# EXPLORING EVERYDAY FUNCTIONING IN CHILDREN WITH ASD

# EXPLORING EVERYDAY FUNCTIONING AND ENVIRONMENTAL CONTEXTS IN THE DEVELOPMENT OF CHILDREN WITH ASD: A FOCUS ON THE PRESCHOOL YEARS

BY

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## Lay abstract

This thesis consists of a series of studies examining factors associated with the abilities of children with autism spectrum disorder and their participation in daily activities. The first study provides a review of the literature examining the association between cultural backgrounds of parents and their engagement in autism child services. The second study explores the patterns of engagement in childhood activities for preschool children with autism using parent-reported measures. This study also examines the associations between environmental factors and the social communication abilities of a child and their participation in childhood activities. The third study examines the social communication abilities of children with autism using a new approach to describing levels of ability, rather than deficits. This study looks at the social communication abilities of preschool children with autism over six months. The importance of this work is that it adds to the literature by generating new knowledge on the abilities of children with autism, rather than their deficits. It also emphasizes the need for support in healthcare settings and in the community to improve these children's participation.

## Abstract

This dissertation explores the functioning and participation of children with autism spectrum disorder (ASD) in their natural environments, with a focus on the preschool years.

Chapter 1 provides the context for this dissertation through introducing the theoretical frameworks that were used, exploring function-based measures, and social communication functioning.

Chapter 2 is a qualitative evidence synthesis of the literature to identify the cultural factors that are associated with parents' engagement in their children's healthcare services. This chapter highlights the challenges that parents of children with ASD faced and the importance of health providers to be culturally competent in family-centered care.

Chapter 3 is a descriptive study that aims to explore the participation patterns of preschool children with ASD at home and in the community. The association of environmental factors and social communication abilities on children's participation are also explored. This chapter emphasizes that children with ASD participated in a variety of activities at home and in the community. It also highlights the importance of supporting parents to engage their children in activities and the need for community to support their participation.

Chapter 4 examines the stability of a function-based categorization system – the Autism Classification System of Functioning: Social Communication (ACSF:SC). Children's social communication abilities were rated using the ACSF:SC at baseline and six months. This chapter indicates that rating of social communication abilities can vary over time. Therefore, frequent assessment using the ACSF:SC is recommended for accurate identification of the child's current social communication abilities.

Chapter 5 discusses the clinical and research implications of this dissertation work. It also discusses knowledge translation opportunities and potential future work.

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I cannot thank my supervisor, Dr. Briano Di Rezze, enough for his endless amount of encouragement, support, and patience throughout my PhD journey. His knowledge and wisdom were instrumental for completing this journey. Working with Briano and learning from him has truly been a privilege.

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## List of Abbreviations and Symbols

| | |
|---|---|
| ACSF:SC | Autism Classification System of Functioning: Social Communication |
| ADHD | Attention Deficit Hyperactivity Disorder |
| AMED | Allied and Complementary Medicine |
| ANOVA | Analysis of Variance |
| ASD | Autism Spectrum Disorder |
| BC | Best Capacity |
| BOSCC | Brief Observation of Social Communication Change |
| CANS | Child and Adolescent Needs and Strengths Assessment |
| CASE | Child and Adolescent Scale of Environment |
| CASP | Child and Adolescent Scale of Participation |
| CFCS | Communication Function Classification System |
| CFFS | Child and Family Follow- up Survey |
| CINAHL | Cumulative Index to Nursing & Allied Health Literature |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorders-5th edition |
| EMBASE | Excerpta Medica database |
| ERIC | Education Resources Information Center |
| FACT | Functional Abilities Classification Tool |
| GMFCS | Gross Motor Function Classification System |
| IBSS | International Bibliography of the Social Sciences |
| ICF | International Classification of Functioning, Disability, and Health |
| ICF-CY | International Classification of Functioning, Disability, and Health-Child and Youth |
| $k_w$ | kappa coefficient |
| MACS | Manual Ability Classification System |
| MeSH | Medical Subject Headings |
| PARC | Pediatric Autism Research Cohort |
| PEM-CY | Participation and Environment Measure for Children and Youth |
| SES | Socioeconomic Status |
| SNA | Specific Negative Agreement |
| SPA | Specific Positive Agreement |
| SSP-2 | Short Sensory Profile 2 |
| TBIs | Traumatic Brain Injuries |
| TP | Typical Performance |
| WHO | World Health Organization |
| YC-PEM | Young Children Participation and Environment Measure |

## Declaration of Academic Achievement

This thesis follows a sandwich style and consists of five chapters. I was the **sole author** of Chapters 1 and 5 and have benefited from the guidance, feedback, and review from my supervisor Dr. Briano Di Rezze and my committee members Prof. Peter Rosenbaum and Dr. Kathy Georgiades.

I was the **first author** for Chapters 2, 3 and 4 and have benefited from the contributions of co-authors as follow:

Chapter **2**: the manuscript was titled "*The Impact of Culture in Diagnosis and Service Engagement for Families of Children with Autism Spectrum Disorder: A Qualitative Evidence Synthesis".* The authors are: G. Khalifa, P. Rosenbaum, K. Georgiades, M. Reitzel, and B. Di Rezze. I was responsible for developing the research question and study design, conducting the database searches and thematic analysis, collecting and summarizing results, and writing the manuscript. BDR contributed to the refinement of the research question and research design, interpretation of findings, and provided editorial feedback and suggestions on the original draft and subsequent revisions. PR and KG contributed to the refinement of the research question and provided editorial feedback and suggestion to enhance the quality of the manuscript. MR contributed to the validation of the developed themes and their refinement.

Chapter **3**: The manuscript was titled *"Exploring the Participation Patterns and Impact of Environment in Preschool Children with ASD".* The authors are: G. Khalifa, P. Rosenbaum, K. Georgiades, E. Duku, and B. Di Rezze. I was responsible for developing the research question and study design, data curation and analysis, interpretation of findings, and writing the manuscript. ED confirmed the accuracy of my statistical analysis and interpretation. BDR contributed to the refinement of the research question and study design and data interpretation, and provided editorial feedback and suggestions on the original draft and subsequent revisions. PR and KG contributed to the refinement of the research question and provided editorial feedback and suggestions to enhance the quality of the manuscript.

Chapter **4**: the manuscript was titled *"Stability of the Autism Classification System of Functioning: Social Communication and associated factors".* The authors are: G. Khalifa, P. Rosenbaum, K. Georgiades, E. Duku, and B. Di Rezze. I was responsible for developing the research question and study design, data curation and analysis, interpretation of findings, and writing the manuscript. ED confirmed the accuracy of my statistical analysis and interpretation. BDR contributed to the refinement of the research question and study design and data interpretation, and provided editorial feedback and suggestions on the original draft and subsequent revisions. PR and KG contributed to the refinement of the research question and provided editorial feedback and suggestion to enhance the quality of the manuscript.

Each manuscript is presented in the format of the target journal for publication. The target journal and publication status are noted for each manuscript in context as at the time of submission of this thesis.

