	16.1	4.1	12.1	7.0
Accepting novelty: Managing behaviour in new situations such as the first time going to the dentist	*Family*	28.0	16.0	16.0	28.0	12.0
	Professional	67.3	24.5	0.0	6.1	2.0
	Combined	47.7	20.3	8.0	17.1	7.0
Responding to demands: Managing behaviour in an appropriate way in response to expectations or demands, such as following one-step instructions	*Family*	56.0 [3]	12.0	0.0	12.0	20.0
	Professional	79.6	18.3	0.0	2.0	0.0
	Combined	67.8 [2]	15.2	0.0	7.0	10.0
Adapting activity level: Managing behaviour with an appropriate level of energy to demands or expectations, such as sitting quietly in story time	*Family*	36.0	16.0	12.0	20.0	16.0
	Professional	61.2	26.5	4.1	6.1	2.0
	Combined	48.6	21.3	8.1	13.1	9.0
Chapter 7: Interpersonal Interactions and Relationships						
Basic interpersonal interactions: Giving and reacting appropriately to signs and hints that occur in social interactions, such as a showing a toy	*Family*	32.0	28.0	12.0	16.0	12.0
	Professional	73.5	22.4	2.0	0.0	2.0
	Combined	52.8	25.2	7.0	8.0	7.0
Initiating social interactions: Initiating and	*Family*	24.0	20.0	0.0	32.0	24.0

responding appropriately in reciprocal social exchange with others, such as peers	*Professional*	91.8 [2]	6.1	0.0	0.0	2.0
	Combined	57.9	13.1	0.0	16.0	14.0
Maintaining social interactions: Regulating behaviours to sustain social exchanges, such as telling a story	*Family*	20.0	28.0	8.0	16.0	28.0
	Professional	65.3	24.5	6.1	0.0	4.1
	Combined	42.7	26.3	7.1	8.0	16.1
Regulating behaviours within interactions: Regulating emotions and impulses, verbal aggression and physical aggression in interactions with others, such as peers at the playground	*Family*	44.0	12.0	12.0	12.0	20.0
	Professional	93.9 [1]	4.1	0.0	0.0	2.0
	Combined	69.0 [1]	8.1	6.0	6.0	11.0
Interacting according to social rules: Complying with social conventions, such as listening when the teacher is talking*	*Family*	33.3	8.3	20.8	16.7	20.8
	Professional	65.3	22.4	6.1	4.1	2.0
	Combined	49.3	15.4	13.5	10.4	11.4
Informal social relationships: Entering into relationships with others, such as with students at the same day-care or preschool	*Family*	32.0	8.0	16.0	16.0	28.0
	Professional	79.6	16.3	2.0	0.0	2.0
	Combined	55.8	12.2	9.0	8.0	15.0
Family relationships: Creating and maintaining family relationships, such as siblings and cousins.	*Family*	48.0	24.0	8.0	16.0	4.0
	Professional	N/A	N/A	N/A	N/A	N/A
	Combined	N/A	N/A	N/A	N/A	N/A
Chapter 8: Major Life Areas						
Pretending: Playing pretend or make-believe activities with imaginary persons, places, things or events	*Family*	32.0	16.0	20.0	16.0	16.0
	Professional	46.9	30.6	10.2	4.1	8.2
	Combined	39.5	23.3	15.1	10.1	12.1
Solitary play: Purposefully sustaining and engaging in activities with toys, or games by self, such as stacking blocks or reading.	*Family*	52.0	32.0	4.0	4.0	8.0
	Professional	38.8	28.6	18.4	8.2	6.1
	Combined	45.4	30.3	11.2	6.1	7.1
Onlooker play: Purposefully observing the activities of others with toys, or games, but not joining their activities, such as watching them across the room.	*Family*	32.0	20.0	16.0	20.0	12.0
	Professional	46.9	24.5	10.2	12.2	6.1
	Combined	39.5	22.3	13.1	16.1	9.1
Engagement in parallel play: Engaging in purposeful activities with toys, or games side-by-side peers also engaged in play but not co-operative, such as colouring at the same table.	*Family*	60.0 [2]	24.0	4.0	4.0	8.0
	Professional	57.1	32.7	8.2	2.0	0.0
	Combined	58.6	28.4	6.1	3.0	4.0
Shared cooperative play: Joining others for sustained engagement in activities with toys, or games with a common goal or purpose, such as playing 'house'.	*Family*	32.0	0.0	20.0	20.0	28.0
	Professional	87.8 [3]	6.1	0.0	2.0	4.1
	Combined	59.9	3.1	10.0	11.0	16.1

*one family response was missing; all other data was complete

[1] Indicates the highest ranked construct within the specified stakeholder group (family, professional or combined)
[2] Indicates the second highest ranked construct within the specified stakeholder group (family, professional or combined)
[3] Indicates the third highest ranked construct within the specified stakeholder group (family, professional or combined)
N.B. Combined percentages were calculated by adding the two percentages and dividing by two to ensure equal weighting of responses for each group

Acknowledgments

The study authors thank all the families, clinicians and educators who participated in the survey. The authors also acknowledge the members of the study team, Olivia Conlon and Shayla Richards, for their assistance with recruitment and administration of this study.

Declaration of Interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this article. Funding for the study was provided graciously by the Autism Society of Edmonton Area and Autism Research Centre Graduate Student Pilot Grant. Tamara Germani is supported by the Women & Children's Research Institute Graduate Studentship, Alberta Innovates-Health Solutions Clinician Fellowship, and Canadian Child Health Clinician Scientist Program Career Enhancement Program Award. Lonnie Zwaigenbaum is supported by the Stollery Children's Hospital Foundation Chair in Autism Research. Sandy Hodgetts is supported by an Alberta Centre for Child, Family and Community Research (ACCFCR) Early Career Transition award.

Chapter 4 References.

[1] Piškur B. 2013. Social participation: Redesign of education, research, and practice in occupational therapy. Scandinavian Journal of Occupational Therapy. 20(1): 2-8.

[2] Law M. 2002. Enhancing participation. Physical & occupational therapy in Pediatrics. 22: 1-3.

[3] Koster M, Pijl SJ, Nakken H, van Houten E. 2010. Social participation of students with special needs in regular primary education in the Netherlands. International Journal of Disability, Development and Education. 57(1): 59-75.

[4] Tobin MC, Drager KD, Richardson LF. 2014. A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. Research in Autism Spectrum Disorders. 8(3): 214-229.

[5] Orsmond GI, Shattuck PT, Cooper BP, Sterzing PR, Anderson KA. 2013. Social participation among young adults with an autism spectrum disorder. Journal of Autism and Developmental Disorders. 43(11): 2710-2719.

[6] American Psychiatric Association (United States of America). 2014. Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5). Washington (DC): American Psychiatric Association.

[7] Centre for Disease Control. 2014. Prevalence of Autism Spectrum Disorder among children aged 8 years. Morbidity and Mortality Weekly Report 63(SS02): 1-21.

[8] Anagnosou E, Zwaigenbaum L, Szatmari P, Fombonne E, Fernandez BA, Woodbury-Smith M, Brian J, Bryson S, Smith IM, Drmic I, et al. 2014. Autism Spectrum Disorder: Advance in evidence-based practice. Canadian Medical Association Journal. 186(7): 509-519.

[9] Hodgetts S, Nicholas D, Zwaigenbaum L, McConnell D. 2013. Families' and professionals' perceptions of family-centered care for children with autism across service sectors. Social Science & Medicine. 96: 138-146.

[10] Koster M, Nakken H, Pijl SJ, van Houten, E. 2009. Being part of the peer group: A literature study focusing on the social dimension of inclusion in education. International Journal of Inclusive Education. 13(2): 117-140.

[11] Rodger S, Umaibalan V. 2011. The routines and rituals of families of typically developing children compared with families of children with autism spectrum disorder: an exploratory study. British Journal of Occupational Therapy. 74(1): 20-26.

[12] McGee GG, Feldman RS, Morrier MJ. 1997. Benchmarks of social treatment for children with autism. Journal of Autism and Developmental Disorders. 27(4): 353-364.

[13] McConnell SR. 2002. Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for educational intervention and future research. Journal of Autism and Developmental Disorders. 32(5): 351-372.

[14] Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, Robinson N. 2006. Lost in knowledge translation: time for a map? Journal of Continuing Education in Health Professions. 26(1): 13-24.

[15] Field B, Booth A, Ilott I, Gerrish K. 2014. Using the knowledge to action framework in practice: a citation analysis and systematic review. Implementation Science. 9(1): 172-186.

[16] Singh I, Elsabbagh M. 2014. Autism research beyond the bench. Autism. 18(7): 754-755.

[17] Elsabbagh M, Yusuf A, Prasanna S, Shikako-Thomas K, Ruff CA, Fehlings, MG. 2014. Community engagement and knowledge translation: progress and challenge in autism research. Autism. 18(7): 771-781.
[18] Creswell JM, Piano Clark VL (United States of America) 2011. Designing and Conducting Mixed Methods Research. Thousand Oaks (CA): SAGE.
[19] Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. 2009. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. Journal of Biomedical Informatics. 42(2): 377-381.
[20] Sandelowski M. 1995. Sample size in qualitative research. Research in Nursing & Health. 18(2): 179-183.
[21] Germani T, Magill-Evans J, Zwaigenbaum L, Sacrey LAR, Askari S, Anaby D. Under review. Participation Measures for Preschool Children with Autism Spectrum Disorder: A Scoping Review. Review Journal of Autism and Developmental Disabilities.
[22] Chien CW, Rodger S, Copley J, Skorka K. 2014. Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health–Children and Youth. Archives of Physical Medicine and Rehabilitation. 95(1): 141-152.
[23] World Health Organization (Switzerland). 2007. International Classification of Functioning, Disability and Health - Child and Youth Version. Geneva (Geneva): WHO Press.
[24] Elo S, Kyngas H. 2008. The qualitative content analysis process. Journal of Advanced Nursing. 62(1): 107-115.
[25] Krippendorff K. (United States of America). 1980. Content Analysis: An Introduction to Its Methodology. Newbury Park, (California): SAGE.
[26] Dey I. (United Kingdom). 1993. Qualitiative Data Analysis: A User-Friendly Guide for Social Scientists. London (England): Routledge Taylor & Francis Group.
[27] Mayan MJ. (United States of America). 2009. Essentials of Qualitiative Inquiry. Walnut Creek, (California): Left Coast Press.
[28] Reichow B. 2012. Overview of meta-analyses on early intensive behavioural intervention for young children with autism spectrum disorders. Journal of Autism and Developmental Disorders. 42(4): 512-520.
[29] Yager J, Iarocci G. 2013. The development of the Multidimensional Social Competence Scale: A standardized measure of social competence in Autism Spectrum Disorders. Autism Research 6(6): 631-641.
[30] Davey H, Imms C, Fossey E. 2015. “Our child's significant disability shapes our lives”: experiences of family social participation. Disability & Rehabilitation. 37(24): 2264-2271.
[31] Kang LJ, Palisano RJ, Orlin MN, Chiarello LA, King GA, Polansky M. 2010. Determinants of social participation—with friends and others who are not family members—for youths with cerebral palsy. Physical Therapy. 90(12): 1743-1757.
[32] de Schipper E, Lundequist A, Coghill D, de Vries PJ, Grandlund M, Holtmann, M, Jonsson U, Karande S, Robison JE, Shulman, C. (2015) Ability and disability in Autism Spectrum Disorder: A systematic literature review employing the International Classification of Functioning, Disability and Health-Children and Youth Version. Autism Research. 8(6): 782-794.

[33] Gan SM, Tung LC, Yeh CH, Chang HY, Wang CH. 2014. The ICF-CY-based structural equation model of factors associated with participation in children with Autism. Developmental Neurorehabilitation. 17(1): 24-33.

Chapter 5: Development and Content Validity of the *Autism Social Participation Classification System* for Preschool Children with Autism Spectrum Disorder

This manuscript is *under review* to the journal *BMC Pediatrics:*

'Germani, T., Zwaigenbaum, L., Hodgetts, S., Magill-Evans, J., Hildebrandt, J., Stolte, M., Mitchell, S., Wennerstorm, K., & Hapchyn, C.A. 'Development and Content Validity of the *Autism Social Participation Classification System* for Preschool Children with Autism Spectrum Disorder.'

Abstract.

Aim: To develop, refine, and begin validation of the Autism Social Participation Classification System (ASPCS) for preschool-aged children with Autism Spectrum Disorder (ASD) who have an increased risk of restricted social participation. Current assessments measure symptoms of ASD but do not describe a child's social participation abilities. A classification system places a child along a continuum based on average social participation in comparision to age-matched peers with ASD.

Method: Using a modified nominal group technique, focus groups of experts and a parent helped develop the ASPCS. Next, a national online Delphi process was utilized to refine and validate content of the ASPCS.

Results: Based on stakeholders' perspectives collected during three rounds of Delphi process, the ASPCS has three components of social participation: *Behaviour*, *Social Desire*, and *Activities & Environment.* Five levels of abilities and supports emerged within each component that are clinically meaningful and distinct. Consensus for each level ranged from 80.5% to 97.6%.

Interpretation: The ASPCS provides a snapshot of a child's abilities to socially participate based on their *Behaviour*, *Social Desire* and *Activities & Environments*. With further validation, it can provide information to support goal setting and intervention for families and clinicians.

Keywords: Autism Spectrum Disorder, Social Participation, Preschool Children, Classification System

Autism Spectrum Disorder (ASD) is a neurodevelopment disorder, typically diagnosed between three to five years old (Burstyn, Sithole, & Zwaigenbaum, 2010; Ouellette-Kuntz et al., 2014). It is characterized by social difficulties, restricted and repetitive behaviours and interests, and restrictions in several occupational domains of functioning (American Psychiatric Association, 2014). The social difficulties include difficulties in social reciprocity, understanding nonverbal communication, as well as developing and maintaining relationships. In addition, insistence on sameness, repetitive behaviours, sensory sensitivities, and aversion to change can impact participation in life activities, including community or social programs.

The construct of social participation includes individuals' behaviour, social activities, as well as appropriate and sufficient environmental support, to promote inclusion and membership in a community and encourage age-appropriate relationships (Blum, Gutierrez, & Peck, 2015; LaVesser & Berg, 2011). To date, no measurement tool exists to measure the social participation of preschool children with ASD. Social participation is important for preschool children with disabilities, including ASD, as this is an age when foundational social and relationships skills are developed and practiced through naturally occurring social activities (e.g., joint play) to promote social competence in later life (Phillips & Hogan, 2015).

Reviews on the measurement of participation exist; however, current measures may not sufficiently cover the breadth and depth of participation components of particular relevance to ASD, specifically within social dimensions (Chien, Rodger, Copley, & Skorka, 2014; Germani et al., under review). Thus, a measure, such as a classification system exclusively focused on social participation, would assist in highlighting the social dimensions of participation that may be difficult for preschool children. Based on a prior study examining stakeholders' perspectives on social participation in preschool children with ASD, behaviour management, social interactions,

and play abilities (i.e., parallel, cooperative play) were essential to consider (Germani, Zwaigenbaum, Magill-Evans, Hodgetts, & Ball, in press). This provided the foundation for the classification system described herein to be meaningful and relevant to the lived experiences of social participation for stakeholders.

Classification systems parse a heterogeneous population into relatively homogeneous categories by function. They are operationally different from assessments, although both types of measures can provide important and reliable information about a particular child. Classification systems describe the child's typical performance and 'average ability' on any given day. The Gross Motor Function Classification System (GMFCS; Palisano et al., 1997) was the first classification system to provide a common language for gross motor abilities and stratify homogenous groups of children with Cerebral Palsy (CP). Three additional classification systems have since been developed focusing on the central constructs for children with CP: Manual Abilities Classification System (MACS; Eliasson et al., 2006), Communication Function Classification System (CFCS; Hidecker et al., 2011), and Eating and Drinking Abilities Classification System (EDACS; Sellers, Mandy, Pennington, Hankins, & Morris, 2014). These classification systems provide valid and purposeful descriptions of essential areas of functioning.

There is an ASD-specific classification system for social communication, called the Autism Classification System of Functioning: Social Communication (ACSF:SC; DiRezze et al., in press). It classifies preschool children on the basis of their social communication abilities, providing functional descriptions beyond 'low-functioning' or 'high-functioning' to help guide professionals and families in making intervention decisions. A social participation-based classification system would capture another area of essential functioning for children with ASD: the ability to participate in activities across many environments by integrating social skills and

behaviour management coupled with appropriately matched activities and environmental supports. Like social communication, social participation is central to preschool children with ASD, and its classification would assist in describing the functional differences that exist within ASD.

Aims and Rationale

A social participation classification system specific for preschool children with ASD is needed for two reasons: (1) there is potential to identify and classify unique social participation components for these children, and (2) there is a need to succinctly describe the level of support needed to participate in recreational and community activities. Thus, the purpose of the study was to develop a new clinical tool to describe the social participation abilities and required supports for preschool children with ASD, the *Autism Social Participation Classification System* (ASPCS). We report on the refinement of this tool using national stakeholder feedback, as well as demonstrate content validity. Much like the GMFCS provided a validated substitute for vague and value-laden terminology (i.e., mild, moderate, severe) when describing motor function in CP (Palisano et al., 1997), the development of the ASPCS is aimed at reframing ASD measurement with a focus on the ability of preschool children, in order to promote community inclusion.

Methods

Research ethics approval was received from University of Alberta Research Ethics Board. The development of the ASPCS followed the methods of related neurodevelopmental classifications, such as the GMFCS, MACS, CFCS, EDACS and ACSF:SC, using multiphase processes and consultation with stakeholders (DiRezze et al., in press; Eliasson et al., 2006; Hidecker et al., 2011; Palisano et al., 1997; Sellers et al., 2014). We employed a similar strategy to that used for the ASCF:SC in targeting preschool children, allowing for a narrower range of

activities and contexts to be explored and increasing the feasibility of developing a simple classification system.

Phase 1: Initial Development of the ASPCS

Participants

Seven expert participants and one parent were recruited from community service agencies that provided intervention for preschool children with ASD, families actively involved in the research community, and the ASD Edmonton parent online network. Experts were defined as having over seven years of experience working with preschool children with ASD (e.g., speech-language pathologist, occupational therapist, psychologist, child psychiatrist) or having a preschool child with ASD. Participants were screened for comfort working with Microsoft Word, speaking in a group, and communicating by email. All participants identified English as their primary language. Focus groups ran monthly from March 2015 to October 2015, with breaks for summer holidays, and one round of a Delphi survey (see *Phase 2*).

Procedures

The five focus groups held at the Glenrose Rehabilitation Hospital were comprised of the same eight experts with follow-up interviews as needed (n=12) following the iterative process in Figure 5.1. In the first group, the purpose of the study and the model of social participation developed in a prior study (Germani et al., in press) was described. In the second group, experts determined the components of social participation essential for classification by ranking themes from the model of social participation, as well as content from the prior focus group and interviews. In the third group, they provided feedback on the first draft of the ASPCS, and established five preliminary levels for four components of social participation: *behaviour, social desire, facilitator support* and *activities & environment.* In the fourth group, they provided

feedback on the second draft of the ASPCS and rated clarity of ASPCS levels to support refinement. Due to other commitments, one expert withdrew after this group. In the fifth group, experts provided feedback on the third draft of the ASPCS considering the responses of the Round 1 Delphi survey. The expert group also recommended simplification from four components to three by including facilitator support within the remaining components. Thus, ongoing refinement utilized expert perspectives resulting in a classification system based on a refined social participation construct that described three related but distinct components: *Behaviour, Social Desire* and *Activities & Environment.*

Focus group data were collected through audio-recordings that were transcribed verbatim. The research facilitator and research assistant made notes during each session to document the group's progress and to provide an audit trail. When participants were unable to attend meetings, a follow-up interview was arranged. In the interview, the experts were asked the same questions, in the same order as in the focus group. After the expert's initial response, the researcher then shared what the group said for each question, and got the individual's recommendations or thoughts related to the group opinion. Individual opinion did not alter the ASPCS, but provided an opportunity for further discussion in the subsequent focus group meeting.