# Chapter 1

# Chapter 1. Introduction

## *Background on ASD*

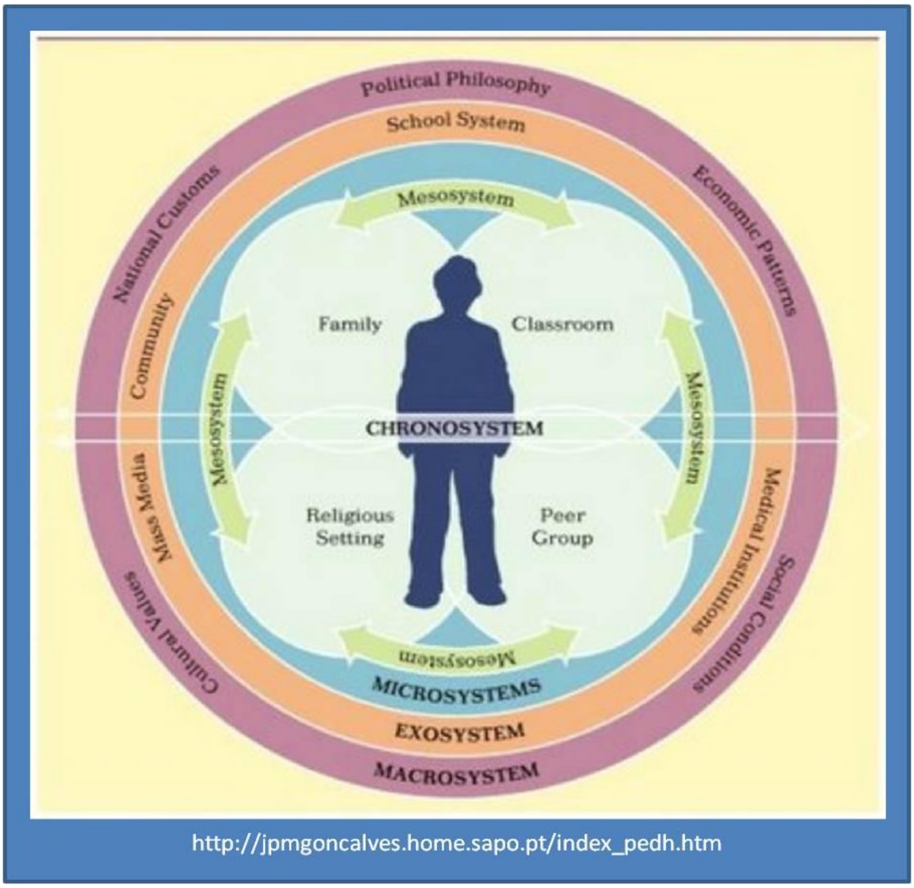
Studies have shown that the number of children diagnosed with Autism Spectrum Disorder (ASD) continues to increase worldwide (Gan, Tung, Yeh, Chang, Wang, 2014), with an estimated prevalence in the US as high as 1 in 54 children (Maenner et al., 2020). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), ASD is characterized by persistent social communication difficulties and restricted, repetitive behaviours (American Psychiatric Association, 2013). ASD symptoms may appear early in life, usually before the second year (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Chawarska et al., 2007), but the majority of children are diagnosed in the preschool years (approximately 3 to 4 years of age) (Cohen & Volkmar, 2014). Given that services usually start after the diagnosis, it is crucial to understand the functional abilities of this age group. Early interventions for children with ASD and their families are essential to improve outcomes, including social, emotional, and cognitive development (Hume, Bellini, & Pratt, 2005; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014).

## *ASD and everyday functioning*

ASD is a lifelong condition that causes restrictions involving various aspects of the individual’s life (Gan et al., 2014). It is usually associated with poor outcomes related to education, employment, social relationships, and quality of life (de Schipper et al., 2016; Lollar & Simeonsson, 2005; Mahdi et al., 2018). Individuals diagnosed with ASD have a broad range of behavioural characteristics and symptoms associated with the condition (Zwaigenbaum et al., 2015; Tager-Flusberg, Paul & Lord, 2005), such as a wide range of language development (verbal and non-verbal) and cognitive abilities. An ASD diagnosis on its own does not provide much information on the reality of a specific child’s ability and functioning in everyday life (Castro & Pinto; 2013; Klein & Kraus de Camargo, 2018). Individuals with ASD usually have deficits in their adaptive functioning, an important indicator of the individual’s outcome (Farley et al., 2009; Kanne et al., 2011). Adaptive behaviours are defined as “the collection of conceptual, social, and practical skills that have been learned by people in order to function in everyday lives" (Luckasson et al. 2002: p. 73 as cited in Hill, Gray, Kamps, & Varela, 2015). Adaptive functioning is often assessed using the Vineland Adaptive Behaviour Scale (Vineland-3) (Farley et al., 2009; Ventola et al., 2014). Vineland-3 measures skills in four areas: communication, daily living skills, socialization, and motor skills (Sparrow, Cicchetti & Saulnier, 2016). A longitudinal study of adults with ASD found that adult success in various areas including employment, social relationships, and social services use was associated with adaptive skills (Farley et al., 2009). In that study, some individuals with high IQ scores who had limited adaptive skills were frustrated with their limitations, while some individuals with borderline IQ scores who had practical adaptive skills were able to live independently with minimal assistance (Farley et al., 2009).

In 2001, the World Health Organization (WHO) published the International Classification of Functioning, Disability, and Health (ICF), followed by the child and youth version (ICF- CY) in 2007. Both outlined a framework for health, detailing the complex nature of everyday functioning and the associated constructs, rather than focusing exclusively on an individual's impairment. The ICF provides a multidimensional biopsychosocial approach to human functioning. The framework outlines two key categories: 1) functioning and disability, and 2) contextual factors (WHO, 2007). Functioning and disability have two components: (1) body functions and structures, (b) activities and participation. Contextual factors include both personal and environmental factors. The ICF views functioning as an outcome of bidirectional and nonlinear interactions between the health condition and contextual factors (WHO, 2007). Functioning is regarded as a dynamic process that involves the continuous interaction between the individual and his or her immediate environment (WHO, 2007).

Using the ICF as a framework allows us to describe child functioning and participation while considering the various factors that could impact it, including the personal factors (e.g. race, habits, education) as well as the various environmental factors (e.g., physical, social, and attitudinal environments) (WHO, 2007). Based on this framework, improving children's functioning requires an understanding of their environment (Noreau & Boschen, 2010; Vaz, Silva, Mancini, Carello, & Kinsella-Shaw, 2017). The impact of the environment on human functioning and development has also been described by the bioecological systems theory (Bronfenbrenner, 1977) that identified the different layers of the environment and their impact on child development [Figure 1]. According to Bronfenbrenner, children's development is affected by their interaction with the environment(s) at various levels (directly and indirectly), including their immediate family, community, and society (Bronfenbrenner, 1977). The younger the child, the more their functioning and opportunities to participate in activities are dependent on their parents, caregivers, and supports around them, including educators and service providers (Humphry, 2002; WHO, 2007). Parents' decisions to involve their children in certain activities are also influenced by their beliefs and their cultural backgrounds (Dunst, Bruder, Trivette, & Hamby, 2006; Humphry, 2002). Furthermore, parents' cultural background can also impact their understanding and acceptance of health- related services to support their child (e.g., ASD diagnostic and related services) (Sritharan & Koola, 2019).



http://jpmgoncalves.home.sapo.pt/index_pedh.htm

*Figure 1.* The bioecological systems theory

### *ASD and culture*

Culture molds behaviours, and the decision as to what is considered acceptable or unacceptable behaviour is highly influenced by culture (Norbury & Sparks, 2013). Culture also influence how families understand and treat neurodevelopmental disorders such as ASD (Kang-Yi et al., 2018). With increasing cultural diversity in Canada and other countries, families of children with ASD are faced with multiple challenges, not only because they have children with an ASD diagnosis, but also due to cultural differences (such as differences in communication and values) (Khanlou et al., 2017; Rivard, Millau, Magnan, Mello & Boulé, 2019).

Early identification and diagnosis of ASD is important as it is the gateway for ASD-related services. Starting interventions early proved beneficial for children’s long-term outcome, family stress and coping, and consequently, society’s financial outlays (Garcia Primo et al., 2020; Sritharan & Koola, 2019). However, several factors may impact the timely access to ASD diagnostic and support services. Some of these factors include the clinical presentation of symptoms (e.g., severe language delay prompts early diagnosis, while hearing impairment may delay the identification of ASD symptoms) (Garcia Primo et al., 2020). In addition, family-related factors, such as living in rural areas with low resources and/or low socioeconomic status of the family, can also impact access to diagnosis services (Garcia Primo et al., 2020; Khanlou et al., 2017)).

Immigration could also be the cause of delay in ASD diagnosis (Garcia Primo et al., 2020; Mandell, Novak, & Zubritsky, 2005). Studies have shown that children with immigrant parents are more likely to be diagnosed later when compared to their peer of non-immigrant parents (Daniels & Mandell, 2014; Mandell, Novak, & Zubritsky, 2005; Sritharan & Koola, 2019). Family may lack understanding of the healthcare system in the host country (Khanlou et al., 2017); they might also not be aware of the available ASD-related services (Sritharan & Koola, 2019). In addition, families’ feelings of shame or guilt might also prevent them from accessing services in a timely manner (Sritharan & Koola, 2019).

### *Function-based tools in the field of ASD*

Changes in social communication in children with ASD are difficult to measure, because the available measures focus on the deficits rather than on the functional abilities of the individual (Bishop et al., 2019). Focusing on deficits overshadows the positive, including the abilities an individual with a disability might have (Cosden, Koegel, Koegel, Greenwell, & Klein, 2006). A study of the perspectives of parents with children recently diagnosed with ASD (n=17) and professionals (n=11) on ASD prognosis found that while parents have a positive outlook, professionals described negative outcomes (Nissenbaum, Tollefson, & Reese, 2002).