Phase 2:Refinement of ASPCS and Establishing Content Validity using Delphi Surveys

Participants

In total, 99 participants were recruited online from across Canada by contacting community organizations, professional organizations, and affiliate online community networks[2]. Parents of children younger than 8 years old were invited to participate, as were clinicians (e.g.,

[2] These included Autism Speaks Canada, Speech-Language and Audiologists Canada, Canadian Association of Occupational Therapists and Facebook groups created by community service providers

occupational therapists, speech language pathologists) with at least two years of experience working with preschool children with ASD. As reported in Table 5.1, on average, professionals had over nine years of clinical practice with ASD, well above the minimum set in the inclusion criteria. Participants were offered a chance to participate in a draw for a $25 Amazon.ca electronic gift card in each round of participation (1 in 10 chance of winning), and an additional entry if technical difficulties were encountered and reported.

Data collection

Participants were provided with a brief orientation to the ASPCS and responded to a series of questions in an online survey, hosted by the Research Electronic Data Capture platform (REDCap; Harris et al., 2009). Questions were asked about each level in each component of social participation: *Behaviour*, *Social Desire* and *Activities & Environment*. Sample statements read: "Level 1 description is clinically meaningful" or "The Level 1 description is distinct," similar to the statements circulated in the GMFCS refinement process (Palisano et al., 1997). Using frequency analysis, consensus was defined *a priori* as at least 80% agreement on a Likert scale from 1 (*Strongly Disagree*) to 7 (*Strongly Agree*). Participants were considered to have 'agreed' with the statements if they selected 6 (*Agree*) or 7 (*Strongly Agree*) in response to the question posed. This was a more conservative calculation of agreement than used for the GMFCS, which considered stakeholder agreement on a 7-point Likert Scale to be 5 (*'Somewhat Agree'*) or higher (Palisano et al., 1997). The Dillman method was also used to recruit responses by sending email reminders to facilitate participation in each round (Wortman, Smyth, Langenbrunner, & Yeaton, 1998). Two stakeholders previewed the survey prior to each round to ensure clarity and sensitivity of statements.

Results

The outcome of Phase 1 was the initial development of the ASPCS, using recurring expert focus groups. The fifth focus group used the Round 1 data from Phase 2. Detailed demographic information on the experts is not provided to ensure anonymity.

The outcome of Phase 2 was a refined and validated classification system for social participation for preschool children with ASD. Phase 2 participant demographics are provided in Table 5.1. Three rounds of the Delphi process were required to obtain stakeholder consensus of 80% or more with varying numbers of participants (Round 1: n=38; Round 2: n=72; Round 3: n=41).

Seventy-eight clinicians participated over the three rounds; the two largest professional groups represented were occupational therapists (n=29) and speech language pathologists (n=29). Twenty-one parents also participated. The mean age of the youngest child with ASD of these parents was 4 years 6 months. Of the 41 participants in Round 3, 95% had also participated in Round 1 or 2.

As reported in Table 5.2, consensus was sought on the clinical meaningfulness and distinctness of each level within each component of the ASPCS: *Behaviour, Social Desire,* and *Activities & Environment.* In Round 1, agreement that levels were clinically meaningful ranged from 71.1% to 100%; for levels being distinct, the range was 63.2% to 100%. Four of the 30 ratings did not reach 80% agreement. Based on comments and suggestions from the focus group and from Round 1 participants, changes were made to enhance clarity, and the distinctiveness of levels. In Round 2, 22 of 30 ratings were above 80% with clinically meaningful levels ranging from 75.0% to 91.7% and distinct levels ranging from 70.8% to 91.7%. Further changes were made from Round 2 to further clarify definitions and descriptors within each of the levels. In Round 3, all levels were above 80%.

The ASPCS, shown in Table 5.3, provides the three components of social participation and parses abilities of preschool children within each component. Notably, feedback from parents indicated a preference that levels of ability are ordered from that needing the most support to the least support; which is the opposite of how levels are ordered in most other classification systems. The ASPCS is also consistent with the order for the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)'s level of supports for persons with ASD (American Psychiatric Association, 2014). The frequently used terms and level definitions provided for participants as part of the orientation to the ASPCS are available in Supplement 1.

Discussion

The objective of this study was to develop and refine the ASPCS for preschool children with ASD utilizing stakeholder input and feedback through multiple stages. As with other classification systems, our goal was to create a simple, quick and valid 'snapshot' of a child's abilities and supports/supervision that would be required for them to be successful in social participation. However, social participation is a broad, multidimensional construct and ultimately could not be collapsed into a single domain, in contrast to constructs that have formed the basis of other classification systems. Consistent with the ICF-CY framework, the construct of social participation is an intersection between functional abilities (e.g., behaviours, social desire), various activities, and the environment.

In Phase 1, the multidisciplinary expert groups provided the majority of the direction and decision-making in collapsing themes from previous stakeholders' perspectives on social participation (Germani et al., in press). This was an essential component to the development of the ASPCS, to ensure that domains selected and levels used to parse the heterogeneity of ASD

reflected many years of experience from persons with a variety of theoretical perspectives and professional backgrounds, including a family member.

In Phase 2, there was generally stronger agreement on clinical meaningfulness and distinctness for Levels 1 and 5 on all three components (only exception was Behaviour Level 1 in Round 2). Difficulties in other levels may relate to the challenges that exist in parsing behaviour associated with a multidimensional 'spectrum' disorder such as ASD. The *Behaviour* component had the lowest levels of agreement with four of five rankings below 80% in Rounds 1 and 2 respectively. This may have been because the second round of the Delphi had the largest number of participants and agreement was more difficult to reach. The influx of participants may have been due to temporal factors such as holidays or an increased interest from professional organizations. The addition of new participants in each round has not been shown to significantly alter results and is used to address attrition over time (Sellers et al., 2014). Having more participants also provided more input for revisions prior to Round 3. Using revisions based on stakeholder input, distinct and meaningful levels were achieved in all areas, likely making the ASPCS applicable to more users.

Based on feedback from family participants, the ASPCS was structured and presented as Levels 5 to 1, which is opposite from the presentation of other classification systems, such as the GMFCS (Palisano et al., 1997) and ACSF:SC (DiRezze et al., in press). While maintaining the integrity of the classification methodology and development process, we moved forward with this change based on the preferences of families involved in the research process.

The purpose of developing the ASPCS is to provide a valid and succinct description of abilities for preschool children with ASD to assist with the description of support needs. Thus users of the ASPCS should not refer to children by level of functioning. Rather a family member

or professional might say “To regulate behavior, Sujata needs continuous direct support (80% - 61% of the time) from a familiar and knowledgeable adult in most activities and transitions,” not “Sujata is a Level 4 in Behaviour of the ASPCS.” This is difficult to do in research and written clinical reports, where there is often an emphasis on brevity and quick access to information. However, when communicating orally between clinicians and/or families, it would be most appropriate to use the full description to be clear, and continue to place the emphasis on what the child can do.

Although classification systems have previously been proposed and utilized with varying degrees of success, they focused on the classification of children with ASD by symptom severity (Wing & Gould, 1979) rather than support needs. By classifying social participation around both individual skills (e.g., behaviours and social desire) as well as child support needs (e.g., familiar/unfamiliar activities and environment), we attempted to bridge to the reality of everyday life in the community. In addition, recent changes to the DSM-5 include symptom subscales, similar to a classification system. The subscales parse severity of social communication and restricted, repetitive behaviours (American Psychiatric Association, 2014) using levels developed by expert and working groups as part of updating the criteria for diagnosing ASD. Broader stakeholders have not validated these two subscales and their subsequent three levels. Studies of the DSM-5 to validate the new criterion explored the sensitivity and specificity in comparison to DSM-IV (Frazier et al., 2012; Mandy, Charman, & Skuse, 2012). None explored the severity subscales. Therefore, the development and utilization of the ASPCS may support the classification of participation restrictions in a way that more holistically reflects the challenges that exist in everyday life, relative to ASD symptom measures.

Strengths and Limitations

This study involved stakeholders at each step of the development and refinement process. This created buy-in and increased the likelihood that the tool would have clinical applicability for clinicians and families. However, there was an unequal representation in Phase 1 and Phase 2 of clinicians in comparison to parents of preschool children with ASD for a number of reasons. Childcare was not provided by the study during focus group meetings for Phase 1. The length of the study (March to October 2015) may have been a deterrent. In Phase 2, there may have been limited perceived direct benefit for participation (only entry in a draw compared to the time required to complete the survey). Future studies should consider family-centered research strategies to engage with parents and reduce barriers to participation in-person (e.g., childcare) and online research methodologies.

Future Directions

Future studies should explore inter-and intra-reliability psychometric properties to further validate the ASPCS and provide insights into its application. The ASPCS would also benefit from cross-cultural examination and diverse context settings. Concurrent validity of current subscale classification within the DSM-5, ACSF:SC and ASPCS could show alignment between the constructs of functioning (i.e., social communication), participation (i.e., social participation), and DSM-5 symptom severity. Although previous classification systems such as the GMFCS (Palisano et al., 1997) have been static over time, the same principle may not apply in ASD, given the dynamic features of social participation.

Conclusion

A social participation classification system provides a valid, succinct, ability-focused description of how a child can socially participate in activities across different settings, such as inclusive community programs or preschool settings. This allows for the promotion of child

abilities with environmental and caregiver supports. In the field of ASD, there has been much attention to ASD symptomology and less attention to the abilities and facilitators of social participation to improve day-to-day life activities. Understanding how children socially participate, and at what classification level, is important when considering higher-level treatment outcomes that target inclusion or community belonging, and may also allow for a better matching of support needs. This study reports the development and initial validity of such a social participation classification system.

Figure 5.1. Iterative Process of Development, Refinement and Content Validity for the Autism Social Participation Classification System

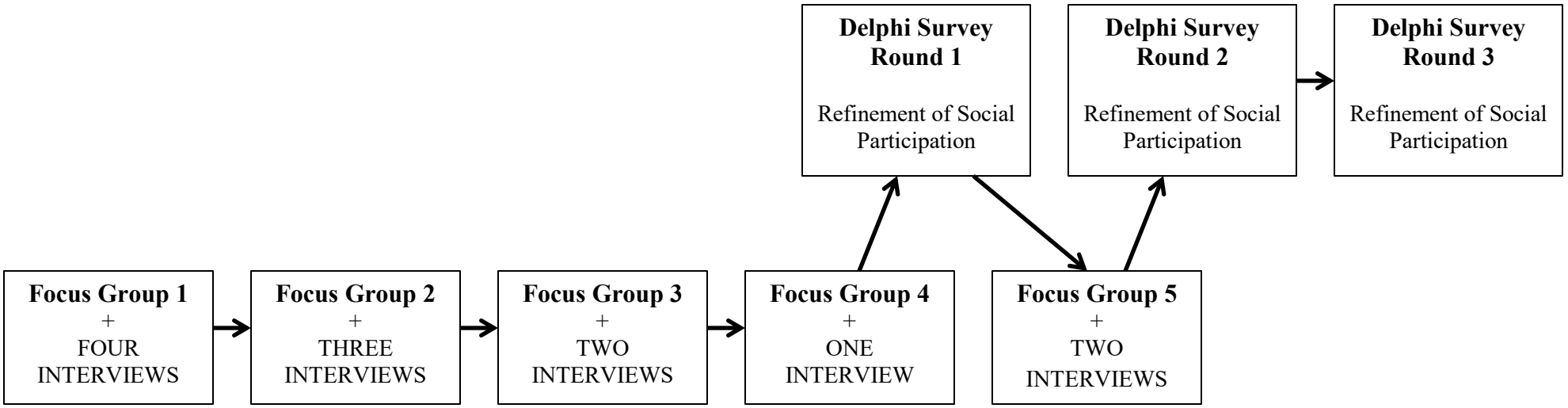


Table 5.1. Characteristics of participants in Delphi Survey

Parent Characteristics:					
		Round 1 (n=5)	Round 2 (n= 20)	Round 3 (n= 11)	Total[2] (n=21)
Total number of children at home	Mode (range)	2, 3 (1-3)	1 (1-3)	2 (1-3)	1, 2 (1-3)
Age of youngest child with ASD in years	Mean (SD)	3.4 (0.89)	4.5 (1.15)	4.0 (1.48)	4.48 (1.12)
	Range	2-4	2-7	1-6	1-7
Participated in Previous Round (#)		N/A	4	11	N/A
Professional Characteristics					
		Round 1 (n=33)	Round 2 (n=52)	Round 3 (n= 30)	Total[2] (n=78)
Years of practice with ASD	Mean (SD)	7.35 (5.18)**	10.77 (7.13)	11.08 (8.01)	9.84 (6.90)**
Occupational Therapist		7	21	8	29
Speech-Language Pathologist		7	25	17	29
Psychologist		4	2	1	4
Developmental Pediatrician		1	0	0	1
Non-Regulated Professional[1]		14	4	4	15
Participated in Previous Round (#)		N/A	9	28	N/A

[1]Included rehab assistants, interventionists, aides, psychometrists, & behaviour therapists
[2] The number of different participants across all three rounds in this category

* = *one missing response*
** = *two missing responses*

Table 5.2. Participant Consensus by Round

	Round 1 (n=38)		Round 2 (n=72)		Round 3 (n=41)	
	Clinically Meaningful	Distinct	Clinically Meaningful	Distinct	Clinically Meaningful	Distinct
Behaviour						
Level 5	94.7%	86.8%	83.3%	80.6%	95.1%	87.8%
Level 4	76.3%	68.4%	88.9%	79.2%	87.8%	85.4%
Level 3	71.1%	63.2%	80.3%*	75.0%	85.4%	82.9%
Level 2	84.2%	81.6%	78.9%*	70.8%	87.8%	85.4%
Level 1	84.2%	86.5%*	81.7%*	77.5%*	95.1%	92.7%
Social Desire						
Level 5	100.0%	92.1%	86.1%	84.7%	95.1%	92.7%
Level 4	97.4%	92.1%	84.7%	81.9%	97.6%	95.1%
Level 3	89.5%	86.8%	83.3%	81.9%	92.7%	90.2%
Level 2	86.8%	86.8%	75.0%	76.4%	87.8%	85.4%
Level 1	94.7%%	89.5%	86.1%	91.7%	87.8%	85.4%
Activities & Environment						
Level 5	100.0%	100.0%	91.7%	84.5%*	92.7%	85.4%
Level 4	92.1%	89.5%	88.9%	80.6%	87.8%	80.5%
Level 3	94.7%	92.1%	85.7%**	79.2%	92.7%	82.9%
Level 2	92.1%	86.8%	87.5%	83.3%	92.7%	90.2%
Level 1	97.4%	94.6%*	91.7%	87.5%	87.8%	90.0%*

*N.B. Shaded areas represent 80% agreement not reached; *missing one participant response; **missing two participants responses*

Table 5.3. The Autism Social Participation Classification System

	BEHAVIOUR	SOCIAL DESIRE	ACTIVITIES & ENVIRONMENT
Level 5	Child needs substantial direct support (100% - 81% of the time) from at least one familiar and knowledgeable adult to regulate behaviour in all activities and transitions.	Child does not indicate desire to interact with others and does not appear to notice others in the environment; even for the purposes of having needs met or related to preferred interests.	Child needs substantial support to complete familiar and unfamiliar activities across all environments.
Level 4	Child needs continuous direct support (80% - 61% of the time) to regulate behaviour from a familiar and knowledgeable adult in most activities and transitions.	Child does not indicate desire to interact with peers or adults in the environment; except for the purpose of having basic needs met.	Child needs continuous support to complete unfamiliar activities in all environments. Child needs a moderate amount of support to complete familiar activities in a familiar environment.
Level 3	Child needs some direct support (60% - 41% of the time) to regulate behaviour from a familiar and knowledgeable adult; such as transitioning between activities or waiting for highly preferred interests.	Child demonstrates some interest and desire to participate with peers (such as observing from a distance); however, social overtures (although they may appear odd or of poor quality) are typically made towards adults in the environment.	Child needs a moderate amount of support to complete unfamiliar activities in all environments. Usually, child can complete familiar activities in familiar environments with indirect support (supervision).
Level 2	Child initially needs intermittent, direct support (40% - 21% of the time) to regulate behaviour, but can readily adapt to behavioural expectations, needing indirect support (supervision) from knowledgeable adults.	Child demonstrates interest and desire to participate with peers, and directs equal amounts of social overtures towards adults and peers (although they may appear odd or of poor quality), typically related to preferred interests.	Child needs intermittent support to complete unfamiliar activities in unfamiliar environments. Child can complete familiar activities in familiar or unfamiliar environments with indirect support (supervision)

Level 1	Child is able to regulate behaviour with minimal direct support (20% or less of the time) or only indirect support (supervision) from knowledgeable adults.	Child usually has a desire for social interactions and demonstrates social overtures to peers and adults (although they may appear odd or of poor quality) that do not need to be directly related to preferred interests.	Child can complete familiar and unfamiliar activities in familiar and unfamiliar environments with indirect support (supervison).

Acknowledgements.

The study authors thank all families, clinicians and educators who participated and provided invaluable insights and contributions at the various stages of the study. Technical support for REDCap was provided by the Women & Children's Research Institute's clinical informatics team, including Pamela Marples, Rick Watts and Shana Rimmer. Funding for the study was graciously provided by the Autism Society of Edmonton Area & Autism Research Centre Graduate Student Pilot Grant, and Glenrose Rehabilitation Hospital Foundation Clinical Seed Grant. TG was supported by the Women & Children's Research Institute Graduate Studentship, Alberta Innovates-Health Solutions Clinician Fellowship and Canadian Child Health Clinician Scientist Program Career Enhancement Program Award. SH was supported by an Alberta Centre for Child, Family and Community Research (ACCFCR) Early Career Transition award. LZ was supported by the Stollery Children's Hospital Foundation Chair in Autism Research. The authors also acknowledge the members of the study team, Olivia Conlon and Shayla Richards, who provided administrative assistance and recruitment support.

Chapter 5 References.

American Psychiatric Association. (2014). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5)*. Washington, DC: American Psychiatric Association.

Blum, G. I., Gutierrez, M., & Peck, C. (2015). Beyond Access: Moving toward Increased Participation, Membership, and Skills in the Inclusive Classroom *Including Learners with Low-Incidence Disabilities* (pp. 13-36): Emerald Group Publishing.

Burstyn, I., Sithole, F., & Zwaigenbaum, L. (2010). Autism spectrum disorders, maternal characteristics and obstetric complications among singletons born in Alberta, Canada. *Chronic Diseases in Canada, 30*(4), 125-134.

Chien, C. W., Rodger, S., Copley, J., & Skorka, K. (2014). Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health–Children and Youth. *Archives of Physical Medicine and Rehabilitation, 95*(1), 141-152.

DiRezze, B., Rosenbaum, P., Zwaigenbaum, L., Cooley-Hidecker, M. J., Stratford, P., Cousins, M., . . . Law, M. (in press). Developing a classification system of social communication functioning of preschool children with autism spectrum disorder. *Developmental Medicine and Child Neurology*.

Eliasson, A.C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A.-M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology, 48*(7), 549-554.

Frazier, T. W., Youngstrom, E. A., Speer, L., Embacher, R., Law, P., Constantino, J., . . . Eng, C. (2012). Validation of proposed DSM-5 criteria for autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51(1*), 28-40.

Germani, T., Magill-Evans, J., Zwaigenbaum, L., Sacrey, L. A. R., Askari, S., & Anaby, D. (under review). Participation measures for preschool children with Autism Spectrum Disorder: A scoping review. *Review Journal of Autism and Developmental Disabilities*.

Germani, T., Zwaigenbaum, L., Magill-Evans, J., Hodgetts, S., & Ball, G. D. (in press). Stakeholder perspectives on social participation in preschool children with ASD. *Developmental Neurorehabilation*.

Hidecker, M. J. C., Paneth, N., Rosenbaum, P. L., Kent, R. D., Lillie, J., Eulenberg, J. B., . . . Evatt, M. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology, 53*(8), 704-710.

LaVesser, P., & Berg, C. (2011). Participation patterns in preschool children with an autism spectrum disorder. *OTJR: Occupation, Participation and Health, 31*(1), 33.

Mandy, W. P., Charman, T., & Skuse, D. H. (2012). Testing the construct validity of proposed criteria for DSM-5 autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(1), 41-50.

Ouellette-Kuntz, H., Coo, H., Lam, M., Breitenbach, M. M., Hennessey, P. E., Jackman, P. D., … . Chung, A. M. (2014). The changing prevalence of autism in three regions of Canada. *Journal of Autism and Developmental Disorders, 44*(1), 120-136.

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*(4), 214-223.

Phillips, R., & Hogan, A. (2015). Recreational participation and the development of social competence in preschool aged children with disabilities: a cross-sectional study. *Disability and Rehabilitation, 37*(11), 981-989.

Sellers, D., Mandy, A., Pennington, L., Hankins, M., & Morris, C. (2014). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine & Child Neurology, 56*(3), 245-251.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*(1), 11-29.

Wortman, P. M., Smyth, J. M., Langenbrunner, J. C., & Yeaton, W. H. (1998). Consensus among experts and research synthesis: a comparison of methods. *International Journal of Technology Assessment in Health Care, 14*(1), 109-122.

Supplemental 5.1. Frequently Used Terms (Part A) and Description of Support by Levels (Part B)

FREQUENTLY USED TERMS (Part A)

Behaviour: Observable actions by a preschool child with ASD that may communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a preschool child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the preschool child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Preschool Children with Autism Spectrum Disorder (ASD): Preschool children with ASD typically between their 3rd and 5th birthdays, are often engaged in school readiness activities, such as attending a play group, preschool, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a preschool child with ASD. This may include visual monitoring of interactions between peers, conversation support, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all preschool children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for preschool children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

DESCRIPTION OF LEVELS (Part B)

There are five levels in the ASPCS that are distinguished by the child's abilities and amount of facilitator effort needed to engage in social participation, with Level 5 requiring the most support and Level 1 requiring the least support.

Level 5 describes '**Substantial**' support - The preschool child needs direct support from a 1:1 facilitator to succeed. This will take all of the facilitators' energy and effort, including hand over hand support for the majority of activities. A second facilitator will likely be needed to guide the activity.

Level 4 describes '**Continuous**' support - The child needs direct support from a 1:1 facilitator and will require most of the facilitators energy and effort. The facilitator may be able to engage in some parts of the activity in side-by-side play to provide prompts, but new and/or challenging activities will require some hand over hand assistance.

Level 3 describes **'Some or Moderate**' support - The child needs direct support from a facilitator in a 1:2 or 1:3 ratio, and requires more energy and effort on the part of the facilitator to succeed by providing prompts, verbal scripts, reassurance, and/or support.

Level 2 describes '**Intermittent**' support - The child initially needs higher levels of energy and effort from a facilitator and direct support (1:2 or 1:3 ratios) in a new program, similar to Level 3. The child could also be described as 'slow to warm up' to activities, environments, or persons but becomes successful over time in ratios that already exist within integrated programs, as described in Level 1 below.

Level 1 describes **'Supervision or Indirect Support**' support - The child can succeed at existing facilitator energy and effort levels and ratios (1:5 or 1:6) within integrated preschool programs.

Chapter 6: Discussion and Implications

This chapter reflects on the prior chapters and reviews the importance of social participation and what has been learned about the construct as it applies to preschool children with ASD over the course of three studies. It also explores the relationship of the ASPCS to other classification systems and taxonomies such as the International Classification of Functioning, Health and Disability – Child and Youth version (ICF-CY; World Health Organization [WHO], 2007) and Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; American Psychiatric Association [APA], 2014), and potential clinical implications of the results. Lastly, this chapter discusses lessons learned from conducting the studies, acknowledges their limitations, and sets out future directions.

The focus of this thesis is on social participation and its classification in preschool children with ASD. Each chapter built towards the development of the classification system, demonstrating the progression from a gap in the literature to the refinement of a construct from stakeholders' perspectives. In Chapter 3, the review of participation measures demonstrated the lack of attention to the social elements of participation, later referred to as social participation. This limited attention to social participation is particularly important for those with the specific diagnosis of ASD. Chapter 4 summarized stakeholder perspectives on social participation in preschool children with ASD, as elicited in a mixed methods web-based survey. This strategy ensured the relevancy and meaningfulness of social participation as a construct to both professionals and those stakeholders living with ASD. Chapter 5 summarized findings from the development of the *Autism Social Participation Classification System* (ASPCS) for preschool children with ASD, aimed at supporting communication between families and professionals regarding the strengths and abilities of a child when preparing them for inclusion in community

activities and settings. The ASPCS also assists in parsing the heterogeneity of ASD in a participation or 'real-world' manner. By including families and professionals at various stages of this thesis, including development and implementation, the findings presented are more likely to be applicable and relevant to end users. As discussed by Graham (2012), patient oriented research lays a strong basis for clinical applicability and meaningful future research.

6.1. Why Social Participation is Important.

Social participation matters to the day-to-day lives of preschool children and their families. Not only does it have long-term positive effects for individuals with ASD transitioning into adulthood (Myers, Davis, Stobbe, & Bjornson, 2015; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013) but it also is a tangible way to ensure that the intervention a child and their family receives (such as behaviour management or social skills) and the level of support (e.g., provision of an aide) are intersecting to create meaningful and enjoyable opportunities to develop a sense of belonging within the community.

As part of social development, social participation gives naturalistic opportunities for practicing social skills for all children regardless of ability or disability. As a group, preschool children with ASD may need a great deal of practice to develop social skills. Developing difficult-to-acquire skills through constant practice even if done in an indirect playful manner is challenging and tiring. Social participation 'practice' needs to genuinely incorporate the strengths and motivations of the child so it is a positive experience that supports their emotional and cognitive development.

Preschool children with ASD have demonstrated differences in respect to social participation compared to their typically developing peers (Chang, Shih, & Kasari, 2015; Restall & Magill-Evans, 1994). However, there were no differences reported in their use of materials or

moving about the space. This indicates that the 'doing with' similar age peers in inclusive settings may be an essential component to how preschool children with ASD build friendships, with the support of knowledgeable adults (Sainato, Morrison, Jung, Axe, & Nixon, 2015; Wolfberg, DeWitt, Young, & Nguyen, 2014). Simply being in the same space as similar age peers isn't sufficient to create relationships or for social participation to occur.

6.2. What Has Been Learned Over the Course of the Three Studies

A social participation classification system, such as the ASPCS, provides a valid, simple, strengths-based description of how a child can socially participate in activities across different settings, such as in community recreational programs or at preschool. This allows for the promotion of the child's abilities without the provision of unnecessary assistance, which is particularly important for developmentally appropriate capacity building in preschool children. Based on the multi-stakeholder perspectives presented in Chapter 4 and expert groups presented in Chapter 5, the essential components of social participation for preschool children with ASD were *Behaviour Management*, *Social Desire*, and *Activities & Environment.* Chapter 4 utilized stakeholders' perspectives to determine the essential components from a national sample, and reported facilitators and barriers. These perspectives provided the initial refinement of the construct to ensure it was meaningful and relevant to our population. Chapter 5 further refined the essential elements for classification, and the subsequent Delphi process of national stakeholders supported the clarification, definitions and language of the ASPCS levels.

Behaviour was identified as a central component of the construct social participation for preschool children with ASD. Behaviour that is disruptive or challenging can be viewed as non-cooperative, and preschool children who display these behaviours are more likely to be rejected by peers (Aeri & Verma, 2004). This has several implications for social participation

opportunities in preschool or community settings. If a peer witnesses a child with ASD having challenging behaviours, it may be difficult to change their attitude or belief about that particular child, especially if they are withdrawn from the classroom for behavioural management or social skills practice. There is a need for the facilitator or educator to work on re-transitioning the preschool child with ASD into the classroom and promoting friendship between peers. Educators also need additional support to provide friendship facilitation, as they are more likely to provide behaviour management strategies than use strategies to promote friendship (Chang et al., 2015). Extending beyond peer relationships, there may also be additional stigma by families or parents, who may not want their child to play with a child who displays challenging behaviours. This may result in a preschool child with ASD being less likely to be invited to special events, such as birthday parties. Thus, early social competence includes behaviour management as an essential component of building peer-to-peer opportunities for social participation (Alessandri, 1992; Bennett et al., 2014).

Another essential component of the construct social participation identified by stakeholders was social desire. As acknowledged by Zwaigenbaum (2001), preschool children with ASD may want to participate with peers but not have the skills or know how to enter the play scenario. This speaks to the internal conflict a preschool child with ASD may experience of wanting to be involved in peer play, but not knowing how. Some children may learn social skills in a particular setting, but are unable to practically apply (or generalize) these skills to other contexts. There may be a role for adult facilitators in the child's environment to assist or support setting-up social participation opportunities to manage these challenges. It also validates how individuals (i.e., educators, parents, peers) around the child heavily influence their social experiences (Baker & Donelly, 2001). Play is an important social activity that occupies a

significant portion of a preschool child's day. As demonstrated by Chang et al. (2015), friendships are important for preschool children with ASD, because these relationships provide opportunities for social participation in free or joint play. Thus, there is a need to work with adults in community settings to promote acceptance of children's differences and build peer friendships as part of targeting social participation (Baker & Donelly, 2001).

The remaining essential component of the construct of social participation was activities and the environment. Previous literature discusses social participation as occurring within the community, which was consistent with the examples stakeholders provided in Chapter 4 (Coster & Khetani, 2008; Koster, Pijl, Nakken, & Van Houten, 2010). Novelty of the activity or environment was reported to be particularly challenging by stakeholders and required a different level of support. The child's preference for activities, regardless of whether they are spontaneous or structured, can contribute positively to their quality of life, and may require environmental adaption to partake in the activity (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012). In our studies, preferences were typically characterized as restricted interests or activities that interfered with engaging in social participation with peers, but this may not always be true. Although stakeholders and experts spontaneously discussed social participation in community programs or preschool settings, a few reported examples focused on the home environment as an opportunity for social participation. The home environment is a common place for preschool children and where socialization starts through play, as the first activity for socialization (Aeri & Verma, 2004). Our studies did not directly explore social participation in the home, or with similar aged siblings or family members, but undoubtedly social participation could and does occur within these relationships and contexts. In fact, siblings and families in the home may be most likely to

provide positive social participation experiences and opportunities given the strong relationships within a very familiar environment.

The ASPCS may be a helpful tool in communicating what abilities a child does have and supports a child needs for social participation to occur with peers in play activities. For example, a preschool child with ASD may be classified as: *Behaviour – Level 5, Social Desire – Level 3, and Activities & Environment – Level 4.* This would allow a community program organizer to accurately plan for the preschool child to have access to a 1:1 adult facilitator, in addition to the adult leading the program. Parents could further share their rationale for the classification of the ASPCS as part of the intake interview in a way that discusses the child's strengths and limitations. The preschool child was reported as *Behaviour – Level 5,* requiring a constant 1:1 adult facilitator because they become easily frustrated and overwhelmed. However, the same child was reported as *Social Desire – Level 3* because the child was observed to have some social desire, often noticing other peers but appearing unsure of how to approach these peers. Considering the parents' experiences in trialing new activities in new environments, the child was reported as *Activities & Environment – Level 4,* as the child was typically successful with familiar activities in familiar environments, which may be going to the bathroom (a familiar activity) at a particular community centre (that the family frequently visits) with only moderate support. Although the ASPCS does not provide the rationale for *why* a behaviour is occurring or what intervention program may be best for the child and their family; it does provide a clear description of the amount of support needed and provides a strengths-based description of a current child's abilities.

6.3. ASPCS and other classification systems

Previous classification systems in neurodevelopmental disabilities have been one dimensional and focused on the functional abilities of children with CP or ASD. The ASPCS classification system has multiple components (i.e., dimensions) and focuses on participation and the level of support needed. Although the use of multiple components may add complexity to the use of the ASPCS, it may better reflect the multiple aspects of social participation that can influence a preschool child's success in being involved with peers. With five levels of three factors, there are potentially 125 unique combinations or 'profiles' that are available for preschool children with ASD. This likely reflects the complexity of the broader spectrum/ phenotype of ASD, but creates challenges in how best to succinctly communicate using a validated classification system. Future inquiry into how to best manage the 125 unique profiles, or if there are frequent combinations of levels that occur together across ASPCS components, is needed to guide utilization and uptake into practice.

Language in relationship to the social participation of preschool children with ASD was not explored in our study, although it can play an important role in the development of a child's social skills. The Autism Classification System of Functioning: Social Communication (ACSF:SC; Di Rezze et al., in press) focuses on parsing a preschool child's abilities on the basis of social communication. The constructs of social participation and social communication are related to each other in that both focus on the social elements or aspects that include others in the environment. They differ in that social participation focuses on doing an activity and social communication focuses on having an exchange of ideas. Both constructs involve another person (to do the activity with or exchange ideas with), and could have similar goals in promoting a child's development (i.e., building relationships, becoming a part of a classroom community).

However, the construct of social communication may not consider behaviour, social desire or activities and environment as essential components, although they may be peripherally considered as facilitators. The construct of social communications typically focuses on the essential components of the exchange (i.e., receptive and expressive) between two individuals, while social participation focuses on the doing together or with two or more individuals. These subtle differences are important when considering whether the primary concern or stratification of abilities needs to be done by the ACSF:SC or ASPCS to reflect a preschool child's social communication (i.e., exchange with another individual) or social participation (i.e., doing with another individual). How ACSF:SC and ASPCS can work together to provide a global picture has yet to be determined. In CP, the use of multiple classification systems has been dealt with by using the classification system that closely matches the construct under consideration. For ASD, a similar approach may be used. For example, if stakeholders are reporting the social communication abilities of a child, then the ACSF:SC would be most appropriate or social participation (e.g., in play groups) would use the ASPCS. However, further inquiry could explore the discriminant validity of these classification systems and their combined utility in clinical practice.

A recent systematic review demonstrated the comprehensiveness of the ICF-CY in describing persons with ASD (including preschool children) and supported further efforts to apply a universal taxonomy to frame research focused on the day-to-day lived experiences of ASD (de Schipper et al., 2015). The ICF-CY as a taxonomy can identify both abilities and restrictions, depending on the supports in place or restrictions for an individual within a particular environment. For example, at home, a parent may provide warnings for transitions and reduce sensory stimuli when completing a joint activity to ensure successful social participation

between siblings. However, at preschool or in the community, an adult facilitator may not be as knowledgeable about the specific supports the preschool child with ASD needs in order to have a successful experience with a peer. Thus, the child may be restricted from participating due to lack of facilitator support and environmental management of sensory stimuli. The systematic review found that the most frequently identified ICF-CY categories of challenges for individuals with ASD related to everyday experiences were (i) *basic interpersonal interactions*, (2) *emotional functions*, (3) *complex interpersonal interactions*, (4) *attention functions*, and (5) *mental functions of language*. These ICF-CY categories reflect the cognitive, communication and social difficulties that are central to the diagnosis of ASD, as well as the manifestation of challenges in everyday life that intersect with the individual's abilities and environment that can create profound restrictions for participation in community or social activities. Although this is a different focus from the studies in this thesis, the results of this study are complementary. The construct of social participation focused on the importance of behaviour as essential, which may be related to emotional or attention functions. As well, emphasis was placed for social participation relating to (i.e., social desire) or doing with others in activities, which may be related to basic and/or complex interpersonal interactions. The remaining ICF-CY category of mental functions of language most likely best relates to the ACSF:SC which focuses on social communication.

Similar to the study in Chapter 4, interdisciplinary experts in ASD participated in an online survey utilizing the taxonomy of the ICF-CY to describe everyday function and participation engagement (de Schipper et al., 2016). The purpose of that study was to validate findings from the literature review using the same ICF-CY taxonomy. Experts agreed that the impact of ASD extended beyond core symptoms of ASD (i.e., social communication difficulties,

and repetitive, restricted interests) into areas of everyday functioning and participation engagement. The majority of ICF-CY categories used by experts to describe functional restrictions experienced by individuals with ASD were categorized in the *Activities & Participation* domain. This validates that restrictions or limitations of an individual with ASD when participating in activities (e.g., social, community) have considerable impact on their daily lives. Thus, the ICF-CY domain, *Activities & Participation,* plays a central role in the ability of individuals with ASD (and potentially their families) to live full and meaningful lives in the community. This directly relates to social participation of preschool children with ASD who may want to play with others or have friendships, but do not have the knowledge of how, or be able to apply their social skills appropriately in joint activities.

The above studies highlight the value of utilizing a global, biopsychosocial taxonomy to describe (and later classify) social participation abilities of preschool children with ASD to accurately capture its many components. Despite the many benefits of using the ICF-CY in refining the construct of social participation, challenges existed in how best to categorize or describe umbrella terms such as behaviours. For example, behaviours such as screaming or anxiety would be under the ICF-CY domain of *Body Structure;* however, other behaviours, such as running or bolting, would be under the ICF-CY domain of *Activities & Participation.* These subtle nuances in the language used to describe various types of behaviours required careful reading, reflecting and frequent reference to the ICF-CY taxonomy, making it less intuitive to use as a framework. Despite these issues in using the ICF-CY to capture behaviours essential to social participation, the benefits outweighed challenges encountered as it is a comprehensive, biopsychosocial framework with a considerable emphasis on the role of a particular health

condition (i.e., ASD) in facilitating or limiting an individual's *Activities & Participation* in a particular environmental (i.e., community) context.

6.4. Clinical Implications

The three studies comprising this thesis have all previously addressed their respective clinical implications. To summarize, Chapter 3 identified four participation measures available for clinical use that had been developed using a sample including preschool children with ASD. Additional diagnosis specific considerations, such as acceptance of novelty, or capacity of personnel to manage behaviours may need to be captured to generate a holistic picture of restrictions or facilitators to social participation that exist. Chapter 4 supported the refinement of the construct of social participation using stakeholders' perspectives. This refined construct provides a meaningful representation of the construct social participation based on stakeholders' experiences to support the conceptual basis of the ASPCS. Chapter 5 provided a newly developed tool to classify social participation, the ASPCS. When classifying multi-component constructs, such as social participation, there is a need to consider what are the most essential components based on expert opinion. The complexity of applying a multi-component classification system has yet to be explored. The trade-off for the added complexity of the ASPCS may result in further clarification or collapsing when applied and trialed within a clinical setting. In addition, there is a need to ensure that the five levels provided within each component are clinically meaningful and distinct using broad stakeholder consensus. At the present time, the ASPCS is not ready for use within the clinical community until additional psychometrics properties are established (as described later).