However, there is a growing body of literature that supports the need for abilities-based tools and interventions (Anderson, Lyons, Giles, Price, & Estle, 2003; Streiner, 2011). A function-based approach helps to identify an individual's assets, which are essential to integrate into intervention planning (Cosden et al., 2006). Furthermore, a function-based approach enables a comprehensive view of the child and their contextual assets, such as their family and community resources, which is also helpful for intervention planning (Cosden et al., 2006).

Few measures have been developed that are abilities-based, such as the Child and Adolescent Needs and Strengths Assessment (CANS manual, 2010), the Functional Abilities Classification Tool (FACT) (Klein & Kraus de Camargo, 2018), the ICF Core Sets for ASD (Bölte et al., 2014) and the Autism Classification System of Functioning: Social Communication (ACSF:SC) (Di Rezze et al., 2016a). CANS is a functional assessment that is designed to communicate the assessment outcomes in a broad range of areas (e.g., Executive functioning, emotional regulation skills, social skills, acculturation, mental health needs) to help parents and professionals make an informed decision for service planning (CANS manual, 2010). The FACT is a proposed functional classification to be used with children with developmental disorders to facilitate intervention planning, collaboration, and reassessment, and to determine the point of entry of support at the school (Klein & Kraus de Camargo, 2018).

While CANS and FACT are not ASD-specific tools, the ICF Core Sets and the ACSF:SC are ASD-specific function-based tools. The ICF Core Sets are developed for a practical use of the ICF-CY in the context of ASD. Using these Core Sets will provide clinicians with an overarching framework to explore key domains relevant for individuals diagnosed with ASD. They can also be used for intervention planning and follow up assessment (Bölte et al., 2014). ACSF:SC is a 5-level descriptive classification of the social communication abilities with reliable ratings by parents and professionals that have been validated for preschool children with ASD (Di Rezze et al., 2016a). The ACSF:SC is not a diagnostic tool but rather a complementary descriptive classification system of child social communication functioning using ability-focused language. An individual who is familiar with the child is asked to provide two ratings of social communication ability, based on “Best capacity” (i.e., best observed ability over the past month) and “typical performance” (i.e., average abilities demonstrated over the past month) (Di Rezze et al., 2016a).

### *Social Communication Functioning in ASD*

The examination of a child’s ability can apply to various developmental characteristics; however, social communication is a hallmark for ASD diagnosis (Anderson, Oti, Lord, & Welch, 2009; Di Rezze, Rosenbaum & Zwaigenbaum, 2012; Volkmar, Paul, Klin & Cohen, 2005). Social communication deficits are present in children with ASD despite their chronological age or cognitive abilities (Anderson et al., 2009; Cunningham, 2012). In the literature, there is no standard definition of social communication (Matson, Matson & Rivet, 2007; Tajik-Parvinchi, under review). To be able to describe and communicate functioning beyond the diagnostic categories, professionals need a language that is clear, consistent, and meaningful for professionals and stakeholders (Castro & Pinto, 2015). The aforementioned ACSF:SC provides a common language to communicate social communication abilities in ASD. The ACSF:SC defines social communication as “the ability to communicate (with or without words) for the **purpose** of interacting with others” (Di Rezze et al., 2016b, p2).

### *Social Communication in the Preschool Years*

Typically developing infants have the capacity to begin a social relationship with their caregiver (Volkmar et al., 2005). Social communication starts early in life with simple skills such as eye gaze and social smiling (Werner, Dawson, Osterling & Dinno, 2000), which provide the child with social opportunities to develop more complex skills (Vernon, Koegel, Dauterman, & Stolen, 2012). Social communication deficits for the majority of children with ASD appear early in life and persist throughout their lifespan (Anderson et al., 2009; Carter, Davis, Klin & Volkmar, 2005; Matson, Matson & Rivet, 2007). Eye gaze, imitation, and joint attention are some of the early skills that are required for future social communication development (Anderson et al., 2009; Carter et al., 2005).

The eye gaze starts as early as the first month of life as infants prefer human faces stimuli (Carter et al., 2005). However, not all children who were later diagnosed with ASD show atypical eye gaze (Young, Merin, Rogers & Ozonoff, 2009). Nevertheless, because children with ASD have limited interest in human faces, they miss social cues that prepare them for more complex social interaction (Vernon et al., 2012).

Imitation skills are essential for social communication behaviour and develop early in life (Williams, Whiten & Singh, 2004). However, children with ASD show deficits in imitating their parents (Williams, Whiten & Singh, 2004). “Peekaboo” and “pat a cake” are examples of social play that require imitation and social dialogue and are usually reported by parents as early examples of deficits in reciprocal social play (Carter et al., 2005; Williams, Whiten & Singh, 2004).

Joint attention appears early in life, usually before the first birthday (Clifford & Dissanayake, 2008; Carter et al., 2005; Wetherby, 2006). It involves sharing emotional meaning between parents, child, and an object (Carter et al., 2005; Wetherby, 2006). It is one of the early forms of nonverbal social communication that is affected in children with ASD (Clifford & Dissanayake, 2008). Joint attention involves two aspects: initiating joint attention, such as using eye contact to establish a shared experience, and responding to joint attention, which consists of the ability to follow parents’ gaze when they are pointing at something in the distance (Wetherby, 2006). Joint attention is an essential skill for the subsequent development of social and behavioural competence in the preschool years (Carter et al., 2005).

### *Changes in social communication over time*

ASD symptoms persist throughout life in the majority of individuals diagnosed with ASD (Anderson et al., 2009). However, the quality, frequency, and intensity of these symptoms change over time (Gotham, Pickles, Lord, 2009). Trajectory studies of social communication demonstrate that some of the skills do eventually develop in most children with ASD, but do so at a slower pace than typically developing children (Paparella, Goods, Freeman, & Kasari, 2011). An example of these skills includes nonverbal joint attention and requesting skills (e.g., reaching, giving, and pointing gestures to make request). While requesting skills appear to have the same sequence of development as seen in typically developed children, nonverbal joint attention skills follow a different pattern of development in children with ASD (Paparella et al., 2011).

In the field of ASD, there are various interventions that target social communication, which contribute to changes in social communication over time (Hansen, Blakely, Dolata, Raulston, & Machalicek, 2014). However, there is a lack of valid and reliable measures to detect changes in social communication (Grzadzinski et al., 2016), as these are often subtle and hard to measure, even though they are meaningful and important changes (Cunningham, 2012; Grzadzinski et al., 2016).

### *Objectives of thesis work*

The overall objectives of this thesis are to examine: 1) the participation and functioning of preschool children with ASD using a function-based tool; and 2) identify the environmental factors associated with levels of functioning of children with ASD.

### *Composition of the dissertation*

This dissertation includes three components, as follows:

1. The first paper is a qualitative evidence synthesis of the literature to identify the cultural factors associated with parents' decision to seek help and engage in services for their child with ASD. Culture is part of the social environment, and an unsupportive environment could hinder a child's development and participation in age-appropriate activities. The purpose of this synthesis was to identify cultural factors that impact parents' decision to seek help and engage in services for their child with ASD. Studies from various cultural backgrounds were

included, and nine factors were identified. This paper highlights several challenges that are faced by parents from different cultural backgrounds and the importance of culturally competent practices to support parents.

2. Participation is essential for well-being and is commonly limited in children with disabilities. There is limited information about the participation patterns of preschool children with ASD. Therefore, the second paper explores their participation pattern using the Young Children Participation and Environment Measure (YC-PEM) for preschool children with ASD across ACSF:SC levels. YC-PEM enabled us to explore participation in different environments. The home and community were selected as they are the natural environments for preschool children with ASD, where their participation in activities usually takes place. The relationship between social communication abilities and participation (frequency and level of involvement) were also explored as social communication is a central feature of ASD diagnosis.
3. To further explore the functioning of preschool children with ASD, the stability of the Autism Classification System of Functioning: Social Communication (ACSF:SC) and the factors associated with social communication were explored over a six-month interval and are reported in the third paper in this thesis. Results indicated that the ACSF:SC is useful for providing a common language to describe the abilities of children with ASD, but frequent ratings using the ACSF:SC is recommended.

The three chapters together explored functioning in different environmental contexts. The environment has an impact on functioning and participation, including the physical, social, or attitudinal environment. In the last chapter, findings from these three chapters have been synthesized, clinical and research implications are provided, and future research directions are outlined.