Understanding how children participate, and at what classification level, is important when measuring higher-level treatment outcomes. Social contexts such as community recreation

programs and preschool classrooms are valuable settings to support child development (Blum, Gutierrez, & Peck, 2015). The findings of this research program have implications for how health care professionals and early educators intervene and promote social participation for young children with ASD. As described above (and discussed in detail in Chapter 4), the refinement of social participation supports professionals working in partnership with families to develop, support and increase social participation in the community. As part of measuring participation, behaviour, environmental demands, peer relationships and activities need to be explored individually and targeted holistically as well as considering the intersection of these areas in order to create meaningful change (see Chapter 5 for further details).

The development of the ASPCS using expert and stakeholder input supports the shift in the field of ASD to focus on the child's strengths and abilities as measured in broad, real-life outcomes. Although the focus of goal setting in clinical practice is often on a specific behaviour or task, there is room for a broader perspective in measuring social participation. Skill acquisition or mastery, such as donning a shirt or holding a pencil, should not be the only outcome worth measuring in a child's intervention program, but also their integration and membership within their peer community (Blum et al., 2015). Until such measures become available, it may be fruitful to use a triad or combination of measures, including those reviewed in Chapter 3, to attempt to measure the components of social participation in clinical practice. Additional measures may include a behavioural assessment (to measure challenging behaviour), and engagement or friendship assessments (as a potential proxy assessment for community belonging). After further validation of the ASPCS, this tool could be used in clinical practice to enhance communication between professionals and/or families about the abilities of a child to participate in social activities, with the appropriate amount of facilitator support.

6.5. Challenges with Online Recruitment & Family Engagement

Several challenges were encountered during this study that related to online recruitment of participants and data collection. In the study of stakeholder perspectives, presented in Chapter 4, the integrity of the data was a concern in the early stages when several responses were identified as fraudulent and misrepresenting family perspectives. Offering direct compensation was believed to have created an incentive for fraudulent responses, which then needed to be addressed. Once the fraudulent responses were identified, incentives were altered for subsequent participants in the surveys, which had an impact on the speed at which responses were collected but significantly reduced incomplete and fraudulent responses.

Recruiting families of preschool children with ASD was challenging throughout the study, particularly parents to participate as experts in focus groups, in comparison to other types of participants. Given that preschool children with ASD are primarily diagnosed in Canada within the preschool age (typically 3-5 years, with the average at 4 years), this may be a particularly turbulent period for families having received a diagnosis and in the process of coordinating services. Research needs to be perceived as directly meaningful and/or beneficial to the family and/or their preschool child. Involvement of parents in the development of the ASPCS provided no direct benefit to the families involved as experts or stakeholders. The recruitment of professionals for the group of experts and stakeholders may have been easier, as the doctoral student was an 'insider' to this group, and could often leverage several professional networks and associations. In addition, professionals often had the support of their workplace to be involved in the studies, and perceived a certain value to being involved in research.

6.6. Limitations

As previously reported, there were several limitations of each study in this thesis. Limitations of the scoping review (Chapter 3) were related to rigour, a potential for bias, and no formal quality assessment. These were inherent limitations due to the review methodology selected in providing a preliminary appraisal of the literature. The study in Chapter 4 was limited by the lack of a comprehensive picture of the cognitive, communication or functional abilities of participants' children. These areas may have implications for the parents' experiences of social participation; however, given the online research methodology utilized, it was not feasible to collect or verify these data. Further differences may exist between parents and professionals given the unique lens each type of stakeholders brings to components of the construct. Further research could explore why these differences may exist between stakeholders, as well as consider including adults with ASD as an additional stakeholder group. In addition, participants were not asked to report ethnicity or cultural backgrounds, which may influence the selection of activities for social participation opportunities. The limitations of Chapter 5 include an unequal (i.e., low) representation of parent participants as experts and stakeholders compared to professionals in the development and refinement of the ASPCS. This may have been due to the length of commitment for the study, as well as practical issues, such as childcare.

In addition to those limitations identified above, there were several overarching limitations to this research program. First, rigorous research methodologies and networks need to be created and maintained as technology and the World Wide Web continue to play a more central role in the lives of individuals with ASD and their families, There is a need for mechanisms to ensure that the data collected is reliable and trustworthy while utilizing various Internet platforms, as they become more freely available. Participants may benefit from the

anonymity of online participation but there are risks for data integrity. It was hoped that by targeting only those accessing ASD networks or communities, participants were truly family members of preschool children with ASD or professionals working with these children. Second, the socio-economic status (SES) of participants remained unknown, which may itself be a limiting factor for opportunities for social participation. It is likely that those with more education and with a higher SES would have more likely participated in the studies, as they would have had the resources (such as flexibility, time and confidence) to participate in person or online. Third, this program of research was limited to English-speaking participants, and the cultural backgrounds and gender of the participants remains unknown. It is plausible that providing additional resources to conduct this program in a variety of languages, as well as specifically sampling for variation in cultural diversity would enhance the cultural representativeness of this construct and the ASPCS. Fourth, the inherent bias of the doctoral student responsible for the design and implementation of this research program may have influenced the study results. As a registered occupational therapist who works with families and preschool children with ASD, there may be a professional and theoretical lens that influenced the results of the project. The networks available to the doctoral student at the start of the research program, namely Canadian Association of Occupational Therapists, may have strongly influenced the results of the Chapter 4, as occupational therapists were the largest respondent group. Lastly, based on the communications with stakeholders during recruitment, it is anticipated that the majority of respondents were mothers or female professionals. This may limit perspectives due to having primarily mothers provide observations, and influence the selection of activities for social participation.

6.7. Future Directions & Conclusion

The overall aim of this research was to refine the construct of social participation and to develop a classification system of social participation abilities and the supports needed to be successful for preschool children with ASD. The aim of the scoping review (Chapter 3) was to review available participation measures for use with preschool children with ASD. The aim of the mixed methods study (Chapter 4) was to refine and determine the essential components of social participation using stakeholders' perspectives. This ensured the construct was meaningful and representative of their day-to-day experiences. The aim of the multiple methods study (Chapter 5) was to develop and refine the ASPCS, using expert groups and stakeholder feedback. The final outcome of this research project is a newly developed classification system to parse social participation abilities for preschool children with ASD, but it also confirmed that stakeholder input and perspective are an incredibly valuable resource in research. Without the insights shared by clinicians, educators and parents, much of this project would not have been possible. By involving stakeholders at multiple phases (i.e., those who are the ultimate end users of this research) the results may be more applicable and useful in planning community or recreational program transitions.

Future directions for the stakeholders' perspectives on social participation for preschool children with ASD could include: (1) a diverse sampling of multicultural backgrounds, (2) adults with ASD, and (3) preschool children with ASD. To include multicultural participants, purposeful sampling could be used while stratifying for maximum variation of cultural and ethnic backgrounds of parents and family members of preschool children with ASD (Palinkas et al., 2015). Although alternative strategies for recruitment of visible minorities would be required, as well as additional research support (e.g., translators) for those families with English as a

second language, the additional perspectives would allow for a rich cultural diversity. A lack of ethnic diversity in ASD research remains an ongoing issue and priority for the field (Pierce et al., 2014). This would likely be more reflective of the diversity present in Canada.

To include adults with ASD, orientation to the goals of the project and reflexivity practices would be required to control for a recency effect that has potential to occur. It would be essential to have adults with ASD to reflect and comment on their early social participation; rather than their most recent experiences with social participation as an adult with ASD. The perspectives gained from adults with ASD would provide reflections as part of a larger life continuum, which may be more meaningful in considering how the construct of social participation evolves over time.

To include preschool children with ASD, methods similar to those used by Singh (2013) could be implemented. Children could be prompted to start discussions on social participation using a mixture of semi-structured and structured questions, standardized pictures, arts (e.g., drawing), and storytelling. Using this mixed arts and activity-based methodology, children are prompted to discuss a particular topic (i.e., social participation), while maintaining fluidity and flexibility in eliciting a variety of answers from participants (Singh, 2013).

Future directions for the development of the ASPCS include establishing inter- and intra-rater reliability for professionals and/or families. Although content validity is essential for determining that the measure is indeed measuring what it is intended to measure, reliability is important for ensuring that the construct is measured consistently across individuals and time points. Additionally, future programs of research in social participation should pay attention to different socio-economic and cultural differences to address the aforementioned limitations. The cultural influence of social participation and expectations of children during social interactions

may also be a critical environmental factor to explore. For example, stakeholders with strong extended family social ties may experience social participation that only revolves around family and cultural community events or families with certain cultural values may primarily select academically based play activities.

The growing emphases of Canadian Institute for Health Research's (CIHR) Strategy for Patient-Oriented Research (SPOR) prioritizes the need for involving stakeholders in every aspect of the research project to ensure that the outcomes support patient needs (CIHR, 2014). For hard-to-reach groups, such as minorities or families experiencing isolation from the community, patient networks (either virtually or in-person) may provide enhanced facilitation or access to these groups (CIHR, 2014). Overall, SPOR fits within the research program mandate of social participation, given its inherent inclusiveness to have families bring their lives into research while having research positively influence family's lives through engagement.

Thus, there is a need to continue collaborating with community and hospital stakeholders to create practical high-quality rehabilitation focusing on social participation for preschool children with ASD. The program of research described here provides a starting point for future research focusing on strength-based perspectives of classifying children, specifically using the ASPCS, on the basis of their abilities in an area that has typically been only discussed as difficulties or restrictions. This contributes to the evolution and acceptance that all children have strengths and abilities to use for social participation with peers in community activities.

Chapter 6 References.

Aeri, P., and Verma, S. (2004). Child's socialization through play among 2–4 year old children. *Anthropologist, 6*(4), 279-281.

Alessandri, S. M. (1992). Attention, play, and social behavior in ADHD preschoolers. *Journal of Abnormal Child Psychology, 20*(3), 289-302.

American Psychiatric Association. (2014). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5)*. Washington, DC: American Psychiatric Association.

Baker, K., & Donelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society, 16*(1), 71-85.

Bennett, T. A., Szatmari, P., Georgiades, K., Hanna, S., Janus, M., Georgiades, S., . . . Thompson, A. (2014). Do reciprocal associations exist between social and language pathways in preschoolers with autism spectrum disorders? *Journal of Child Psychology and Psychiatry, 56*(8), 874-883

Blum, G. I., Gutierrez, M., & Peck, C. (2015). Beyond Access: Moving toward Increased Participation, Membership, and Skills in the Inclusive Classroom *Including Learners with Low-Incidence Disabilities* (pp. 13-36): Emerald Group Publishing.

Canadian Insitute for Health Research. (2014). Strategy for Patient-Oriented Research Patient Engagement-Framework. *Canadian Institute for Health Research.* Acceessed online June 22, 2016.

Chang, Y.-C., Shih, W., & Kasari, C. (2015). Friendships in preschool children with autism spectrum disorder: What holds them back, child characteristics or teacher behavior? *Autism*, *20*(1), 65-74.

Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability & Rehabilitation, 30*(8), 639-648.

Dahan-Oliel, N., Shikako-Thomas, K., & Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Quality of Life Research, 21*(3), 427-439.

de Schipper, E., Lundequist, A., Coghill, D., de Vries, P. J., Granlund, M., Holtmann, M., . . . Shulman, C. (2015). Ability and Disability in Autism Spectrum Disorder: A Systematic Literature Review Employing the International Classification of Functioning, Disability and Health - Children and Youth Version. *Autism Research*, *8*(6), 782-794.

de Schipper, E., Mahdi, S., de Vries, P., Granlund, M., Holtmann, M., Karande, S., . . . Bölte, S. (2016). Functioning and disability in autism spectrum disorder: A worldwide survey of experts. *Autism Research*, epub ahead of print.

DiRezze, B., Rosenbaum, P., Zwaigenbaum, L., Cooley-Hidecker, M.J., Stratford, P., Cousins, M., Camden, C., Law, M. (in press). Developing a classification system of social communication functioning of preschool children with autism spectrum disorder. *Developmental Medicine and Child Neurology.*

Graham, I. D. (2012). Knowledge synthesis and the Canadian Institutes of Health Research. *Systematic Review, 1*(6).

Koster, M., Pijl, S. J., Nakken, H., & Van Houten, E. (2010). Social participation of students with special needs in regular primary education in the Netherlands. *International Journal of Disability, Development and Education, 57*(1), 59-75.

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with Autism Spectrum Disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders*, *45*(8), 2378-2381.

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710-2719.

Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research, 42*(5), 533-544.

Pierce, N.P., O'Reilly, M.F., Sorrells, A.M., Fragale, C.L., White, P.J., Aguilar, J.M., & Cole, H.A. (2014). Ethnicity reporting practices for empirical research in three autism-related journals. *Journal of Autism and Developmental Disorders, 44*, 1507-1519.

Restall, G., & Magill-Evans, J. (1994). Play and preschool children with autism. *American Journal of Occupational Therapy, 48*(2), 113-120.

Sainato, D. M., Morrison, R. S., Jung, S., Axe, J., & Nixon, P. A. (2015). A comprehensive inclusion program for kindergarten children With Autism Spectrum Disorder. *Journal of Early Intervention, 37*(3), 208-225.

Singh, I. (2013). Brain talk: Power and negotiation in children's discourse about self, brain and behaviour. *Sociology of Health & Illness, 35*(6), 813-827.

Wolfberg, P., DeWitt, M., Young, G. S., & Nguyen, T. (2014). Integrated play groups: Promoting symbolic play and social engagement with typical peers in children with ASD Across Settings. *Journal of Autism and Developmental Disorders, 45*(3), 830-845.

World Health Organization. (2007). *International Classification of Functioning, Disability and Health - Child and Youth Version*. Geneva, Switzerland: WHO Press.

Zwaigenbaum, L. (2001). Autistic spectrum disorders in preschool children. *Canadian Family Physician, 47*, 2037-2042.

Thesis Bibliography.

Adolfsson, M., Malmqvist, J., Pless, M., & Granuld, M. (2011). Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disability and Rehabilitation, 33*(13-14), 1230-1244.

Aeri, P., & Verma, S. (2004). Child's socialization through play among 2–4 year old children. *Anthropologist, 6*(4), 279-281.

Alessandri, S. M. (1992). Attention, play, and social behavior in ADHD preschoolers. *Journal of Abnormal Child Psychology, 20*(3), 289-302.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders, fourth edition (4th ed., text rev.)*. Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2014). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5)*. Washington, DC: American Psychiatric Association.

Anagnosou, E., Zwaigenbaum, L., Szatmari, P., Fombonne, E., Fernandez, B.A., Woodbury-Smith, M., … Scherer, S. (2014). Autism Spectrum Disorder: Advance in evidence-based practice. *Canadian Medical Association Journal, 186*(7): 509-519.

Anderson, S., Allen, P., Peckham, S., & Goodwin, N. (2008). Asking the right questions: Scoping studies in the commissioning of research on the organization and delievery of health services. *Health Research Policy & Systems, 6*(1),1-12.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32.

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*, 103-114.

Baker, K., & Donelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society, 16*(1), 71-85.

Bedell, G. (2004). Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *NeuroRehabilitation, 19*(3), 191-205.

Bedell, G. (2009). Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilation, 12*(5), 342-351.

Bedell, G. M., & Dumas, H. M. (2004). Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. *Brain Injury, 18*(1), 65-82.

Bennett, T. A., Szatmari, P., Georgiades, K., Hanna, S., Janus, M., Georgiades, S., . . . Thompson, A. (2014). Do reciprocal associations exist between social and language pathways in preschoolers with autism spectrum disorders? *Journal of Child Psychology and Psychiatry, 56*(8), 874-883

Berg, C., & LaVesser, P. (2006). The Preschool Activity Card Sort. *OTJR: Occupation, Participation and Health, 26*(4), 143- 151.

Blum, G. I., Gutierrez, M., & Peck, C. (2015). Beyond Access: Moving toward Increased Participation, Membership, and Skills in the Inclusive Classroom *Including Learners with Low-Incidence Disabilities* (pp. 13-36): Emerald Group Publishing.

Bolte, S., de Schipper, E., Robison, J. E., Wong, V. C., Selb, M., Singhal, N., . . . Zwaigenbaum, L. (2014). Classification of functioning and impairment: the development of ICF core sets for autism spectrum disorder. *Autism Research, 7*(1), 167-172. doi:10.1002/aur.1335

Bossaert, G., de Boer, A. A., Frostad, P., Pijl, S. J., & Petry, K. (2015). Social participation of students with special educational needs in different educational systems. *Irish Educational Studies, 34*(1), 1-12.

Bult, M.K., Verschuren, O., Kertoy, M.K., Lindeman, E., Jongmans, M.J., & Ketelaar, M. (2013). Psychometric evaluation of the Dutch version of the Assessment of Preschool Children's Participation (APCP): Construct validity and test-retest reliability. *Physical & Occupational Therapy in Pediatrics, 33*(4), 372-383.

Burstyn, I., Sithole, F., & Zwaigenbaum, L. (2010). Autism spectrum disorders, maternal characteristics and obstetric complications among singletons born in Alberta, Canada. *Chronic Diseases in Canada, 30*(4), 125-134.

Canadian Insitute for Health Research. (2014). Strategy for Patient-Oriented Research Patient Engagement-Framework. *Canadian Institute for Health Research.* Acceessed online June 22, 2016.

Castelloe, P., & Dawson, G. (1993). Subclassification of children with autism and pervasive developmental disorder: A questionnaire based on Wing's subgrouping scheme. *Journal of Autism and Developmental Disorders, 23*(2), 229-241.

Castro, S., & Pinto, A. (2015). Matrix for Assessment of Activities and Participation: Measuring functioning beyond diagnosis in young children with disabilities. *Developmental Neurorehabilation, 18*(3), 177-189.

Centre for Disease Control. (2014). Prevalence of Autism Spectrum Disorder among children aged 8 years. *Morbidity and Mortality Weekly Report, 63*(SS02), 1-21.

Chang, Y.-C., Shih, W., & Kasari, C. (2015). Friendships in preschool children with autism spectrum disorder: What holds them back, child characteristics or teacher behavior? *Autism*, *20*(1), 65-74.

Chien, C.W., Rodger, S., & Copley, J. (2015). Development and psychometric evaluation of a new measure for children's participation in hand-use life situations. *Archives of Physical Medicine & Rehabilitation, 96*(6), 1045-1055.

Chien, C.W., Rodger, S., Copley, J., & McLaren, C. (2013). Measures of participation outcomes related to hand use for 2-to 12-year-old children with disabilities: A systematic review. *Child: Care Health and Development, 40*(4), 458-471.

Chien, C. W., Rodger, S., Copley, J., & Skorka, K. (2014). Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health–Children and Youth. *Archives of Physical Medicine and Rehabilitation, 95*(1), 141-152.

Christensen, D.L., Bilder, D.A., Zahorodny, W., Pettygrove, S., Durkin, M.S., Fitzgerald, R.T., Rice, C., Kurzius-Spencer, M., Baio, J., & Yeargin-Allsopp, M. (2016). Prevalence and characteristics of Autism Spectrum Disorder among 4-year-old children in the Autism and Developmental Disabilities Monitoring Network. *Journal of Developmental & Behavioral Pediatrics, 37*(1), 1-8.

Creswell, J.M. & Piano Clark, V.L. (2011) *Designing and Conducting Mixed Methods Research.* Thousand Oaks, CA: SAGE.

Colquhoun, H.L., Levac, D., O'Brien, K.K., Straus, S., Tricco, A.C., Perrier, L., Kastner, M., & Moher, D. (2014). Scoping reviews: Time for clarity in definitions, methods and reporting. *Journal of Clinical Epidemiology, 67*, 1291-1294.

Cosbey, J., Johnston, S. S., & Dunn, M. L. (2010). Sensory processing disorders and social participation. *American Journal of Occupational Therapy, 64*(3), 462-473.

Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability & Rehabilitation, 30*(8), 639-648.

Dahan-Oliel, N., Shikako-Thomas, K., & Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Quality of Life Research, 21*(3), 427-439.

Daniels, A. M., & Mandell, D. S. (2013). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism*, *18*(5), 583-597.

Davey, H., Imms, C., & Fossey, E. (2015) "Our child's significant disability shapes our lives": experiences of family social participation. *Disability & Rehabilitation, 37*(24), 2264-2271.

Davis, K., Drey, N. & Gould, D. (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies, 46*(10), 1386-1400.

de Schipper, E., Lundequist, A., Coghill, D., de Vries, P. J., Granlund, M., Holtmann, M., . . . Shulman, C. (2015). Ability and Disability in Autism Spectrum Disorder: A Systematic Literature Review Employing the International Classification of Functioning, Disability and Health - Children and Youth Version. *Autism Research*, *8*(6), 782-794.

de Schipper, E., Mahdi, S., de Vries, P., Granlund, M., Holtmann, M., Karande, S., . . . Bölte, S. (2016). Functioning and disability in autism spectrum disorder: A worldwide survey of experts. *Autism Research*, epub ahead of print.

Dey, I. (1993) *Qualitiative Data Analysis: A User-Friendly Guide for Social Scientists,* London: Routledge Taylor & Francis Group.

DiRezze, B., Rosenbaum, P., Zwaigenbaum, L., Cooley-Hidecker, M.J., Stratford, P., Cousins, M., Camden, C., & Law, M. (in press). Developing a classification system of social communication functioning of preschool children with autism spectrum disorder. *Developmental Medicine and Child Neurology.*

Dumont, C., Gervais, M., Fougeyrollas, P., & Bertrand, R. (2004). Toward an explanatory model of social participation for adults with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 19*(6), 431-444.

Eliasson, A.C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A.-M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology, 48*(7), 549-554.

Elo, S. & Kyngas, H. (2008) The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107-115.

Elsabbagh, M., Yusuf, A., Prasanna, S., Shikako-Thomas, K., Ruff, C.A., & Fehlings, M.G. (2014) Community engagement and knowledge translation: progress and challenge in autism research. *Autism, 18*(7), 771-781.

Emde, M. & Fuchs, M. (2013). Using interactive feedback to enhance responses quality in Web surveys: The case of open-ended questions. *General Online Research Conference.*

Field, B., Booth, A., Ilott, I., & Gerrish, K. (2014) Using the knowledge to action framework in practice: a citation analysis and systematic review. *Implementation Science* 9: 172.

Frazier, T. W., Youngstrom, E. A., Speer, L., Embacher, R., Law, P., Constantino, J., . . . Eng, C. (2012). Validation of proposed DSM-5 criteria for autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51(1*), 28-40.

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 Neurorehabilitation, 17*(1), 24-33.

Germani, T., Magill-Evans, J., Zwaigenbaum, L., Sacrey, L. A. R., Askari, S., & Anaby, D. (under review). Participation measures for preschool children with Autism Spectrum Disorder: A scoping review. *Review Journal of Autism and Developmental Disabilities*.

Germani, T., Zwaigenbaum, L., Magill-Evans, J., Hodgetts, S., & Ball, G. D. (in press). Stakeholder perspectives on social participation in preschool children with ASD. *Developmental Neurorehabilation*.

Germani, T., Zwaigenbaum, L., Magill-Evans, J., Hodgetts, S., Hildebrandt, J., Stolte, M., Mitchell, S., Wennerstorm, K., & Hapchyn, C.A. (under review). Development and content validity of the Autism Social Participation Classification System for preschool children with Autism Spectrum Disorder. *BMC Pediatrics.*

Goldingay, S., Stagnitti, K., Sheppard, L., McGillivray, J., McLean, B., & Pepin, G. (2013). An intervention to improve social participation for adolescents with autism spectrum disorder: Pilot study. *Developmental Neurorehabilation*, *18*(2), 122-130.

Graham, I. D. (2012). Knowledge synthesis and the Canadian Institutes of Health Research. *Systematic Review, 1*(6).

Graham, I.D., Logan, J., Harrison, M.B., Straus, S.E., Tetroe, J., Caswell, W., & Robinson, N. (2006) Lost in knowledge translation: time for a map? *Journal of Continuing Education in Health Professions, 26*(1), 13-24.

Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal, 26*(2), 91-108.

Harding, J., Harding, K., Jamieson, P., Mullally, M., Politi, C., Wong-Sing, E., . . . Petrenchik, T. M. (2009). Children with disabilities' perceptions of activity participation and environments: A pilot study. *Canadian Journal of Occupational Therapy, 76*(3), 133-144.

Harris, P.A., Taylor, R., Thielke, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J.G. (2009) Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377-381.

Hemmingsson, H., & Jonsson, H. (2005). An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health—some critical remarks. *American Journal of Occupational Therapy, 59*(5), 569-576.

Hidecker, M. J. C., Paneth, N., Rosenbaum, P. L., Kent, R. D., Lillie, J., Eulenberg, J. B., . . . Evatt, M. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology, 53*(8), 704-710.

Hodgetts, S., Nicholas, D., Zwaigenbaum, L., & McConnell, D. (2013). Families' and professionals' perceptions of family-centered care for children with autism across service sectors. *Social Science & Medicine, 96*, 138-146.

Hoogsteen, L., & Woodgate, R. L. (2010). Can I play? A concept analysis of participation in children with disabilities. *Physical & Occupational Therapy in Pediatrics, 30*(4), 325-339.

Hsu, C.C., & Sandford, B.A. (2007). The Delphi technique: making sense of consensus. *Practical assessment, Research & Evaluation, 12*, 1-8.

Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics, 120*(5), 1183-1215.

Kang, L.J., Palisano, R.J., Orlin, M.N., Chiarello, L.A., King, G.A., & Polansky, M. (2010) Determinants of social participation—with friends and others who are not family members—for youths with cerebral palsy. *Physical Therapy, 90*(12), 1743-1757.

Khetani, M. A., Graham, J. E., Davies, P. L., Law, M. C., & Simeonsson, R. J. (2015). Psychometric properties of the Young Children's Participation and Environment Measure. *Archives of Physical Medicine and Rehabilitation, 96*(2), 307-316.

King, G.A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P. (2005) Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development, 33*(1), 28-39.

Koster, M., Nakken, H., Pijl, S.J., & van Houten, E. (2009) Being part of the peer group: A literature study focusing on the social dimension of inclusion in education. *International Journal of Inclusive Education, 13*(2), 117-140.

Koster, M., Pijl, S. J., Nakken, H., & Van Houten, E. (2010). Social participation of students with special needs in regular primary education in the Netherlands. *International Journal of Disability, Development and Education, 57*(1), 59-75.

Koster, M., Timmerman, M. E., Nakken, H., Pijl, S. J., & van Houten, E. J. (2009). Evaluating social participation of pupils with special needs in regular primary schools. *European Journal of Psychological Assessment, 25*(4), 213-222.

Krippendorff, K. (1980) *Content Analysis: An Introduction to Its Methodology,* Newbury Park, CA: SAGE.

Krosnick, J.A. & Fabrigar, L.R. (1997). Chapter 6: Designing rating scales for effective measurement in surveys. In L. E. Lyberg, P. Biemer, M. Collins, et al. (Eds.) *Survey Measurement and Process Quality.* New York, NY: John Wiley & Sons.

LaVesser, P., & Berg, C. (2011). Participation patterns in preschool children with an autism spectrum disorder. *OTJR: Occupation, Participation and Health, 31*(1), 33.

Law, M. (2002a) Enhancing participation. *Physical & occupational therapy in Pediatrics* 22: 1-3.

Law, M. (2002b). Participation in the occupations of everyday life. *American Journal of Occupational Therapy, 56*(6), 640-649.

Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., King, G., & Hanna, S. (2004). Participation of children with physical disabilities: Relationships with diagnosis, physical function, and demographic variables. *Scandinavian Journal of Occupational Therapy, 11*(4), 156-162.

Law, M., Haight, M., Milroy, B., Willms, D., Stewart, D., & Rosenbaum, P. (1999). Environmental factors affecting the occupations of children with physical disabilities. *Journal of Occupational Science, 6*(3), 102-110.

Law, M., King, G., Petrenchik, T., Kertoy, M., & Anaby, D. (2012). The Assessment of Preschool Children's Participation: Internal consistency and construct validity. *Physical & Occupational Therapy in Pediatrics, 32*(3), 272-287.

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science, 5*(1), 1-9.

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.

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.

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480-1486.

Mandich, A.D., Polatajko, H.J., Miller, L.T., & Baum, C. (2004). *Paediatric Activity Card Sort (PACS)*. Ottawa: CAOT Publications ACE.

Mandy, W. P., Charman, T., & Skuse, D. H. (2012). Testing the construct validity of proposed criteria for DSM-5 autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(1), 41-50.

Mayan, M.J. (2009) *Essentials of Qualitiative Inquiry,* Walnut Creek, California: Left Coast Press.

McConachie, H., Colver, A.F., Forsyth, R.J., Jarvis, S.N., & Parkinson, K.N. (2006). Participation of disabled children: how should it be characterised and measured? *Disability & Rehabilitation, 28*(18), 1157-1164.

McConnell, S.R. (2002) Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for educational intervention and future research. *Journal of Autism and Developmental Disorders, 32*(5), 351-372.

McGee, G.G., Feldman, R.S., & Morrier, M.J. (1997) Benchmarks of social treatment for children with autism. *Journal of Autism and Developmental Disorders, 27*(4), 353-364.

Morris, C., Kurinczuk, J., & Fitzpatrick, R. (2005). Child or family assessed measures of activity performance and participation for children with cerebral palsy: a structured review. *Child: Care, Health, and Development, 31*(4), 397-407.

Morris, C., Shilling, V., McHugh, C., & Wyatt, K. (2011). Why is it crucial to involve families in all stages of childhood disability research. *Developmental Medicine & Child Neurology, 53,* 769-771.

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with Autism Spectrum Disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders*, *45*(8), 2378-2381.

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710-2719.

Ouellette-Kuntz, H., Coo, H., Lam, M., Breitenbach, M. M., Hennessey, P. E., Jackman, P. D., … . Chung, A. M. (2014). The changing prevalence of autism in three regions of Canada. *Journal of Autism and Developmental Disorders, 44*(1), 120-136.

Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research, 42*(5), 533-544.

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*(4), 214-223.

Patton, M.Q. (1990) *Qualitative Evaluation and Research Methods,* Thousand Oaks, CA: Sage Publications.

Parten, M. B. (1932). Social participation among pre-school children. *Journal of Abnormal and Social Psychology, 27*(3), 243.

Pierce, N.P., O'Reilly, M.F., Sorrells, A.M., Fragale, C.L., White, P.J., Aguilar, J.M., & Cole, H.A. (2014). Ethnicity reporting practices for empirical research in three autism-related journals. *Journal of Autism and Developmental Disorders, 44*, 1507-1519.

Piškur, B. (2013) Social participation: Redesign of education, research, and practice in occupational therapy. *Scandinavian Journal of Occupational Therapy, 20*(1), 2-8.

Piškur, B., Daniëls, R., Jongmans, M. J., Ketelaar, M., Smeets, R. J., Norton, M., & Beurskens, A. J. (2013). Participation and social participation: are they distinct concepts? *Clinical Rehabilitation*, 0269215513499029.

Phillips, R., & Hogan, A. (2015). Recreational participation and the development of social competence in preschool aged children with disabilities: a cross-sectional study. *Disability and Rehabilitation, 37*(11), 981-989.

Phillips, R. L., Olds, T., Boshoff, K., & Lane, A. E. (2013). Measuring activity and participation in children and adolescents with disabilities: A literature review of available instruments. *Australian Occupational Therapy Journal, 60*(4), 288-300.

Reichow, B. (2012). Overview of meta-analyses on early intensive behavioural intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(4): 512-520.

Resnik, L., & Plow, M. A. (2009). Measuring participation as defined by the International Classification of Functioning, Disability and Health: an evaluation of existing measures. *Archives of Physical Medicine and Rehabilitation, 90*(5), 856-866.

Restall, G., & Magill-Evans, J. (1994). Play and preschool children with autism. *American Journal of Occupational Therapy, 48*(2), 113-120.

Rhodes, S., Bowie, D., & Hergenrather, K. (2003). Collecting behavioural data using the world wide web: considerations for researchers. *Journal of Epidemiology and Community Health, 57,* 68-73.

Rodger, S. & Umaibalan, V. (2011) The routines and rituals of families of typically developing children compared with families of children with autism spectrum disorder: an exploratory study. *British Journal of Occupational Therapy, 74*(1), 20-26.

Rosenbaum, P., Eliasson, A.-C., Hidecker, M. J. C., & Palisano, R. J. (2014). Classification in childhood disability Focusing on function in the 21st century. *Journal of Child Neurology, 29(*8), 1036-1045.

Rosenbaum, P., Palisano, R., Bartlett, D., Galuppi, B., & Russell, D. (2008). Development of the Gross Motor Function Classification System for cerebral palsy. *Developmental Medicine and Child Neurology, 50*(4), 249-253.

Rosenberg, L., Jarus, T., & Bart, O. (2010). Development and initial validation of the Children Participation Questionnaire (CPQ). *Disability & Rehabilitation, 32*(20), 1633-1644.

Sainato, D. M., Morrison, R. S., Jung, S., Axe, J., & Nixon, P. A. (2015). A comprehensive inclusion program for kindergarten children With Autism Spectrum Disorder. *Journal of Early Intervention, 37*(3), 208-225.

Sakzewski, L., Boyd, R., & Ziviani, J. (2007). Clinimetric properties of participation measures for 5-to 13-year-old children with cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology, 49*(3), 232-240.

Sellers, D., Mandy, A., Pennington, L., Hankins, M., & Morris, C. (2014). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine & Child Neurology, 56*(3), 245-251.

Shattuck, P. T., Orsmond, G. I., Wagner, M., & Cooper, B. P. (2011). Participation in social activities among adolescents with an autism spectrum disorder. *PLoS One, 6*(11), e27176. doi:10.1371/journal.pone.0027176

Shikako-Thomas, K., & Law, M. (2015). Policies supporting participation in leisure activities for children and youth with disabilities in Canada: from policy to play. *Disability & Society*, *30*(3), 381-400.

Singh, I. (2013). Brain talk: Power and negotiation in children's discourse about self, brain and behaviour. *Sociology of Health & Illness, 35*(6), 813-827.

Singh, I. & Elsabbagh, M. (2014) Autism research beyond the bench. *Autism, 18*(7), 754-755.

Sylvestre, A., Nadeau, L., Charron, L., Larose, N., & Lepage, C. (2013). Social participation by children with developmental coordination disorder compared to their peers. *Disability & Rehabilitation, 35*(21), 1814-1820.

Szatmari, P., Charman, T., & Constantino, J. N. (2012). Into, and out, of the "Valley of Death": research in autism spectrum disorders. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(11), 1108-1112.

Szatmari, P., Georgiades, S., Duku, E., Bennett, T. A., Bryson, S., Fombonne, E., . . . Thompson, A. (2015). Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with autism spectrum disorder. *JAMA Psychiatry, 72*(3), 276-283.

Tanner, K., Hand, B. N., O'Toole, G., & Lane, A. E. (2015). Effectiveness of interventions to improve social participation, play, leisure, and restricted and repetitive behaviors in people with autism spectrum disorder: A systematic review. *American Journal of Occupational Therapy, 69*(5), pg 69051800101-690518001012. doi: 10.5014/ajot.2015.017806.

Tobin, M.C., Drager, K.D., & Richardson, L.F. (2014) A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders, 8*(3), 214-229.

Tsao, L.-L., Odom, S. L., Buysse, V., Skinner, M., West, T., & Vitztum-Komanecki, J. (2008). Social participation of children with disabilities in inclusive preschool programs: Program typology and ecological features. *Exceptionality, 16*(3), 125-140.

Waterhouse, L., Morris, R., Allen, D., Dunn, M., Fein, D., Feinstein, C., . . . Wing, L. (1996). Diagnosis and classification in autism. *Journal of Autism and Developmental Disorders, 26*(1), 59-86.

Whalley Hammell, K. (2004). Deviating from the norm: A sceptical interrogation of the classificatory practices of the ICF. *British Journal of Occupational Therapy, 67*(9), 408-411.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*(1), 11-29.

Wolfberg, P., DeWitt, M., Young, G. S., & Nguyen, T. (2014). Integrated play groups: Promoting symbolic play and social engagement with typical peers in children with ASD Across Settings. *Journal of Autism and Developmental Disorders, 45*(3), 830-845.

Wood, E., & Rosenbaum, P. (2000). The Gross Motor Function Classification System for cerebral palsy: a study of reliability and stability over time. *Developmental Medicine and Child Neurology, 42,* 292-296.

World Health Organization. (2007). *International Classification of Functioning, Disability and Health - Child and Youth Version*. Geneva, Switzerland: WHO Press.

Wortman, P. M., Smyth, J. M., Langenbrunner, J. C., & Yeaton, W. H. (1998). Consensus among experts and research synthesis: a comparison of methods. *International Journal of Technology Assessment in Health Care, 14*(1), 109-122.

Yager, J. & Iarocci, G. (2013). The development of the Multidimensional Social Competence Scale: A standardized measure of social competence in Autism Spectrum Disorders. *Autism Research, 6*(6), 631-641.

Young, N. L., Yoshida, K. K., Williams, J. I., Bombardier, C., & Wright, J. G. (1995). The role of children in reporting their physical disability. *Archives of Physical Medicine and Rehabilitation, 76*(10), 913-918.

Ziviani, J., Desha, L., Feeney, R., & Boyd, R. (2010). Measures of participation outcomes and environmental considerations for children with acquired brain injury: A systematic review. *Brain Impairment, 11*(02), 93-11

Zwaigenbaum, L. (2001). Autistic spectrum disorders in preschool children. *Canadian Family Physician, 47*, 2037-2042.

Appendix A

SCOPING REVIEW DATA EXTRACTION FORM

Date of Review: _____ Reviewer: SA/ TG/ LARS

Assessment								
Publisher/ Access								
Reference(s)								
Cost/ Training								
Validity								
Reliability								
Sample/ Norms								
Purpose								
Type of Assessment								
Respondent								
Time to Administer								
Content of Assessment Included (Y/N) and notes	Behaviour (repetitive/ sameness)	Novelty of Activity	Novelty of Environment	Participation	Peer Relationships	Support from Environment	Structure of Environment	Availability of Aide
	Y // N	Y // N	Y // N	Y // N (i.e., social)	Y // N	Y // N	Y // N	Y // N
Included i (Y/N) and why			Y // N					

N.B. This is a final version of the data extraction form after several iterations

Appendix B

Confidential

Professional Survey

Please complete the survey below.