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# Chapter 2

# Chapter 2

## Title: The Impact of Culture in Diagnosis and Service Engagement for Families of Children with Autism Spectrum Disorder: A Qualitative Evidence Synthesis

**Introduction to Chapter 2:** This chapter explores the cultural factors that are associated with parents' decision to seek diagnosis and intervention services. It informs the thesis by exploring the impact of the social environment on child development and the uptake of services for children with ASD. This research will describe culture-based challenges faced by parents of children with ASD that healthcare providers need to be aware of for better family- and child-centred care. Diagnostic services are the first step for parents on their journey through the service system with their child with ASD, and this first experience could have an impact on child functioning and participation.

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## Abstract

**Objective:** Autism spectrum disorder (ASD) is the fastest growing childhood neurodevelopmental disorder. The prevalence of ASD is believed to be increasing globally, regardless of culture or ethnicity. The aim of this qualitative evidence synthesis was to identify the factors that impact on parents' decisions to seek help and engage in services for their child with ASD. **Methods:** Qualitative studies were identified in AMED, PsycINFO, ERIC, IBSS, Social Sciences Abstracts, CINAHL, PubMed, and EMBASE, through a comprehensive search from October 2018 to February 2019. Included studies were original qualitative studies that explored the influence of parents' culture on ASD, published in English within a peer-reviewed journal. A thematic synthesis using a systematic procedure with two independent reviewers was conducted with the selected studies, using the results/findings section of each paper. **Results:** A total of 29 studies were included in this review, identifying nine factors related to parents' decision to seek help and engage in services: 1) lack of general knowledge about child development and impairments, 2) beliefs about the causes of ASD, 3) symptoms of the child, 4) race/ ethnicity, 5) socioeconomic status, 6) language barrier, 7) community perception & societal acceptance, 8) extended family, and 9) challenges engaging with services. These factors were reported by parents from various cultural backgrounds. **Conclusions:** The identified factors highlight the challenges faced by families of various cultural backgrounds, and emphasize the importance of culturally competent practices to provide family-centered care. These findings also lead to recommendations on what to integrate into future practice.

***Keywords:*** Autism Spectrum Disorder, cross- cultural, cultural differences, treatment practices, services.

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by a pattern of restrictive, repetitive behaviors and challenges in social communication (American Psychiatric Association, 2013). ASD is one of the fastest growing childhood disabilities (Ardhanareeswaran & Volkmar, 2015; Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014). It is estimated that 1 in 59 children in the US, and 1 in 66 in Canada, is diagnosed with ASD (Baio et al., 2018; Centers for Disease Control and Prevention, 2018; Public Health Agency of Canada, 2018). Reports indicate that ASD affects all ethnic and racial groups (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014). Although the prevalence of ASD is high in Western countries, other countries around the world have a lower prevalence. For example, the prevalence rate of ASD in Saudi Arabia is 18 per 10,000 children, and 29 per 10,000 in the United Arab Emirates (Ouhtit et al., 2015). Moreover, children from ethnic minority families are reportedly less likely to receive an ASD diagnosis, and, when they do, they are typically older than ethnic majority children (Croen, Grether, & Selvin, 2002; Hewitt et al., 2016).

Several factors contribute to these prevalence discrepancies, including assessment methods, knowledge of ASD, and diagnostic procedures with varying levels of psychometric evidence supporting the reliability and validity of these approaches (Posserud, Lundervold, Lie, & Gillberg, 2010; Zaroff & Uhm, 2012). Cultural differences in the perception of ASD symptoms may also contribute to varying prevalence estimates worldwide (Zaroff & Uhm, 2012). Culture comprises the beliefs, attitudes, behaviors, and values shared by a group of people (Matsumoto, 2001). Culture influences the manner in which individuals communicate their illness and what symptoms they may be willing to report (U.S. Office of the Surgeon General, U.S. Center for Mental Health Services, & U.S. National Institute of Mental Health, 2001). Culture also plays a vital role in decision-making regarding health, such as when and from whom medical care should be pursued (Lai & Surood, 2009). Cultural differences are likely to impact how populations understand and provide treatment for children with ASD, based on a lack of consensus on the etiology of ASD (Kang-Yi et al., 2018), differing behavioral norms between cultures (Kang-Yi et al., 2018; Ravindran & Myers, 2013), and the lack of a universally accepted, predictable course of intervention (Kang-Yi et al., 2018). Thus, selection of a given therapy route may rely on the local set of cultural beliefs, as demonstrated by research among Asian and East Asian communities within and outside of the US (Kang-Yi et al., 2018; Ravindran & Myers, 2013). Despite the importance of cultural influences, there remains a lack of rigorous reviews on the topic of cultural impact and ASD.

In a narrative review, Mandell and Novak (2005) explored the role of culture on parents' decision to subscribe to a specific intervention. They described that parents' interpretations of ASD symptoms dictated the type of intervention chosen for their child. Additionally, the first symptoms detected by parents varied from culture to culture. For example, in India, the symptoms initially arousing concern from parents related to social issues, while, for non-Indian parents, they related to language deficits. Families also tended to attribute symptoms to non-health factors (e.g., a child's failure to respond to parental direction may be interpreted as "willfulness"). Furthermore, familial beliefs on the cause and prognosis of ASD may impact treatment decisions. If ASD is believed to result from gastrointestinal dysfunction, parents will opt for gastrointestinal and anti-fungal therapeutics. Families believing that ASD is curable will use interventions promoted as curative, while those believing that ASD is a chronic condition may fail to pursue any type of intervention. Finally, these authors explored ethnic disparities in healthcare systems, wherein ethnic minorities received a diagnosis later and usually engaged in services less often (Mandell & Novak, 2005).

Another narrative review by Bernier, Mao, and Yen (2010) explored cultural differences in diagnosis, acceptance, and treatment of ASD. They indicated the importance of considering the effect of both macro- and micro-level cultural factors. The macroscopic factors included the availability of services and funded treatment options, as well as societal acceptance of the disorder. Factors at the micro-level included parents' perspectives on ASD and their reactions to the diagnosis, which ultimately influence the choice of treatment.

Cultural beliefs on appropriate social behaviors can affect the diagnosis of ASD. As a component of non-verbal communication, lack of eye contact is deemed pivotal for ASD diagnosis in many countries; however, some Asian cultures consider eye contact disrespectful. Bernier et al. (2010) also indicated some of the Indian cultural beliefs that impact the likelihood of seeking diagnosis. For example, Indians believe that boys do not speak early; therefore, the diagnosis of ASD is usually delayed (Bernier et al., 2010). Delayed diagnosis can also occur when continuing medical education and recertification is not required in some societies. This engenders a situation wherein older, more respected physicians are not up-to-date on clinical guidelines for ASD diagnosis, possibly resulting in missed or incorrect diagnosis. Many cultures, such as Native Hawaiian and

Native American communities, have languages where the term ASD (or its diagnosis) does not exist. Discrimination against ethnic minorities, especially African Americans, has been proposed as a factor contributing to delayed diagnosis (Bernier et al., 2010; Liptak et al., 2008). Likewise, literature from Chinese and South Asian communities indicates that stigma surrounding ASD has led to delayed diagnosis and parents avoiding seeking help (Bernier et al., 2010). Finally, treatment goals and decisions are influenced by cultural beliefs. For example, the use of complementary and alternative medicine was common for Western and Chinese families, while Mexican American families prioritize being polite and obeying authority figures, and Anglo-American mothers more often value self-directed learning and independent thinking. Overall, the existing reviews in the literature provide a preliminary understanding of culture's impact on ASD. However, these works were demonstrably unsystematic in their methodology; literature searches and subsequent analyses that purported to identify cultural factors were limited in transparency and thereby failed to capture a sufficiently comprehensive scope of literature at the intersection of ASD and culture.

Several qualitative studies have explored cultural impacts on ASD diagnosis and intervention; however, there are no known previous systematic attempts to search the qualitative evidence, synthesize and integrate their findings, and deduce their implications for clinical practices. Qualitative studies provide deep understanding of the impact of culture on ASD. Furthermore, qualitative methodologies can also explore hypotheses or factors that can lay the groundwork for subsequent quantitative analyses (George & Apter, 2004; Perez et al., 2007). The aim of this qualitative evidence synthesis is to delineate and synthesize qualitative studies to identify factors that influence parents' decision to seek help and engage in services for their child with ASD. The study also details the clinical implications and underscores the importance of considering these factors for culturally competent practices.

## Methods

A qualitative evidence synthesis using a thematic synthesis approach was undertaken to answer the following research question: What are the factors that influence parents’ decision to acknowledge developmental concerns in their child with possible ASD and engage in services to obtain a diagnosis and necessary supports?