Thank you!

Please provide us with some information about yourself and the child(ren) with ASD you work with.

I am a:

- ☐ Behavioural Therapist
- ☐ Educator
- ☐ Medical Doctor
- ☐ Nurse (Practitioner)
- ☐ Nurse (Registered)
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Psychologist
- ☐ Social Worker
- ☐ Speech Language Pathologist
- ☐ Respite Worker/ Interventionist
- ☐ Other

Other: _____

Province or Territory:

- ☐ Alberta
- ☐ British Columbia
- ☐ Manitoba
- ☐ New Brunswick
- ☐ Newfoundland & Labrador
- ☐ Northwest Territories
- ☐ Nova Scotia
- ☐ Nunavut
- ☐ Ontario
- ☐ Prince Edward Island
- ☐ Quebec
- ☐ Saskatchewan
- ☐ Yukon

Postal Code: _____

Number of Children with ASD in my current practice (on average weekly): _____

Years of Practice _____

Age Range of Children with ASD in Years (i.e. 2 - 5 years old) _____

Professionals typically involved in my client's care:

(check all that apply)

- ☐ Behavioural Therapist
- ☐ Educator
- ☐ Medical Doctor
- ☐ Nurse (Practitioner)
- ☐ Nurse (Registered)
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Psychologist
- ☐ Social Worker
- ☐ Speech Language Pathologist
- ☐ Respite Worker/ Interventionist
- ☐ Other

Other; please specify: _____

In my practice, clients MAY be receiving intervention for:

(check all that apply)

- ☐ Behaviour
- ☐ Communication
- ☐ Feeding
- ☐ Family Relationships
- ☐ Mental Health
- ☐ Gross Motor (such as walking, running)
- ☐ Fine Motor (such as buttoning, hand writing)
- ☐ Peer-to-Peer Relationships
- ☐ Free Play
- ☐ Psychological Well-being
- ☐ Self-Care (such as dressing)
- ☐ Sensory
- ☐ Toileting
- ☐ Other
- ☐ Not Applicable

Other; please specify _____

Please rate all items below from Strongly Agree to Strongly Disagree, in terms of how important the item is for describing a client's social participation or "doing" in activities with peers.

Routines & Behaviour Management

	Strongly Agree	Agree	Somewhat Agree	Neutral	Somewhat Disagree	Disagree	Strongly Disagree
Follows the guidance of others for basic daily routines, such as getting ready for recess	○	○	○	○	○	○	○
Handles changes to the usual sequence of activities, such as getting ready for recess in a different order	○	○	○	○	○	○	○
Acting in an appropriate way in response to new situations, people or experiences, such as meeting a new teacher	○	○	○	○	○	○	○
Managing behavior in new situations, such as going to a new play group for the first time	○	○	○	○	○	○	○
Managing behavior in an appropriate way in response to expectations or demands, such as following one-step instructions	○	○	○	○	○	○	○
Managing behavior with an appropriate level of energy to demands or expectations, such as sitting quietly in story time	○	○	○	○	○	○	○

Please answer the following questions:

What strategies do you use to increase a client's motivation to participate socially?

In your experience, what sensory elements of the environment impact a client's participation in social activities?

In your experience, what types of behaviours impact a client's participation in social activities?

Please rate all items below from Strongly Agree to Strongly Disagree, in terms of how important the item is for describing a client's social participation or "doing" in activities with peers.

Social Interactions & Relationships

	Strongly Agree	Agree	Somewhat Agree	Neutral	Somewhat Disagree	Disagree	Strongly Disagree
Giving and reacting appropriately to non-verbal cues that occur in social interactions, such as showing a toy	○	○	○	○	○	○	○
Initiating and responding appropriately in reciprocal social exchange with others, such as peers	○	○	○	○	○	○	○
Regulating behaviours to sustain social exchanges, such as telling a story	○	○	○	○	○	○	○
Regulating emotions and impulses, verbal aggression and physical aggression in interactions with others, such as peers at the playground	○	○	○	○	○	○	○
Complying with social conventions, such as listening when the teacher is talking	○	○	○	○	○	○	○
Entering into relationships with others, such as with students at the same day-care or pre-school	○	○	○	○	○	○	○

Please answer the following questions:

How does the familiarity of individuals, activities, or the environment impact social participation?

Where does your client(s) have the greatest success participating in social activities?

Please rate all items below from Strongly Agree to Strongly Disagree, in terms of how important the item is for describing a client's social participation or "doing" in activities with peers.

Learning & Play

	Strongly Agree	Agree	Somewhat Agree	Neutral	Somewhat Disagree	Disagree	Strongly Disagree
Playing pretend and make-believe activities with imaginary persons, places, things or events	○	○	○	○	○	○	○
Purposefully sustaining and engaging in activities with toys or games by self, such as stacking blocks or reading.	○	○	○	○	○	○	○
Purposefully observing the activities of peers with toys or games, but not joining their activities, such as watching from across the room.	○	○	○	○	○	○	○
Engaging in purposeful activities with toys or games side-by-side peers also engaged in play but not co-operative such as a colouring at the same table.	○	○	○	○	○	○	○
Joining others for sustained engagement in activities with toys or games with a common goal or purpose, such as playing 'house.'	○	○	○	○	○	○	○

Please answer the following questions:

When enrolling a client in a new activity, what factors do you consider to ensure the social participation will be successful?

How does a client's preference for a particular activity impact their social participation?

Please provide your contact information including your email address for us to send you the electronic gift card for $10.00 within two business days.

Email address: _____

Email Address (to confirm): _____

Please select if you would like an iTunes or Amazon.ca gift card:

◯ iTunes (can be used at the iTunes Store, App Store, Mac App Store and iBooks Store)
◯ Amazon.ca
◯ I do not want to provide my email address and will not receive an electronic gift card

PLEASE NOTE: This survey is monitored by a third party for fraudulent responses, including but not limited to: the same person taking the survey more than once, individuals participating outside of Canada, circulation of this survey on internet chatrooms and participants ineligible to complete survey but do so anyways.

Family Survey

Please complete the survey below.

Thank you!

Please provide us with some information about yourself and your child(ren) with ASD.

I am a:

- ◯ Parent
- ◯ Step-Parent
- ◯ Sibling
- ◯ Grandparent
- ◯ Aunt or Uncle
- ◯ Foster Parent
- ◯ Other

Other _____

Province or Territory:

- ☐ Alberta
- ☐ British Columbia
- ☐ Manitoba
- ☐ New Brunswick
- ☐ Newfoundland & Labrador
- ☐ Northwest Territories
- ☐ Nova Scotia
- ☐ Nunavut
- ☐ Ontario
- ☐ Prince Edward Island
- ☐ Quebec
- ☐ Saskatchewan
- ☐ Yukon

Postal Code _____

Number of Children with ASD: _____

Total Number of Children _____

Date of Birth of My Child with ASD (i.e. Jan 3 2010): _____
(If multiple children, please input age of youngest child)

Professionals Involved in my child(ren)'s care:

(check all that apply)

- ☐ Behavioural Therapist
- ☐ Educator
- ☐ Medical Doctor
- ☐ Nurse (Practitioner)
- ☐ Nurse (Registered)
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Psychologist
- ☐ Social Worker
- ☐ Speech Language Pathologist
- ☐ Respite Worker/ Interventionist
- ☐ Other

Other, please specify _____

My Child(ren) currently receives intervention for:

(check all that apply)

- ☐ Behaviour
- ☐ Communication
- ☐ Feeding
- ☐ Family Relationships
- ☐ Mental Health
- ☐ Gross Motor (such as walking, running)
- ☐ Fine Motor (such as dressing, hand writing)
- ☐ Peer-to-Peer Relationships
- ☐ Free Play
- ☐ Psychological Well-being
- ☐ Self-Care (e.g., Dressing)
- ☐ Sensory
- ☐ Toileting
- ☐ Other
- ☐ Not Applicable

Other, please specify _____

Please rate all items below from Strongly Agree to Strongly Disagree, in terms of how important the item is for describing your child's social participation or "doing" in activities.

Routines & Behaviour Management

	Strongly Agree	Agree	Somewhat Agree	Neutral	Somewhat Disagree	Disagree	Strongly Disagree
Follows the guidance of others for basic daily routines, such as getting ready for bed	○	○	○	○	○	○	○
Handles changes to the usual sequence of activities, such as completing the bedtime routine in a different order	○	○	○	○	○	○	○
Acting in a appropriate way in response to new situations, people, or experiences, such as meeting a new teacher	○	○	○	○	○	○	○
Managing behavior in new situations such as the first time going to the dentist	○	○	○	○	○	○	○
Managing behavior in an appropriate way in response to expectations or demands, such as following one-step instructions	○	○	○	○	○	○	○
Managing behavior with an appropriate level of energy to demands or expectations, such as sitting quietly in story time	○	○	○	○	○	○	○

Please answer the following questions:

What strategies do you use to increase your child's motivation to participate socially?

In your experience, what sensory elements (i.e. noise, bright lights) of the environment impact your child's participation in social activities?

In your experience, what types of behaviours impact your child's participation in social activities?

Please rate all items below from Strongly Agree to Strongly Disagree, in terms of how important the item is for describing your child's social participation or "doing" in activities.

Social Interactions & Relationships

	Strongly Agree	Agree	Somewhat Agree	Neutral	Somewhat Disagree	Disagree	Strongly Disagree
Giving and reacting appropriately to signs and hints that occur in social interactions, such as a showing a toy	○	○	○	○	○	○	○
Initiating and responding appropriately in reciprocal social exchange with others, such as peers	○	○	○	○	○	○	○
Regulating behaviours to sustain social exchanges, such as telling a story	○	○	○	○	○	○	○
Regulating emotions and impulses, verbal aggression and physical aggression in interactions with others, such as peers at the playground	○	○	○	○	○	○	○
Complying with social conventions, such as listening when the teacher is talking	○	○	○	○	○	○	○
Entering into relationships with others, such as with students at the same day-care or pre-school	○	○	○	○	○	○	○
Creating and maintaining family relationships, such as siblings and cousins.	○	○	○	○	○	○	○

Please answer the following questions:

How does the familiarity of individuals, activities, or the environment impact social participation?

Where does your child have the greatest success participating in social activities?

Please rate all items below from Strongly Agree to Strongly Disagree, in terms of how important the item is for describing your child's social participation or "doing" in activities.

Learning & Play

	Strongly Agree	Agree	Somewhat Agree	Neutral	Somewhat Disagree	Disagree	Strongly Disagree
Playing pretend or make-believe activities with imaginary persons, places, things or events	○	○	○	○	○	○	○
Purposefully sustaining and engaging in activities with toys, or games by self, such as stacking blocks or reading.	○	○	○	○	○	○	○
Purposefully observing the activities of others with toys, or games, but not joining their activities, such as watching them across the room.	○	○	○	○	○	○	○
Engaging in purposeful activities with toys, or games side-by-side peers also engaged in play but not co-operative, such as colouring at the same table.	○	○	○	○	○	○	○
Joining others for sustained engagement in activities with toys, or games with a common goal or purpose, such as playing 'house'.	○	○	○	○	○	○	○

Please answer the following questions:

When enrolling your child in a new activity, what factors do you consider to ensure the social participation will be successful?

How does your child's preference for a particular activity impact their social participation?

Please provide your contact information including your email address for us to send you the electronic gift card for $10.00 within two business days

Email Address: _____

Email Address (to confirm): _____

Please select if you would like an iTunes or Amazon.ca gift card:

◯ iTunes (can be used at the iTunes Store, App Store, Mac App Store and iBooks Store)
◯ Amazon.ca
◯ I do not want to provide my email address and will not receive an electronic gift card

PLEASE NOTE: This survey is monitored by a third party for fraudulent responses, including but not limited to: the same person taking the survey more than once, individuals participating outside of Canada, circulation of this survey on internet chatrooms and participants ineligible to complete survey but do so anyways.

Appendix C

Expert Focus Group 1: Facilitator Guide

Purpose of Session:

1. Orient experts to purpose project, consent, describe communication throughout project
2. Orient to experts to construct of *Social Participation*
3. Orient to previous classification systems in childhood disability

Time Allotted	Item/ Action	Responsible Person
9:00 am (15 minutes)	1. Orient to study 2. Explain risks/ benefits 3. Describe communication, missing a meeting, withdrawal from project *do not need to audio record this section	Facilitator and Co-Facilitator
9:15 am (45 minutes)	1. What is participation? What is activity? 2. What is Social Participation? 3. What experiences/observations do you have with social participation? 4. What did Stakeholders share about Social Participation? 5. Are these similar/different with your experiences?	Facilitator (co-facilitator to start recording and pass materials)
10:00 am (10 minutes)	Break – coffee, muffins, etc.	Co-facilitator
10:10 am (30 minutes)	1. Measurement of Participation (examples) 2. What is a classification system? 3. What a classification system isn't 4. How a classification system can be used; possibilities and opportunities within your own settings; what limitations do you think you would encounter?	Facilitator
10:40 am (10 minutes)	1. Questions re: study 2. Preparation for next meeting	Facilitator (co-facilitator to collect materials)

Expert Focus Group 2: Facilitator Guide

Purpose of Session:

1. Receive feedback on *ASPCS Guide Draft 1* for revision
2. Determine 'building blocks' of *Social Participation* for classification

Time Allotted	Item/ Action	Responsible Person
9:05 am (25 minutes)	**1. Feedback on orientation tool "Autism Social Participation Classification System: Draft 1"** - What was clear? What was unclear? - What terms seems to be missing? (For example, this could be to help you better understand the *need* or *purpose* for the tool)	Facilitator (Lead)
9:30 am (60 minutes)	**1. Hand out 'communication' map to members of group** - Provide a minute or two to read and take in the map **2. Explain similarities in level of complexity between communication and social participation** "Communication is complex; similar to social participation. Other classification systems have focused on communication as their 'topic of interest. Communication was narrowly defined as these six 'building blocks' by experts, similar to yourselves for the purpose of classification. The purpose of our next activity is determine what are the 'building blocks' of social participation for meaningful classification in ASD, again at the preschool age" **3. Hand out 'social participation' package to members of group** "I am now going to hand out a map and the "building blocks" we've accumulated across our stakeholder survey, individual interviews as well as our focus group meeting."	Facilitator (Lead) + Co-Facilitator to pass materials

	4. Provide instructions for activity "I will give you some time to read through the building blocks. After you've read through the building blocks, place the top 4-6 blocks that you perceive as the most important on the map; put the rest to the side. If there are two blocks that seem to overlap and you think could be combined into one, put them together with a paper clip. Feel free to make notes or highlight key parts to remind yourself as needed. If you think there is a block missing, take a blank block from the middle and create one. Do your best to complete the activity as individually as possible. We will then share around the table what each person thought was the essential 'building blocks'. Are there any questions?" **5. Activity completion** (~ 7 minutes) **6. Sharing of Results of Activity** "One at a time we will share the top 'blocks' – please be sure to read the number beside the title for each for recording purposes. After everyone has shared; we will open the floor to a more general discussion." - one at a time, experts share their top 4-6 building blocks, in a consecutive fashion **7. Follow-up questions (Group)** - It seems that _____ came up as a common theme; can anyone share their rationale for including it as an essential block? - If any blocks over lapped, how do you see them as combined or as being similar? - If any blocks were created, how do you differentiate the new block from the other blocks on the table? Can you explain the added value piece of your block?	

	8. Follow-up questions (Individuals) - If any blocks over lapped, how do you see them as combined or as being similar? - Where there any blocks that came to your mind as "on-the-fence" that you feel is missing? - If any blocks were created, how do you differentiate the new block from the other blocks on the table? Can you explain the added value piece of your block? **9. For Individuals only ✐ Share the findings of groups (via table)** - Are there any surprises from what you thought was the essential components of social participation? - What strengths/ limitations do you see based on the group consensus?	
10:30 am (10 minutes)	1. Questions re: today's session 2. Preparation for next meeting ✐ email will go out as reminder + any information requested by participants	

Development of the *Autism Social Participation Classification System*

Expert Focus Group 3: Facilitator Guide

Purpose of Session:
1. Share Communication Function Classification System
2. Share and receive feedback on the draft ASPCS Level Identification Chart, and Levels

Time Allotted	Item/ Action	Responsible Person
9:05 am (25 minutes)	**1. Share Communication Function Classification System** - Previously, we shared the *Communication Function Classification System* 'building blocks.' Now we are going to share the *Communication Function Classification System Level Identification Chart*. You'll see the flow chart to get to the levels; which are on the next page and described. - I'll give you a moment to review and comment on the classification system: **1) What seems clear? Unclear?** **2) This classification system doesn't have pictures but rather pictograms of exchanges, what is clear, helpful, or confusing?**	Facilitator (Lead)
9:30 am (60 minutes)	**1. Share the (draft) ASPCS Level Identification Chart** - There was lots of information we got about the child's environment and it's been pulled out for now, or as much as possible; and we'll re-include it after we've sorted 'child factors' and 'partner/ recipient factors' - One the recurring themes we heard was the importance of the being able to regulate behaviors (or self-regulate) as a precursor to social participation; if one's internal state isn't within the ideal zone then it's hard to do much else (let alone interact with others!) - Then we heard about motivation or desire to be included or part of social participation exchanges - On the next page, you'll see preliminary levels of child factors and partner/ recipient factors. I will give you several minutes to read through, make edits or suggestions for further explanation or definition. We will then move a series of questions. **1) Based on the descriptions provided, do these seem like three natural categories based on your experience; or do these seem like similar types of kids?** **2) One of our goals is to start developing Levels 2 and 4. In your experience, what separates the two types of children described?** **3) How does familiarity of adult mediator (and environment) play a role?** **4) What piece is missing, or still requires inclusion from your perspective?**	Facilitator (Lead) + Co-Facilitator to pass materials
10:30 am (10 minutes)	1. Questions re: today's session 2. Preparation for next meeting ✐ email will go out as reminder + any information requested by participants	

Expert Focus Group 4: Facilitator Guide

Purpose of Session:

1. Introductions of ASPCS participant team
2. Share and receive feedback on the draft ASPCS Levels

Time Allotted	Item/ Action	Responsible Person
9:05 am (10 minutes)	**1. Re-introductions of entire ASPCS participant team** - Name, profession/ relationship	Facilitator (Lead)
9:15 am (75 minutes)	**1. Share the (draft) ASPCS Level Package** - Take a moment to review the introduction to the ASPCS and the ASPCS itself (on the last page) - We are also going to do evaluate each level in each domain by itself, then have an opportunity for a group discussion. **Level-Specific Questions** - Let's focus on the Child domain of Behaviour, take a moment to read each level and think about how clear each level is. If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest? - Next, let's focus on the Child domain of Social Desire. Take a moment to read and evaluate each level. If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest? - Next, let's focus on the Facilitator Domain. Take a moment to read and evaluate each level. If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest? - Next, let's focus on the Activities & Environment Domain. Take a moment to read and evaluate each level. If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest?	Facilitator (Lead) + Co-Facilitator to pass materials

Development of the *Autism Social Participation Classification System*

	General Questions - Thinking about the children between their third and fifth birthdays, that you have seen in the past few weeks, are there any missing 'pieces' that you would need included in this classification system to work with families to support social participation? - What ascetic features would support the usability of the classification system? Domains on each page? Odd levels shaded in faint blue? Check marks boxes for each level?	
10:15 am (10 minutes)	1. Questions re: today's session 2. Preparation for next meeting ✐ email will go out as reminder + any information requested by participants; its in October!	

Expert Focus Group 5: Facilitator Guide

Purpose of Session:

1. Share project updates and feedback received to date
2. Respond to feedback to date on the draft ASPCS Levels

Time Allotted	Item/ Action	Responsible Person
9:05 am (10 minutes)	**1. Greetings, Update on project** - Introduce new research assistant on project - Goals of today - Share process of obtaining feedback to date – and what it has the feedback been	Facilitator (Lead)
9:15 am (75 minutes)	**1. Share the (draft) ASPCS Level Package** - Take a moment to review the modified ASPCS - There were some levels in the domain that all individuals felt were clear and distinct. We won't cover those again unless they need to be modified to make the others more clear. - Today, we will focus only those that remain unclear or need more clarity - We will then have an opportunity for a group discussion **Level-Specific Questions** - Let's focus on the Child domain of Behaviour, take a moment to read each level and think about how clear each level is. Do you agree with the feedback provided by the online participants? If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest? - Next, let's focus on the Child domain of Social Desire. Take a moment to read and evaluate each level. Do you agree with the feedback provided by the online participants If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest? - Next, let's focus on the Facilitator Domain. Take a moment to read and evaluate each level.!Do you agree with the feedback provided by the online participants If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest? - Next, let's focus on the Activities & Environment Domain. Take a moment to read and evaluate each level.!Do you agree with the feedback provided by the online participants If there are edits you would suggest, you can write it on the ASPCS itself or in the space provided. - One at a time, please share what level(s) was/were most clear? Least clear? What changes would you suggest?	Facilitator (Lead) + Co-Facilitator to pass materials

Development of the *Autism Social Participation Classification System*

	General Questions - Thinking about the children between their third and fifth birthdays, that you have seen in the past few weeks, are there any missing 'pieces' that you would need included in this classification system to work with families to support social participation? - What ascetic features would support the usability of the classification system? Does seeing the domains one at a time more or less helpful? What would give you a better sense of the whole child?	
10:15 am (10 minutes)	1. Questions re: today's session 2. Moving forward ✍ will be contacting you when moves to publication/ preparation 3. Thank-you so much for your ongoing participation!	

Appendix D

Confidential

Content Validity of the ASPCS - Round 1

Background of Study: For pre-school children, social participation provides an opportunity to learn and develop new skills and relationships. We want to understand social participation in pre-school children with Autism so we can support development of new skills.

Purpose: This study aims to ensure the clarity of different levels to describe the abilities of pre-school children with Autism in social participation. Your answers will be used to refine a new measure to classify the abilities and strengths of pre-school children with Autism for participation in social activities.

Eligibility: We need your input if you are a professional with at least 2 years' experience working with pre-school children diagnosed with Autism OR a family member with at least one child with Autism. The child needs to be less than 8 years old.

Ethics Approval & Consent: This study has been approved by the University of Alberta Research Ethics Board on August 19, 2015. This study is part of a graduate student research project. This survey will take approximately 30 minutes. Your participation is entirely voluntary. We encourage you to give your best answer or select the most appropriate answer.

There are no identified risks or direct benefits from answering the questions. At the end of the survey, you have the option to your email address to enter a draw for an electronic $25 Amazon.ca gift card (1 in 10 chances to win), or decline to enter.

Your personal information and email address will not be connected to your answers, other than for the purposes of monitoring for fraud responses. Your answers will not be shared for any other purposes.

Please select one of the following:

- ◯ I understand the benefits and risks as explained above
- ◯ I do NOT understand the benefits and risks as explained above

Please select one of the following:

- ◯ I consent to participate in the survey
- ◯ I do NOT consent to participate in the survey

Please provide some background information

I am a:
- ◯ Parent of child with Autism (less than 8 years old)
- ◯ Professional who works with Pre-School Children with Autism

Please specify:
- ◯ Behaviour Therapist
- ◯ Behaviour Therapy Assistant
- ◯ Developmental Pediatrician
- ◯ Early Educator
- ◯ Interventionist/ Respite Aide
- ◯ Occupational Therapist
- ◯ Occupational Therapy Assistant
- ◯ Pediatrician
- ◯ Psychologist
- ◯ Psychometrist
- ◯ Registered Nurse or Nurse Practitioner
- ◯ Social Worker
- ◯ Speech Language Pathologist
- ◯ Other

Please specify your profession _____

Age of Child(ren) with Autism: _____
(Please provide youngest child's age)

Number of Children with Autism _____
(All children with Autism, regardless of age)

Total Number of Children _____

Number of Years of Practice with this Population: _____
(Example: 5 Years)

I live in:
- ◯ Alberta
- ◯ British Columbia
- ◯ Manitoba
- ◯ New Brunswick
- ◯ Newfoundland and Labrador
- ◯ Northwest Territories
- ◯ Nova Scotia
- ◯ Nunavut
- ◯ Ontario
- ◯ Prince Edward Island
- ◯ Quebec
- ◯ Saskatchewan
- ◯ Yukon

Postal Code: _____
(Example: L2N 6P6)

Our new tool is called 'The Autism Social Participation Classification System ' or ASPCS.

We would like your feedback to improve the tool and determine if each of the 5 levels are clear and distinct.

The purpose is to describe children with Autism by their strengths and abilities using valid categories, or 'levels'.

The ASPCS is intended to be used to describe a child's typical day or usual abilities, referred to as performance. It also can be used to describe a child's best ability, referred to as capacity.

The ASPCS will support communication between healthcare professionals, educators and families, and planning for a child's inclusion in community programs.

There are three important parts to social participation for preschool children with Autism: The Child, The Facilitator, and Activities & Environment. We will present each area individually, and ask a series of questions about each level.

You will be asked to leave a comment for any levels that you rated as neutral, somewhat disagree, disagree, or strongly disagree.

The domain of Child Factors has two parts: Behaviour and Social Desire.

This first section describes the amount of support the pre-school child with Autism needs to regulate behaviour. It is expected that all pre-school children need some supervision to regulate behaviour.

Take a moment to read each level then answer the questions below.

Child Factors (Behaviour, Part A)

Level 5
- Child needs *ongoing and substantial* ***direct support*** from a familiar and knowledgeable adult to regulate behavior in all activities and transitions.

Level 4
- Child needs *a moderate amount of ongoing* ***direct support*** to regulate behaviour from a familiar and knowledgeable adult in *most* activities and transitions.

Level 3
- Child needs *some ongoing* ***direct support*** to sustain self-regulation from a familiar and knowledgeable adult; particularly with waiting for highly preferred interests.

Level 2
- Child *initially* needs some ***direct support*** to regulate behavior.
- However, child readily adapts to clear behavioural expectations needing supervision from knowledgeable adults.

Level 1
- Child is able to regulate behaviour needing only supervision from knowledgeable adults.

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 5 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 4 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 4 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 3 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 3 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 2 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 2 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 1 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 1 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

This is the second part of the Child Factors domain, called Social Desire.

This section describes the amount of social desire the pre-school child with Autism has demonstrated across various social settings.

Take a moment to read each level then answer the questions below.

Child Factors (Social Desire, Part B)

Level 5
- Child does not indicate desire to interact with others; *even* for the purposes of having needs met or related to preferred interests.

Level 4
- Child does not indicate desire to interact with others and does not notice others in the environment; *except* for the purpose of having basic needs meet or preferred interests.

Level 3
- Child has *some* interest and desire to participate with others and may notice others in the environment; usually related to preferred interests.

Level 2
- Child *initially* has *limited* interest and desire to participate with others and notices others in the environment
- However, over time child develops more interest and notices peers in the environment, typically related to preferred interests.

Level 1
- Child *usually* has a desire for social interactions and is *usually* aware of others in the environment, does not need to be related to preferred interests

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 5 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 4 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 4 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 3 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 3 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 2 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 2 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 1 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 1 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

This is the Facilitator domain.

A facilitator is a person responsible, usually in a 1:1 or 1:2 ratio, for the child or children with Autism to proactively ensure community integration. Other names of this person may include early educator assistant, interventionist, or inclusion facilitator.

This domain describes the amount of work or effort the facilitator will need to put into the peer-to-peer interaction in order for the pre-school child to be successful.

All pre-school children are expected to have some level of supervision, especially to repair interactions.

Take a moment to read each level then answer the questions below.

Facilitator

Level 5
- Child needs the facilitator to set-up, sustain, and repair interactions between the child and a peer.
- Child cannot sustain any interactions with a peer without a facilitator.

Level 4
- Child needs the facilitator to set-up, sustain and repair interactions between the child and a peer.
- Child *may* be able to sustain *brief* interactions with a peer at arms-length supervision by facilitator.

Level 3
- Child needs the facilitator to *occasionally* be involved in all components of set-up, responding and repairing interactions.
- Child *occasionally* can sustain interaction with a peer when facilitator fades to arms-length monitoring.

Level 2
- Child *initially* needs the facilitator to be involved in two of the three components of set-up, responding and repairing interactions.
- Child *usually* can sustain interaction with a peer when facilitator fades to arms-length monitoring.

Level 1
- Child *only* needs the facilitator to move from arms-length monitoring of interactions for *brief, direct* involvement to support the repair of social interactions with peers.

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 5 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 4 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 4 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 3 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 3 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 2 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 2 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 1 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 1 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

This is the Activities & Environment domain.

A familiar environment may be the child's home or relative's home. An unfamiliar environment may be a community daycare or recreational program, such as swimming.

A familiar activity may be toileting or reading a book. An unfamiliar activity may be 'playing house' or 'sitting in circle time'.

All pre-school children are expected to have some level of supervision, especially when involved in a cooperative game.

Take a moment to read each level then answer the questions below.

Activities & Environment

Level 5
- Child needs *ongoing and sustained* ***direct support*** from a knowledgeable adult to complete familiar and unfamiliar activities across all environments.

Level 4
- Child needs a *moderate amount of* ***direct support*** from a knowledgeable adult to complete familiar activities in a familiar environment.
- Child needs *sustained and ongoing* ***direct support*** from a knowledgeable adult for unfamiliar activities in all environments.

Level 3
- Child needs *occasional* ***direct support*** by a knowledgeable adult to complete unfamiliar activities in unfamiliar environments.
- Over time, child is able to complete familiar activities in familiar environments with the supervision of a knowledgeable adult.

Level 2
- Child needs *occasional* ***direct support*** to complete unfamiliar activities in unfamiliar environments, and knowledgeable adult can *usually* fade to close supervision.
- Child can complete familiar activities in familiar or unfamiliar environments with supervision.

Level 1
- Child is able to complete familiar and unfamiliar activities in familiar and unfamiliar environments with the supervision of a knowledgeable adult.

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 5 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 4 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 4 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 3 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 3 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 2 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 2 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 1 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 1 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

Please provide your email address if you would like to be entered for the draw of a $25 Amazon.ca electronic gift card (1 in 10 chance of winning; limited to one entry per person).

If you do not want to be entered into the draw, please leave the email address blank.

Email Address: _____

Confirm Email Address: _____

I would like to participate in follow-up surveys for additional chances to enter in the draw:
◯ Yes
◯ No

If yes, please leave your email address: _____

Content Validity of the ASPCS - Round 2

Background of Study: For pre-school children, social participation provides an opportunity to learn and develop new skills and relationships. We want to understand social participation in pre-school children with Autism so we can support development of new skills.

Purpose: This study aims to ensure the clarity of different levels to describe the abilities of pre-school children with Autism in social participation. Your answers will be used to refine a new measure to classify the abilities and strengths of pre-school children with Autism for participation in social activities.

Eligibility: We need your input if you are a professional with at least 2 years' experience working with pre-school children diagnosed with Autism OR a family member with at least one child with Autism. The child needs to be less than 8 years old.

Ethics Approval & Consent: This study has been approved by the University of Alberta Research Ethics Board on August 19, 2015. This study is part of a graduate student research project. This survey will take approximately 30 minutes. Your participation is entirely voluntary. We encourage you to give your best answer or select the most appropriate answer.

There are no identified risks or direct benefits from answering the questions. At the end of the survey, you have the option to enter your email address to enter a draw for an electronic $25 Amazon.ca gift card (1 in 10 chances to win), or decline to enter.

Your personal information and email address will not be connected to your answers, other than for the purposes of monitoring for fraud responses. Your answers will not be shared for any other purposes.

Please select one of the following:

- ◯ I understand the benefits and risks as explained above
- ◯ I do NOT understand the benefits and risks as explained above

Please select one of the following:

- ◯ I consent to participate in the survey
- ◯ I do NOT consent to participate in the survey

Please provide some background information

I am a:
- ◯ Parent of child with Autism (less than 8 years old)
- ◯ Professional who works with Pre-School Children with Autism

Please specify:
- ◯ Behaviour Therapist
- ◯ Behaviour Therapy Assistant
- ◯ Developmental Pediatrician
- ◯ Early Educator
- ◯ Interventionist/ Respite Aide
- ◯ Occupational Therapist
- ◯ Occupational Therapy Assistant
- ◯ Pediatrician
- ◯ Psychologist
- ◯ Psychometrist
- ◯ Registered Nurse or Nurse Practitioner
- ◯ Social Worker
- ◯ Speech Language Pathologist
- ◯ Other

Please specify your profession _____

Age of Child(ren) with Autism: _____
(Please provide youngest child's age)

Number of Children with Autism _____
(All children with Autism, regardless of age)

Total Number of Children _____

Number of Years of Practice with this Population: _____
(Example: 5 Years)

I live in:
- ◯ Alberta
- ◯ British Columbia
- ◯ Manitoba
- ◯ New Brunswick
- ◯ Newfoundland and Labrador
- ◯ Northwest Territories
- ◯ Nova Scotia
- ◯ Nunavut
- ◯ Ontario
- ◯ Prince Edward Island
- ◯ Quebec
- ◯ Saskatchewan
- ◯ Yukon

Postal Code: _____
(Example: L2N 6P6)

I have participated in a previous round of this survey on the ASPCS:
- ◯ Yes
- ◯ No

Our new tool is called 'The Autism Social Participation Classification System ' or ASPCS.

We would like your feedback to improve the tool and determine if each of the 5 levels are clear and distinct.

The purpose of the ASPCS is to: (1) describe the current abilities of the child at present to support preparation to engage in community activities or program transitions; (2) enhance communication between parents and professionals for the child's needs; and (3) reliably group together pre-school children with ASD for intervention or inclusive recreation programs who have similar needs.

The ASPCS is intended to be used to describe a child's typical day or usual abilities, referred to as performance. The ASPCS also can be used to describe a child's best ability, referred to as capacity.

There are two important parts to social participation for preschool children with Autism: The Child and Activities & Environment. We will present each area individually, and ask a series of questions about each level.

There are several Frequently Used Terms in the ASPCS.

Please take a moment to orient yourself to the terms below. These will also be presented at the bottom of each page for your reference.

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

The domain of Child Factors has two parts: Behaviour and Social Desire.

This first section describes the amount of support the pre-school child with Autism needs to regulate behaviour. It is expected that all pre-school children need some supervision to regulate behaviour.

There are five levels in the ASPCS that are distinguished by the child's abilities and amount of facilitator effort needed to engage in social participation, with Level 5 requiring the most support and Level 1 requiring the least support.

Level 5 describes 'Ongoing and Continuous' support - The pre-school child needs direct support from a 1:1 facilitator to succeed. This will take all (100%) of the facilitators' energy and effort, including hand over hand support for all activities. A second facilitator may be needed to guide the activity.

Level 4 describes 'Continuous' support - The child needs direct support from a 1:1 facilitator and will require most (80%) of the facilitators energy and effort. The facilitator may be able to engage in some parts of the activity in side-by-side play to provide prompts, but new and challenging activities will require some hand over hand assistance.

Level 3 describes 'Some or Moderate' support - The child needs direct support from a facilitator in a 1:2 or 1:3 ratio, and requires more (50%) energy and effort on the part of the facilitator to succeed by providing prompts, feedback and support.

Level 2 describes 'Intermittent' support - The child initially needs higher levels of support (such as 1:2 or 1:3 ratios) and direct support, feedback, and prompting in a new program. The child could also be described as 'slow to warm up' to activities, environments, or persons but become successful over time in ratios that already exist within integrated programs, as described in Level 1 below.

Level 1 describes 'Supervision or Indirect Support' support - The child can succeed at facilitator energy, effort, and ratios that exist within integrated preschool programs (1:5 or 1:6).

Take a moment to read each level of Behaviour then answer the questions below.

CHILD FACTORS: BEHAVIOUR (PART A)

LEVEL 5
• Child needs ongoing and substantial direct support from a familiar and knowledgeable adult to regulate behavior in all activities and transitions.

LEVEL 4
• Child needs continuous direct support to regulate behaviour from a familiar and knowledgeable adult in most activities and transitions.

LEVEL 3
• Child needs a moderate amount of support to regulate behaviour from a familiar and knowledgeable adult; particularly with waiting for highly preferred interests

---

LEVEL 2
• Child initially needs intermittent, direct support to regulate behavior, but can readily adept to behavioural

expectations, needing indirect support (supervision) from knowledgeable adults

---

LEVEL 1

• Child is able to regulate behaviour with only indirect support (supervision) from knowledgeable adults.

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	○	○	○	○	○	○	○
Level 5 definition provides a distinct description	○	○	○	○	○	○	○
Level 4 definition is meaningful	○	○	○	○	○	○	○
Level 4 definition provides a distinct description	○	○	○	○	○	○	○
Level 3 definition is meaningful	○	○	○	○	○	○	○
Level 3 definition provides a distinct description	○	○	○	○	○	○	○
Level 2 definition is meaningful	○	○	○	○	○	○	○
Level 2 definition provides a distinct description	○	○	○	○	○	○	○
Level 1 definition is meaningful	○	○	○	○	○	○	○
Level 1 definition provides a distinct description	○	○	○	○	○	○	○

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree:

_____

For Your Reference: Frequently Used Terms

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

This is the second part of the Child Factors domain, called Social Desire.

This section describes the amount of Social Desire the pre-school child with Autism has demonstrated across various social settings.

Identical to the section above, there are five levels in the ASPCS that are distinguished by the child's abilities and amount of facilitator effort needed to engage in social participation, with Level 5 requiring the most support and Level 1 requiring the least support.

Level distinctions are provided here again for your reference.

Level 5 describes 'Ongoing and Continuous' support - The pre-school child needs direct support from a 1:1 facilitator to succeed. This will take all (100%) of the facilitators' energy and effort, including hand over hand support for all activities. A second facilitator may be needed to guide the activity.

Level 4 describes 'Continuous' support - The child needs direct support from a 1:1 facilitator and will require most (80%) of the facilitators energy and effort. The facilitator may be able to engage in some parts of the activity in side-by-side play to provide prompts, but new and challenging activities will require some hand over hand assistance.

Level 3 describes 'Some or Moderate' support - The child needs direct support from a facilitator in a 1:2 or 1:3 ratio, and requires more (50%) energy and effort on the part of the facilitator to succeed by providing prompts, feedback and support.

Level 2 describes 'Intermittent' support - The child initially needs higher levels of support (such as 1:2 or 1:3 ratios) and direct support, feedback, and prompting in a new program. The child could also be described as 'slow to warm up' to activities, environments, or persons but become successful over time in ratios that already exist within integrated programs, as described in Level 1 below.

Level 1 describes 'Supervision or Indirect Support' support - The child can succeed at facilitator energy, effort, and ratios that exist within integrated preschool programs (1:5 or 1:6).

Take a moment to read each level of Social Desire then answer the questions below.