Eight databases that contain the vast majority of ASD-related research, including international studies, were searched systematically, including AMED (Allied and Complementary Medicine), PsycINFO, ERIC, IBSS (International Bibliography of the Social Sciences), Social Sciences Abstracts, CINAHL, PubMed, and EMBASE. A list of keywords was developed to search these databases. A university librarian was consulted to ensure the comprehensiveness of the search. Various search tools were employed, including subject heading, MeSH terms, and Boolean operators to narrow, widen, or combine literature searches.

For the search terms, keywords included (autism spectrum disorder, ASD, autistic disorder, or Asperger syndrome) AND (culture, ethnicity, cross-cultural, cultural differences, Asian culture, Arabic culture, Chinese culture, or Indian culture) AND (treatment practices, diagnosis, intervention, or services). The cultures included have some of the largest populations in the world who are immigrating to Western countries, although the broader keyword “culture” was also included to avoid limiting the search results exclusively to the aforementioned cultures.

Studies were included if they were published in English in a peer-reviewed journal, and if they consisted of original qualitative studies that explored the influence of parents' culture on ASD. Studies were excluded if they: (1) used exclusively quantitative methods; (2) included participants with diagnoses other than ASD (e.g., intellectual disability, ADHD); (3) compared the presentation of ASD traits among different cultural groups; (4) examined the psychometric properties of outcome measures between cultural groups; or (5) were case studies of an individual with ASD from a specific ethnicity.

A three-stage process was used to select the studies: (1) scanning the study titles; (2) inclusion of studies with relevant titles to scan their abstract; and (3) retrieval of studies that met the inclusion criteria, which underwent the full-text review stage.

## Thematic Analysis

A thematic analysis approach was used to identify the factors that impact parents' decisions to seek diagnosis and/or engage in services for a child suspected of having ASD. The approach followed Braun and Clarke's (2006) steps for thematic analysis for each selected paper, namely (1) generate initial codes systematically throughout the entire data set; (2) search for themes by collating the codes into potential themes and gathering the relevant data for each theme; (3) review themes to ensure that the generated themes are appropriate for the extracted codes as well as for the entire data set; and (4) define and name themes, which involves ongoing analysis to refine the specifics, definitions, and names of each theme. A second reviewer was recruited to validate the themes (factors) to confirm the rigor of the findings as well as to refine the names of the themes. A code book with description of the factors and codes was provided to the second reviewer along with the data extraction table that included the assigned factors to each study. The second reviewer reviewed the papers, verified the assigned factors, and added any missed factor. Upon further discussion between the two reviewers, the names of two factors were refined such that one sub-code was added and one sub-code was refined.

### Data Extraction

Papers that met the inclusion criteria and passed the full-text review stage were summarized using a specific table format. The table was used to present, as clearly as possible, the study design, population age, geographical location of the study, cultural composition of the participants, aim of the study, key findings, and factors and codes. Cultural composition was used to describe the ethnicities, religions, and languages of the participants. In the Table 1, studies are reported in two groups: cultural studies “within country”, and cultural studies “between countries”. ‘Within country’ refers to studies that were conducted in a country with an identified majority culture, but where the participants in the study were of a cultural minority (e.g., a study done in US with participants of Latino descent). ‘Between countries’ refers to studies that were conducted in different countries, with participants representing the majority culture from those countries.

[Table 1 is near here]

## Results

Figure 1 is a flow diagram that outlines the selection process and the number of papers at each step. A total of 29 studies met the inclusion criteria and were retrieved for the review (25 qualitative studies and 4 mixed methods studies). The majority of the excluded studies were quantitative studies (*n* = 31), case studies (*n* = 6), comparative cross-sectional studies (*n* = 16) or studies testing the psychometric properties of tools among different cultural groups (*n* = 18).

[Figure 1 is near here]

The majority of the studies that belong to the "within country" group (*n* = 17) were conducted in the US (*n* = 13). Two studies were conducted in the UK; one was conducted in Canada; one was conducted in South Africa; and yet another was conducted in the US, Canada, and Kuwait. Across these 13 studies, participants endorsed a wide range of cultural origins: Latino, Hispanic, Korean, Indian, Chinese, Pakistan, Bangladesh, African (North, Central, and West), European (West and East), Russian, Caribbean, Middle Eastern, and East Asian.

There were 12 "between countries" studies: three conducted in India, two in China, and one in each of the following countries (with two studies involving two countries): UK, Saudi Arabia, Jordan, Ethiopia, Kenya, France, South Korea, Pakistan, and Vietnam.

Thematic analysis identified nine factors related to parents' decision to seek help and engage in ASD-related services. Sub-codes related to the main factors were also identified (Table 2). Through discussion of concepts outlined and refined from a codebook on identified factors, consensus was reached between two independent reviewers who co-developed and utilized the codebook in an iterative process.

[Table 2 is near here]

The following sections provide detailed descriptions for each of the identified factors listed in Table 2.

1. Lack of general knowledge about child development and impairments. This factor points out that parents' lack of knowledge acted as a barrier to seek help for their child. Some parents knew nothing or very little about ASD in general (Zuckerman et al., 2014b), and some thought that ASD or the symptoms they observed were temporary and that the child would outgrow them (Fox, Aabe, Turner, Redwood, & Rai, 2017; Huang & Zhou, 2016; Ijalba, 2016). Furthermore, some parents perceived each symptom in isolation rather than recognizing them as a constellation that underlies a specific disorder (Grinker & Cho, 2013; Zuckerman et al., 2014a). For instance, intellectual issues may fail to be associated with social, behavioral, or speech abnormalities, and, in most cases, parents focused on treating speech issues at the exclusion of behavioral ones (Huang & Zhou, 2016). Additionally, some parents' interpretation of early signs also delayed seeking external support for their child. In most cases, early signs were normalized by family and friends, resulting in a lack of pursuit of appropriate medical intervention. In several studies, a common reason cited by parents for their child's developmental delays was a familial or cultural history of delayed language acquisition, leading to the erroneous conclusion that such delays were inconsequential (Desai, Divan, Wertz, & Patel, 2012; Ijalba, 2016; Jegatheesan, Fowler, & Miller, 2010).

Parents may also be misinformed about developmental milestones, which may contribute to delays in seeking treatment (Ijalba, 2016; Zuckerman et al., 2014a). In one study, parents knew that a healthy child must speak at some point, but they believed that it was normal for children not to start speaking until they were five years old (Ijalba, 2016).

2. Beliefs about the etiology of ASD. In most studies, parents' beliefs about the cause of ASD—whether cultural, religious, or personal in nature—determined the course and type of help they sought. Common cultural beliefs included parents' wrongdoings (Kang-Yi et al., 2018), curses (Gona et al., 2015; Zechella & Raval, 2016), or other supernatural causes such as evil eye and black magic (Alqahtani, 2012; Gona et al., 2015). Religion was sometimes believed to be the cause of the ASD (Ravindran & Myers, 2013; Zechella & Raval, 2016) and sometimes the cure (Ijalba, 2016). Religion was also a means by which some parents could cope with their child's diagnosis and care (Estrada & Deris, 2014; Lobar, 2014). For example, parents espousing Buddhist beliefs conceptualized any disability as arising from sin or immorality (Ha, Whittaker, Whittaker, & Rodger, 2014). Parents from other religious groups believed that ASD is a test from, or the will of, God (Lobar, 2014; Minhas et al., 2015). Parents who believed in religion as a cure for ASD relied on spiritual prayers, recitation of the holy book, or religious healers as interventions (Alqahtani, 2012; Lobar, 2014; Tilahun et al., 2016). Parents endorsed a variety of personal beliefs on the cause of ASD, ranging from biomedical causes, such as vaccination or genetics (Millau & Mello, 2018; Ravindran & Myers, 2013), to environmental factors, such as poor parenting or stressful home environments (Grinker & Cho, 2013), to mothers placing blame on themselves (Al-Dababneh, Al-Zboon, & Baibers, 2017; Lopez, Magaña, Xu, & Guzman, 2018) due to abnormalities or events during gestation (Desai et al., 2012) or because they failed to form a proper attachment with their child (Alqahtani, 2012; Sarrett, 2015).

3. Symptoms exhibited by the child. The type of symptoms with which the child presents may also impact time to treatment. A child with challenging behavior that

disrupts either the family's daily lives (Desai et al., 2012; Minhas et al., 2015) or social gatherings will expedite support seeking relative to a socially withdraw child who does not interfere with daily life. In one case, a mother thought that her child, who was not attached to her, was a "blessing in disguise" because the child would not miss her upon leaving the house (Desai et al., 2012).

4. Race/ethnicity. Some parents of children with ASD felt they received differential treatment because of their race or ethnicity, such as having their concerns dismissed (Zuckerman et al., 2014b), their children denied services (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015), or their knowledge of ASD underestimated by their physician (Dababnah, Shaia, Campion, & Nichols, 2018). As a corollary of this perceived racism, when some parents noticed the symptoms, they avoided or delayed seeking help for their child out of fear of further persecution from healthcare providers (Burkett et al., 2015; Dababnah et al., 2018).

5. Socioeconomic status (SES). Parental SES may directly or indirectly impact their decision to seek help. They may have limited or no medical coverage for accessing services, limited transportation (Guler, de Vries, Seris, Shabalala, & Franz, 2018; Ha et al., 2014; Lobar, 2014; Zuckerman et al., 2014b), or low-paying jobs, which are characteristically inflexible, thereby precluding days off from work to attend appointments (Zuckerman et al., 2014b). In Vietnam, very few public services are available. Private centers do exist in Vietnam; however, participants indicated that they were unable to afford their services (Ha et al., 2014).

6. Language barriers. Parents lacking proficiency in the language spoken in the healthcare system—usually English—posed a barrier once parents decided to seek

external aid. Such parents endorsed difficulties expressing their concerns, navigating the diagnostic process, or even scheduling an appointment (Fox et al., 2017; Zuckerman et al., 2014b). In addition, once parents received the diagnosis of ASD, they usually began to search proactively for information on ASD to help them understand this condition. However, in most cases, either there was no available information (Tait, Fung, Hu, Sweller, & Wang, 2016) or the available information was of poor quality (Zuckerman et al., 2014a) or in English, thereby prohibiting a detailed understanding of ASD (Fox et al., 2017). The internet occasionally proved to be a valuable source of information (Burkett et al., 2015; Jegatheesan et al., 2010; Munroe, Hammond, & Cole, 2016). In one study, parents reported that the educational material was translated to their language, but the translation was incorrect or dialectically insensitive (Zuckerman et al., 2014a). In a study from China, parents searched the internet for information about ASD but found little information available in their language. They were, however, able to find information in English, but evinced difficulty understanding it—especially when medical terminologies were used (Tait et al., 2016).

Another language-related concern faced by parents comprised their use of their mother tongue at home, which usually differs from the language used by their healthcare providers. In several studies, parents reported that they had been explicitly or implicitly advised to avoid using their mother tongue with their child as it might further confuse the child, whose linguistic development was already compromised (Ijalba, 2016; Jegatheesan et al., 2010). In fact, some parents believe that their child’s ASD diagnosis was caused by the use of multiple languages at home (Sarrett, 2015). In one study, a mother was instructed to discontinue using her native language at home, but neither parent was fluent in English, and this mother reported that she ceased speaking to her son for over a year due to her feelings of guilt (Ijalba, 2016).

7. Community perception and societal acceptance. Society's reactions to a given diagnosis or disability play a determining role in how parents respond. The majority of studies reported the manner in which social perceptions affected parents negatively. Stigma from the community led parents to feel shame and embarrassment, to deny the validity of the ASD diagnosis, to avoid or delay seeking services, and to experience social isolation (Burkett et al., 2015; Huang & Zhou, 2016; Ijalba, 2016; Kang-Yi et al., 2018; Lopez et al., 2018; Zuckerman et al., 2014a, 2014b). Stigma also led some parents to hide or isolate their child (Fox et al., 2017; Tilahun et al., 2016; Zuckerman et al., 2014b). In one study in China, parents of children with ASD rejected them and placed them for adoption (Tait et al., 2016). Many communities lack knowledge or have misconceptions about ASD, especially given that ASD is a "hidden disability", making it difficult for people to comprehend what is wrong with the child, who appears normal but behaves abnormally (Fox et al., 2017; Munroe et al., 2016). In some cultures, ASD does not exist, leading the child with ASD to be subsumed under a marginalized group (e.g., "bizarre", "crazy", or "idiots"; [Burkett et al., 2015; Fox et al., 2017; Grinker & Cho, 2013; Lopez et al., 2018; Zuckerman et al., 2014b]).

In some cultures, scholastic achievement is deemed extremely important, thus impacting how a family is perceived socially (Grinker & Cho, 2013; Huang & Zhou, 2016; Kang-Yi et al., 2018; Tait et al., 2016). Consequently, some families avoid seeking help or obtaining a diagnosis until the child is formally enrolled in school. Furthermore, in some instances, as long as the child is progressing well academically, parents may avoid any sort of intervention regardless of the behavioral challenges with which the child might present (Grinker & Cho, 2013).

8. Spouse and extended family. Receiving an ASD diagnosis is a stressful event, and parents—especially mothers—require support to properly cope with such news. In a number of studies, mothers reported that family members provided them with support, helped care for the child, and helped locate information and services for ASD (Burkett et al., 2015; Estrada & Deris, 2014; Huang & Zhou, 2016; Lopez et al., 2018). The spouse was also reported to be a source of support (Guler et al., 2018). However, in several studies, mothers reported that their family, including their spouse, was a source of stress. These mothers reported that their spouse insisted their child was normal and remained resistant to the ASD label (Dababnah et al., 2018; Fox et al., 2017), and were uncooperative throughout the diagnostic process (Zuckerman et al., 2014b). Extended families imposed their beliefs on the cause of ASD, stemming from cultural or religious beliefs (Jegatheesan et al., 2010; Zechella & Raval, 2016); sometimes they also blamed the mother for the diagnosis (Munroe et al., 2016), or believed the behavior of the child was a result of poor parenting style or lack of adequate discipline (Dababnah et al., 2018; Lopez et al., 2018). Extended family members may also propose solutions, usually of cultural or religious origin, for the child (e.g., soliciting the help of traditional or religious healers [Fox et al., 2017]). Some parents reported that their child's diagnosis was not accepted by their family and they were shamed and avoided (Dababnah et al., 2018; Munroe et al., 2016).

9. Challenges engaging with services. Parents' experiences with the healthcare system affect their decision to seek help and engage their children in therapeutic services.

In several studies, parents had difficulties interacting with their physician, citing a lack of trust or feeling of safety or compassion (Estrada & Deris, 2014; Jegatheesan et al., 2010; Zuckerman et al., 2014a). Sometimes physicians, despite frequently sharing the cultural background of the parents, nevertheless blamed the mother for her child's behavior, resulting in the mother avoiding further interaction with the healthcare system (Desai et al., 2012). Parents also reported that their primary healthcare providers dismissed their concern about their child, which delayed diagnosis (Chamak & Bonniau, 2013; Dababnah et al., 2018; Tait et al., 2016). In several studies, parents reported difficulties accessing an interpreter, rendering the navigation of the diagnostic process more difficult and confusing, which further delayed diagnosis (Zuckerman et al., 2014a, 2014b). Access to services was another common challenge faced by parents when deciding whether to seek help for their child. These challenges included lack of geographical proximity to the service locale, prohibitive costs of the service, or lack of awareness of available services (Fox et al., 2017; Jegatheesan et al., 2010; Zuckerman et al., 2014b). Once families received the diagnosis, their understanding of the condition and their expectation of the treatment outcome determined the type of intervention they would consider engaging in. Some parents received advice and suggestions that conflicted with their cultural beliefs, leading to rejection of any intervention. In one study, a physician asked the parents to keep the child's life "simple" and avoid interacting with many family members and neighbors. This advice clashed with the family lifestyle and was difficult to follow (Jegatheesan et al., 2010). In addition, when parents thought that ASD was curable, they kept spending time and money trying different interventions and searching for a cure (Ha et al., 2014; Minhas et al., 2015). Furthermore, when there were discrepancies in the goals of the intervention between parents and the healthcare provider, parents discontinued the services (Jegatheesan et al., 2010).

## Discussion

This qualitative evidence synthesis explored the cultural factors that impact parents' decisions to seek help and engage in services for their child with ASD. Several factors have been identified, as reported by parents from various cultural backgrounds around the world. The majority of these factors were common among the included studies; however, a few were identified only in the studies where participants were of cultural minorities.