CHILD FACTORS: SOCIAL DESIRE (PART B)

LEVEL 5
• Child does not indicate desire to interact with others; even for the purposes of having needs met or related to preferred interests.

LEVEL 4
• Child does not indicate desire to interact with others and does not notice others in the environment; except for the purpose of having basic needs meet or preferred interests

---

LEVEL 3
• Child has some interest and desire to participate with others and may notice others in the environment; usually related to preferred interests.

LEVEL 2
• Child initially has limited interest and desire to participate with others but notices others in the environment
• However, over time child develops more interest and notices peers in the environment, typically related to preferred interests.

LEVEL 1
• Child usually has a desire for social interactions and is usually aware of others in the environment, does not need to be related to preferred interests

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	○	○	○	○	○	○	○
Level 5 definition provides a distinct description	○	○	○	○	○	○	○
Level 4 definition is meaningful	○	○	○	○	○	○	○
Level 4 definition provides a distinct description	○	○	○	○	○	○	○
Level 3 definition is meaningful	○	○	○	○	○	○	○
Level 3 definition provides a distinct description	○	○	○	○	○	○	○
Level 2 definition is meaningful	○	○	○	○	○	○	○
Level 2 definition provides a distinct description	○	○	○	○	○	○	○
Level 1 definition is meaningful	○	○	○	○	○	○	○
Level 1 definition provides a distinct description	○	○	○	○	○	○	○

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

For Your Reference: Frequently Used Terms

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

This is the Activities & Environment domain.

Identical to the sections above, there are five levels in the ASPCS that are distinguished by the child's abilities and amount of facilitator effort needed to engage in social participation, with Level 5 requiring the most support and Level 1 requiring the least support.

Level distinctions are provided here again for your reference.

Level 5 describes 'Ongoing and Continuous' support - The pre-school child needs direct support from a 1:1 facilitator to succeed. This will take all (100%) of the facilitators' energy and effort, including hand over hand support for all activities. A second facilitator may be needed to guide the activity.

Level 4 describes 'Continuous' support - The child needs direct support from a 1:1 facilitator and will require most (80%) of the facilitators energy and effort. The facilitator may be able to engage in some parts of the activity in side-by-side play to provide prompts, but new and challenging activities will require some hand over hand assistance.

Level 3 describes 'Some or Moderate' support - The child needs direct support from a facilitator in a 1:2 or 1:3 ratio, and requires more (50%) energy and effort on the part of the facilitator to succeed by providing prompts, feedback and support.

Level 2 describes 'Intermittent' support - The child initially needs higher levels of support (such as 1:2 or 1:3 ratios) and direct support, feedback, and prompting in a new program. The child could also be described as 'slow to warm up' to activities, environments, or persons but become successful over time in ratios that already exist within integrated programs, as described in Level 1 below.

Level 1 describes 'Supervision or Indirect Support' support - The child can succeed at facilitator energy, effort, and ratios that exist within integrated preschool programs (1:5 or 1:6).

Take a moment to read each level of Activities & Environment then answer the questions below.

ACTIVITIES & ENVIRONMENT

LEVEL 5
• Child needs ongoing and substantial support to complete familiar and unfamiliar activities across all environments.

LEVEL 4
• Child needs continuous support to complete unfamiliar activities in all environments.
• Child needs some support to complete familiar activities in a familiar environment.

LEVEL 3
• Child needs some support to complete unfamiliar activities in all environments.
• Usually, child can complete familiar activities in familiar environments with indirect support (supervision)

LEVEL 2
• Child initially needs intermittent support to complete unfamiliar activities in unfamiliar environments
• Child can complete familiar activities in familiar or unfamiliar environments with indirect support (supervision)

LEVEL 1
• Child can complete familiar and unfamiliar activities in familiar and unfamiliar environments with indirect support (supervison)

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	○	○	○	○	○	○	○
Level 5 definition provides a distinct description	○	○	○	○	○	○	○
Level 4 definition is meaningful	○	○	○	○	○	○	○
Level 4 definition provides a distinct description	○	○	○	○	○	○	○
Level 3 definition is meaningful	○	○	○	○	○	○	○
Level 3 definition provides a distinct description	○	○	○	○	○	○	○
Level 2 definition is meaningful	○	○	○	○	○	○	○
Level 2 definition provides a distinct description	○	○	○	○	○	○	○
Level 1 definition is meaningful	○	○	○	○	○	○	○
Level 1 definition provides a distinct description	○	○	○	○	○	○	○

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

For Your Reference: Frequently Used Terms

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

Please provide your email address if you would like to be entered for the draw of a $25 Amazon.ca electronic gift card (1 in 10 chance of winning; limited to one entry per person).

If you do not want to be entered into the draw, please leave the email address blank.

Email Address: _____

Confirm Email Address: _____

I would like to participate in follow-up surveys for additional chances to enter in the draw:
◯ Yes
◯ No

If yes, please leave your email address: _____

Content Validity of the ASPCS - Round 3

Background of Study: For pre-school children, social participation provides an opportunity to learn and develop new skills and relationships. We want to understand social participation in pre-school children with Autism so we can support development of new skills.

Purpose: This study aims to ensure the clarity of different levels to describe the abilities of pre-school children with Autism in social participation. Your answers will be used to refine a new measure to classify the abilities and strengths of pre-school children with Autism for participation in social activities.

Eligibility: We need your input if you are a professional with at least 2 years' experience working with pre-school children diagnosed with Autism OR a family member with at least one child with Autism. The child needs to be less than 8 years old.

Ethics Approval & Consent: This study has been approved by the University of Alberta Research Ethics Board on August 19, 2015. This study is part of a graduate student research project. This survey will take approximately 30 minutes. Your participation is entirely voluntary. We encourage you to give your best answer or select the most appropriate answer.

There are no identified risks or direct benefits from answering the questions. At the end of the survey, you have the option to enter your email address to enter a draw for an electronic $25 Amazon.ca gift card (1 in 10 chances to win), or decline to enter.

Your personal information and email address will not be connected to your answers, other than for the purposes of monitoring for fraud responses. Your answers will not be shared for any other purposes.

Please select one of the following:

- ◯ I understand the benefits and risks as explained above
- ◯ I do NOT understand the benefits and risks as explained above

Please select one of the following:

- ◯ I consent to participate in the survey
- ◯ I do NOT consent to participate in the survey

Please provide some background information

I am a:
- ◯ Parent of child with Autism (less than 8 years old)
- ◯ Professional who works with Pre-School Children with Autism

Please specify:
- ◯ Behaviour Therapist
- ◯ Behaviour Therapy Assistant
- ◯ Developmental Pediatrician
- ◯ Early Educator
- ◯ Interventionist/ Respite Aide
- ◯ Occupational Therapist
- ◯ Occupational Therapy Assistant
- ◯ Pediatrician
- ◯ Psychologist
- ◯ Psychometrist
- ◯ Registered Nurse or Nurse Practitioner
- ◯ Social Worker
- ◯ Speech Language Pathologist
- ◯ Other

Please specify your profession _____

Age of Child(ren) with Autism: _____
(Please provide youngest child's age)

Number of Children with Autism _____
(All children with Autism, regardless of age)

Total Number of Children _____

Number of Years of Practice with this Population: _____
(Example: 5 Years)

I live in:
- ◯ Alberta
- ◯ British Columbia
- ◯ Manitoba
- ◯ New Brunswick
- ◯ Newfoundland and Labrador
- ◯ Northwest Territories
- ◯ Nova Scotia
- ◯ Nunavut
- ◯ Ontario
- ◯ Prince Edward Island
- ◯ Quebec
- ◯ Saskatchewan
- ◯ Yukon

Postal Code: _____
(Example: L2N 6P6)

I have participated in a previous round of this survey on the ASPCS:
- ◯ Yes
- ◯ No

Our new tool is called 'The Autism Social Participation Classification System ' or ASPCS.

We would like your feedback to improve the tool and determine if each of the 5 levels are clear and distinct.

The purpose of the ASPCS is to: (1) describe the current abilities of the child at present to support preparation to engage in community activities or program transitions; (2) enhance communication between parents and professionals for the child's needs; and (3) reliably group together pre-school children with ASD for intervention or inclusive recreation programs who have similar needs.

The ASPCS is intended to be used to describe a child's typical day or usual abilities, referred to as performance. The ASPCS also can be used to describe a child's best ability, referred to as capacity.

There are two important parts to social participation for preschool children with Autism: The Child, and Activities & Environment. We will present each area individually, and ask a series of questions about each level.

There are several Frequently Used Terms in the ASPCS.

Please take a moment to orient yourself to the terms below. These will also be presented at the bottom of each page for your reference.

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

The domain of Child Factors has two parts: Behaviour and Social Desire.

This first section describes the amount of support the pre-school child with Autism needs to regulate behaviour. It is expected that all pre-school children need some supervision to regulate behaviour.

There are five levels in the ASPCS that are distinguished by the child's abilities and amount of facilitator effort needed to engage in social participation, with Level 5 requiring the most support and Level 1 requiring the least support.

Level 5 describes 'Substantial' support - The pre-school child needs direct support from a 1:1 facilitator to succeed. This will take all of the facilitators' energy and effort, including hand over hand support for all activities. A second facilitator will likely be needed to guide the activity.

Level 4 describes 'Continuous' support - The child needs direct support from a 1:1 facilitator and will require most of the facilitators energy and effort. The facilitator may be able to engage in some parts of the activity in side-by-side play to provide prompts, but new and/or challenging activities will require some hand over hand assistance.

Level 3 describes 'Some or Moderate' support - The child needs direct support from a facilitator in a 1:2 or 1:3 ratio, and requires more energy and effort on the part of the facilitator to succeed by providing prompts, verbal scripts, reassurance, and/or support.

Level 2 describes 'Intermittent' support - The child initially needs higher levels of energy and effort from a facilitator and direct support (1:2 or 1:3 ratios) in a new program, similar to Level 3. The child could also be described as 'slow to warm up' to activities, environments, or persons but becomes successful over time in ratios that already exist within integrated programs, as described in Level 1 below.

Level 1 describes 'Supervision or Indirect Support' support - The child can succeed at existing facilitator energy and effort levels and ratios (1:5 or 1:6) within integrated preschool programs.

Take a moment to read each level of Behaviour then answer the questions below.

CHILD FACTORS: BEHAVIOUR (PART A)

LEVEL 5
• Child needs substantial direct support (100% - 81% of the time) from at least one familiar and knowledgeable adult to regulate behaviour in all activities and transitions.

LEVEL 4
• Child needs continuous direct support (80% - 61% of the time) to regulate behaviour from a familiar and knowledgeable adult in most activities and transitions.

LEVEL 3
• Child needs some direct support (60% - 41% of the time) to regulate behaviour from a familiar and knowledgeable adult; such as transitioning between activities or waiting for highly preferred interests.

LEVEL 2
• Child initially needs intermittent, direct support (40% - 21% of the time) to regulate behaviour, but can readily adapt to behavioural expectations, needing indirect support (supervision) from knowledgeable adults.

LEVEL 1
• Child is able to regulate behaviour with minimal direct support (20% or less of the time) or only indirect support (supervision) from knowledgeable adults.

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 5 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 4 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 4 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 3 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 3 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 2 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 2 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯
Level 1 definition is meaningful	◯	◯	◯	◯	◯	◯	◯
Level 1 definition provides a distinct description	◯	◯	◯	◯	◯	◯	◯

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

For Your Reference: Frequently Used Terms

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

This is the second part of the Child Factors domain, called Social Desire.

This section describes the amount of Social Desire the pre-school child with Autism has demonstrated across various social settings.

Identical to the section above, there are five levels in the ASPCS that are distinguished by the child's abilities and amount of facilitator effort needed to engage in social participation, with Level 5 requiring the most support and Level 1 requiring the least support.

Level distinctions are provided here again for your reference.

Level 5 describes 'Substantial' support - The pre-school child needs direct support from a 1:1 facilitator to succeed. This will take all of the facilitators' energy and effort, including hand over hand support for all activities. A second facilitator will likely be needed to guide the activity.

Level 4 describes 'Continuous' support - The child needs direct support from a 1:1 facilitator and will require most of the facilitators energy and effort. The facilitator may be able to engage in some parts of the activity in side-by-side play to provide prompts, but new and/or challenging activities will require some hand over hand assistance.

Level 3 describes 'Some or Moderate' support - The child needs direct support from a facilitator in a 1:2 or 1:3 ratio, and requires more energy and effort on the part of the facilitator to succeed by providing prompts, verbal scripts, reassurance, and/or support.

Level 2 describes 'Intermittent' support - The child initially needs higher levels of energy and effort from a facilitator and direct support (1:2 or 1:3 ratios) in a new program, similar to Level 3. The child could also be described as 'slow to warm up' to activities, environments, or persons but becomes successful over time in ratios that already exist within integrated programs, as described in Level 1 below.

Level 1 describes 'Supervision or Indirect Support' support - The child can succeed at existing facilitator energy and effort levels and ratios (1:5 or 1:6) within integrated preschool programs.

Take a moment to read each level of Social Desire then answer the questions below.

CHILD FACTORS: SOCIAL DESIRE (PART B)

LEVEL 5
• Child does not indicate desire to interact with others and does not appear to notice others in the environment; even for the purposes of having needs met or related to preferred interests.

LEVEL 4
• Child does not indicate desire to interact with peers or adults in the environment; except for the purpose of having basic needs met.

LEVEL 3
• Child demonstrates some interest and desire to participate with peers (such as observing from a distance); however, social overtures (although they may appear odd or of poor quality) are typically made towards adults in the environment

---

LEVEL 2
• Child demonstrates interest and desire to participate with peers, and directs equal amounts of social overtures towards adults and peers (although they may appear odd or of poor quality), typically related to preferred interests

---

LEVEL 1
• Child usually has a desire for social interactions and demonstrates social overtures to peers and adults (although they may appear odd or of poor quality) that does not need to be directly related to preferred interests

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	○	○	○	○	○	○	○
Level 5 definition provides a distinct description	○	○	○	○	○	○	○
Level 4 definition is meaningful	○	○	○	○	○	○	○
Level 4 definition provides a distinct description	○	○	○	○	○	○	○
Level 3 definition is meaningful	○	○	○	○	○	○	○
Level 3 definition provides a distinct description	○	○	○	○	○	○	○
Level 2 definition is meaningful	○	○	○	○	○	○	○
Level 2 definition provides a distinct description	○	○	○	○	○	○	○
Level 1 definition is meaningful	○	○	○	○	○	○	○
Level 1 definition provides a distinct description	○	○	○	○	○	○	○

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

For Your Reference: Frequently Used Terms

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

This is the Activities & Environment domain.

Identical to the sections above, there are five levels in the ASPCS that are distinguished by the child's abilities and amount of facilitator effort needed to engage in social participation, with Level 5 requiring the most support and Level 1 requiring the least support.

Level distinctions are provided here again for your reference.

Level 5 describes 'Substantial' support - The pre-school child needs direct support from a 1:1 facilitator to succeed. This will take all of the facilitators' energy and effort, including hand over hand support for all activities. A second facilitator will likely be needed to guide the activity.

Level 4 describes 'Continuous' support - The child needs direct support from a 1:1 facilitator and will require most of the facilitators energy and effort. The facilitator may be able to engage in some parts of the activity in side-by-side play to provide prompts, but new and/or challenging activities will require some hand over hand assistance.

Level 3 describes 'Some or Moderate' support - The child needs direct support from a facilitator in a 1:2 or 1:3 ratio, and requires more energy and effort on the part of the facilitator to succeed by providing prompts, verbal scripts, reassurance, and/or support.

Level 2 describes 'Intermittent' support - The child initially needs higher levels of energy and effort from a facilitator and direct support (1:2 or 1:3 ratios) in a new program, similar to Level 3. The child could also be described as 'slow to warm up' to activities, environments, or persons but becomes successful over time in ratios that already exist within integrated programs, as described in Level 1 below.

Level 1 describes 'Supervision or Indirect Support' support - The child can succeed at existing facilitator energy and effort levels and ratios (1:5 or 1:6) within integrated preschool programs.

Take a moment to read each level of Activities & Environment then answer the questions below.

ACTIVITIES & ENVIRONMENT

LEVEL 5
• Child needs substantial support to complete familiar and unfamiliar activities across all environments.

LEVEL 4
• Child needs continuous support to complete unfamiliar activities in all environments.
• Child needs a moderate amount of support to complete familiar activities in a familiar environment.

LEVEL 3
• Child needs a moderate amount of support to complete unfamiliar activities in all environments.
• Usually, child can complete familiar activities in familiar environments with indirect support (supervision)

LEVEL 2
• Child needs intermittent support to complete unfamiliar activities in unfamiliar environments
• Child can complete familiar activities in familiar or unfamiliar environments with indirect support (supervision)

LEVEL 1
• Child can complete familiar and unfamiliar activities in familiar and unfamiliar environments with indirect support (supervison)

	Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
Level 5 definition is meaningful	○	○	○	○	○	○	○
Level 5 definition provides a distinct description	○	○	○	○	○	○	○
Level 4 definition is meaningful	○	○	○	○	○	○	○
Level 4 definition provides a distinct description	○	○	○	○	○	○	○
Level 3 definition is meaningful	○	○	○	○	○	○	○
Level 3 definition provides a distinct description	○	○	○	○	○	○	○
Level 2 definition is meaningful	○	○	○	○	○	○	○
Level 2 definition provides a distinct description	○	○	○	○	○	○	○
Level 1 definition is meaningful	○	○	○	○	○	○	○
Level 1 definition provides a distinct description	○	○	○	○	○	○	○

Please provide comments and feedback for any levels you rated as neutral, somewhat disagree, disagree or strongly disagree: _____

For Your Reference: Frequently Used Terms

Behaviour: Observable actions by a pre-school child with ASD that can communicate an internal state of dysregulation, needs or wants, or emotions to a person or environment.

Direct Support: An adult who provides behavioural and cognitive strategies, such as visual schedules, first-then boards, and prompting, to support behaviour regulation of a pre-school child with ASD.

Facilitator: The pro-active adult(s) in the environment who recognizes the strengths of the pre-school child with ASD to overcome the challenges of social interactions and play. Typically the facilitator uses scaffolding, modeling, and scripting to promote play-based behaviours between child and self or child and peer(s).

Pre-School Children with Autism Spectrum Disorder (ASD): Pre-school children with ASD typically between their 3rd and 5th birthdays, are usually engaged in school readiness activities, such as attending a play group, pre-school, or community/ recreation activities, such as swimming or crafts.

Indirect Support (Supervision): The interaction and coaching by a knowledgeable adult with a pre-school child with ASD. This may include visual monitoring of interactions between peers, listening of conversations, provision of re-affirming statements, and reconciliation of disagreements. It is expected that all pre-school children within this age group require some degree of supervision at home and in the community.

Social Participation: A pivotal construct for pre-school children with ASD during early development, as it provides an opportunity to develop and acquire foundational social skills and peer relationships that contribute to individual, family, and community wellbeing and belonging.

Stakeholders: Individuals who have a personal or professional interest in preschool children with ASD. Individuals typical include persons with ASD, parents and family members of individuals with ASD, professionals, clinicians and educators who work with or consult for persons with ASD.

Please provide your email address if you would like to be entered for the draw of a $25 Amazon.ca electronic gift card (1 in 10 chance of winning; limited to one entry per person).

If you do not want to be entered into the draw, please leave the email address blank.

Email Address: _____

Confirm Email Address: _____

I would like to participate in follow-up surveys for additional chances to enter in the draw:
◯ Yes
◯ No

If yes, please leave your email address: _____