Two factors identified exclusively in the "within country" studies have impacted access and engagement in ASD services: the language barrier and race/ethnicity. Language has been identified in the literature as a common barrier to healthcare for immigrants and newcomers (Derose, Escarce, & Lurie, 2007; Kim & Keefe, 2010). A lack of English proficiency was found to affect not only access to healthcare, but also the quality of healthcare the patients received, including their safety (Derose et al., 2007). One study examined barriers to providing healthcare to newcomers in Canada, from the perspective of Canadian family physicians (*n* = 598), who identified communication and cultural differences as the predominant barriers (Papic, Malak, & Rosenberg, 2012). More than half of these physicians found caring for immigrant patients to be more challenging than caring for non-immigrant patients. Furthermore, very few physicians were found to have had training on providing care to immigrant patients (Papic et al., 2012). Immigrants and newcomers with children with ASD identified the same barriers with respect to their language abilities. Perceived racial discrimination was identified as another common, well-documented barrier immigrant families may face. Studies found disparities in healthcare access, quality, and utilization between Latino and Black children when compared to White children with developmental disabilities or ASD (Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Magaña, Parish, & Son, 2015; Montes & Halterman, 2011). The same trend has been observed in Europe, where ethnic minority children were underrepresented among children referred for ASD treatment (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009). Research suggests that race and language barriers could be intertwined and lead to bias when diagnosing children from ethnic minorities (Begeer et al., 2009). A physician may observe a communication problem in a child from an ethnic minority but conclude that the language barrier is to blame; whereas, if another child—usually Caucasian—presented with identical symptoms, they are more likely to be attributed to ASD (Begeer et al., 2009).

Bernier and colleagues divided cultural factors related to diagnosis and treatment of ASD into macro- and micro-level factors. A model was developed in our paper that integrates the findings from both our review and that of Bernier et al. (2010) (Figure 2). Some of the factors identified were common to both reviews; however, our study also identified novel factors at both the micro- and macro-level. One of the important factors that we identified was “challenges engaging with services” and all of its related sub-codes.

[Figure 2 is near here]

Furthermore, Bernier’s review mentioned the impact of stigma in Chinese and South Asian communities, but our review found that stigma was common among almost all of the included studies from various countries, and also identified the impact of communities' misconceptions about ASD on parents' decisions.

## Limitations and Strengths

This review has some potential limitations. One is that, due to limited resources, only papers in English were included. Therefore, information published in other languages was overlooked. Another limitation, concerning the included papers themselves, is that authors occasionally identified the religions of the participants but failed to specify which religious group held a particular belief.

One of the potential strengths of this review is that, to our knowledge, this is the first paper that comprehensively and systematically searched the literature and synthesized the qualitative evidence in an effort to describe the key cultural factors impacting the accessing of services for children with ASD. Furthermore, the studies included were conducted in over 12 countries, ensuring the inclusion of a breadth of cultural backgrounds.

## Clinical Implications

This review highlights the importance of cultural competency training for healthcare providers. Clinicians must understand the challenges experienced by cultural groups in accessing healthcare, and how best to communicate with them. Clinicians must also remain flexible when dealing with culturally diverse families by maintaining sensitivity to their cultural values and beliefs. Kleinman's (1981) explanatory model of illness could be a starting point for clinicians when interacting with these families. Kleinman's model provides a set of questions that can help clinicians better understand a family's beliefs and their intervention goals and decisions; this is crucial for establishing a therapeutically beneficial relationship with families of children with ASD, and to keep the family engaged and improving the outcome. When exploring Kleinman's questions with the families of children with ASD, the following recommendations should be considered (note that these recommendations should apply to *all* families):

1. Clinicians must remain aware of the language they employ when dealing with families of children with ASD. Medical jargon can be unfamiliar and intimidating, which may contribute to parents' confusion or reticence. One of our common findings was a lack of knowledge about ASD. Some parents had made the decision to immigrate for better access to interventions and services for their children. Unfortunately, these parents still have difficulties understanding their child's condition and how best to deal with it. Some of the parents who participated in one study (Zuckerman et al., 2014b) were still not sure what ASD meant.

2. Increasing health literacy and knowledge translation are other important considerations. ASD is a common disorder surrounded by myths and misinformation. Accurate information must be delivered in a simplistic, tailored manner that considers the targeted audience.

3. Engaging the spouse and extended family, such as grandparents, in the diagnostic and interventional processes could help increase their understanding of the condition and reduce undue blame on the mother. This may subsequently reduce the stress commonly seen among mothers of children with ASD. Furthermore, the combined model proposed in this review (Fig. 2) could also be used as a resource to help clinicians become more culturally competent in the treatment of ASD. The micro-level factors, in particular,

could provide potential ideas to consider and explore when dealing with immigrant families.

### Future Research

Future studies could further examine the impact of SES on family decisions to engage in services (e.g., Does SES impact a family's decision to seek help, or do they not have the means or knowledge to seek help?). Another important step for future research is to explore how to integrate the factors identified in this study into a version of Kleinman's model that could be used when working with families of children with ASD and potentially other disabilities.

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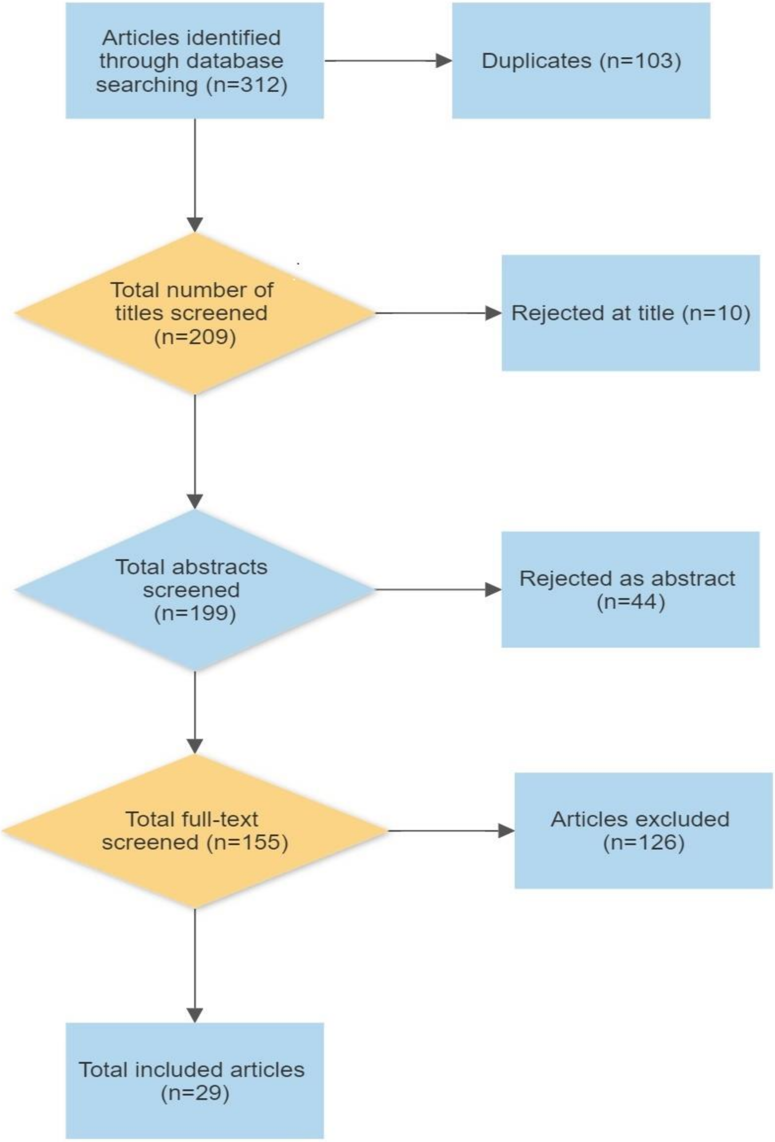

*Figure 1.* Flow chart of the article selection process.

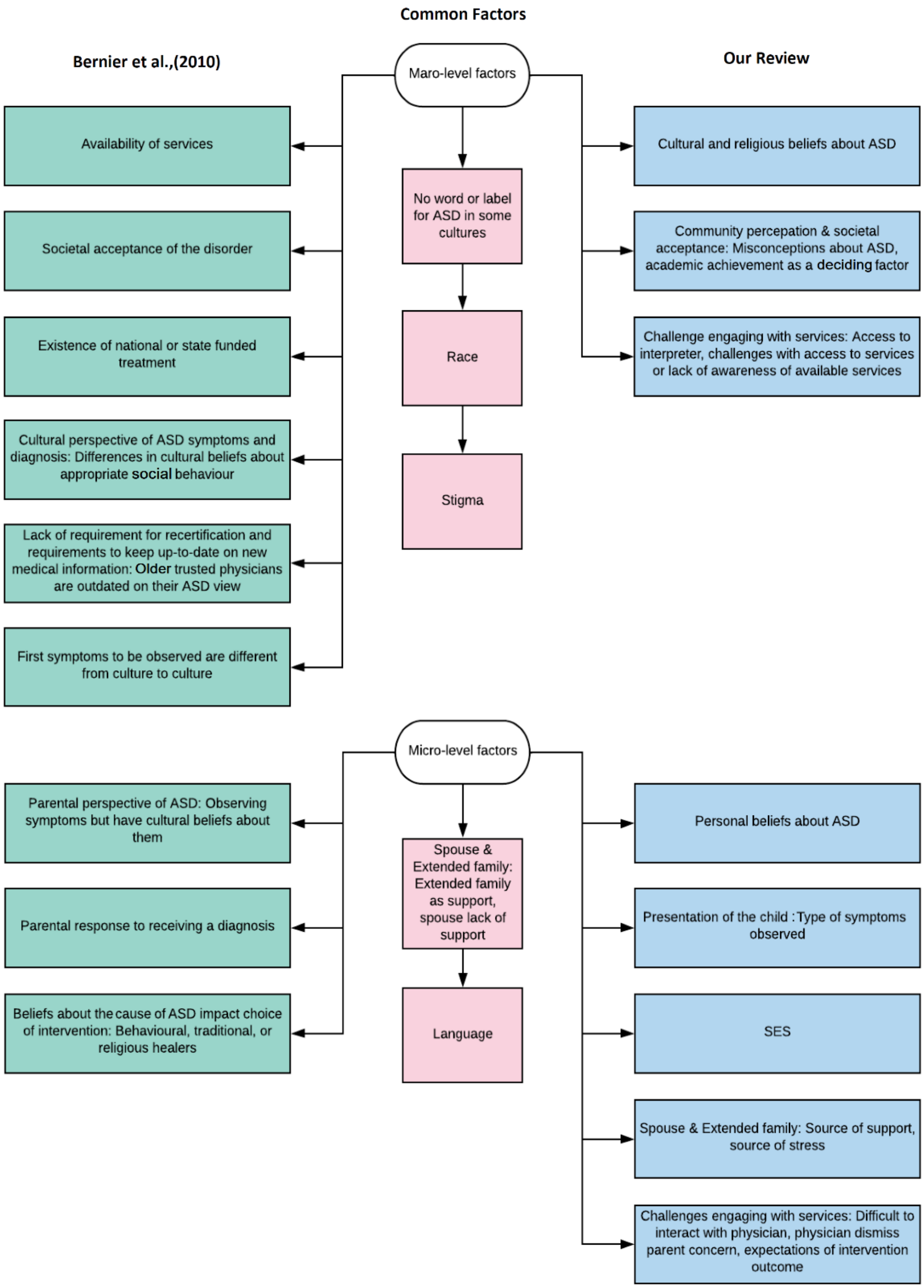

*Figure 2.* Cultural factors associated with ASD diagnosis and engagement in services: A proposed integrated model.

Table 1

*Summaries of Articles Selected to be Included in the Qualitative Evidence Synthesis*

| Studies of cultural differences "Within a Country" | | | | | | | |
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| Citation | Study design | Population age | Geographical location | Cultural composition | Aim of the study | Key findings | Factor & codes |
| Kang-Yi et al. (2018) | -Qualitative study<br>-open-ended, semi-structured interviews | _______ | US | -Korean<br>-Most of the participants were Christian | To understand Korean immigrants' beliefs and attitudes toward ASD diagnosis and other developmental disabilities | -Parents are avoided or treated differently<br>-ASD is viewed as demeaning the value of one's family, and a sense of shame<br>-Parents fear diagnosis will affect the child's future<br>-Community does not want their children to interact with those with ASD<br>-Hesitancy to access services due to stigma<br>-Community believes the cause of ASD is a curse<br>-Potential avoidance in marrying someone with family with disability<br>-Child needs to succeed (academically) to promote family prestige and social mobility | 1. Community perception & societal acceptance<br>2. Beliefs about the etiology of ASD |
| Zuckerman et al. (2014a) | -Qualitative study | 2–10 years | US | Latino parents | To understand community knowledge and view | -Symptoms represent problems in family relations | 1. Lack of general knowledge |

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| | -Focus groups and semi-structured interviews | | | | of ASD and how their views affect their care-seeking for children with ASD | -Behaviors may be in normal range<br>-Separation of language delay from behavioral problem<br>-Parents lack knowledge about ASD<br>-Lack of information about developmental resources<br>-Poor quality of information<br><br>Healthcare access and quality:<br>-Access to adequate interpreter<br>-Access to developmental surveillance<br>-Quality of doctor-patient relationship<br><br>Community mental health stigma:<br>-Embarrassment, shame, rejection<br>-Denial<br>-Burden on the family | about child development and impairments<br>2. Language barriers<br>3. Community perception & societal acceptance<br>4. Challenges engaging with services |
| Ijalba (2016) | -Qualitative study<br>-Phenomenological interviews and thematic analyses | 37–45 months | US | Hispanic | To understand the experience of raising a child with ASD for Hispanic immigrant mothers | -Feeling stigmatized and isolated<br>-Limited knowledge about ASD for themselves and others<br>-Perceived as neglecting their child because of child behaviors | 1. Community perception & societal acceptance<br>2. Lack of general knowledge about child development |

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| | | | | | | -Other mothers prevent their children from interacting with them<br>-Child behaviors are embarrassing and lead to social isolation<br>-Belief that ASD is temporary<br>-Place trust on their religion to cure ASD<br>-Developmental milestones are perceived broadly (e.g., child will catch up)<br>-Family history of language delay<br>-Cultural and personal beliefs about ASD<br>-Feeling of guilt and inadequacy because they can’t communicate in English | and impairments<br>3. Beliefs about the etiology of ASD<br>4. Spouse & extended family<br>5. Language barriers |
| Zuckerman et al. (2014b) | -Qualitative study<br>-Focus group | 2–10 years | US | Latino<br>Most participants were Spanish-speaking, with less than high school education | To assess barriers to ASD diagnosis in the Latino community | -Little/No knowledge of ASD at diagnosis and parents unclear what ASD is<br>-Lack of community knowledge because “ASD does not exist in Mexico”<br>-Parents avoid help due to stigma<br>-Perception of disability as shameful<br>-Avoidance of discussing developmental concerns | 1. Lack of general knowledge about child development and impairments<br>2. Community perception & societal acceptance<br>3. Language barriers<br>4. Challenges engaging with services |

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| | | | | | | -Families hide children with ASD<br>-Fathers view having child with disability as a poor reflection on them<br>-Fathers dismiss mother’s concern, are uncooperative with the diagnostic process, take a passive role in childcare<br>-Limited English made navigating diagnostic process and expressing concerns difficult<br>-Poor access or quality of interpreter<br>-Unaware of services available<br>-Poverty—made seeking care difficult<br>-Primary health provider dismissed parents’ concern | 5. Race/ethnicity<br>6. SES |
| Lobar (2014) | -Qualitative study<br>-Ethnomethodological study | 5–15 years | US | Hispanic of various ethnic groups (Majority) Non-Hispanic White | To examine perceptions of parents/caregivers of children with ASD regarding their actions, norms, understandings, and assumptions related to the adjustment to this chronic illness | -Told by friend/family members that child has a problem<br>-Child’s behavior triggered to seek diagnosis to access help for him<br>-Difficult time with diagnosis and shuffled from one professional to another<br>-Could not access community events | 1. Symptoms exhibited by the child<br>2. Challenges engaging with services<br>3. SES<br>4. Lack of general knowledge about child development and impairments |

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| | | | | | | because of child behavior<br>-Structure and routine are important<br>-Poverty major concern for service access<br>-Need to educate self about services and child needs<br>-Community and in the school need to learn more about ASD-Religion provided strength | 5. Community perception & societal acceptance<br>6. Beliefs about the etiology of ASD |
| Zechella and Raval (2016) | -Qualitative study<br>-Semi-structured interviews | 6–23 years | US | Indian<br>One couple was Christian, and all other participants were Hindu | To examine unique challenges experienced by Asian Indian parents of children with IDD in US | -Explanation for cause of ASD is a curse<br>-Family members struggled to accept diagnosis<br>-Family members suggested intervention reflected by religious belief<br>-Migration for better access to care and higher societal acceptance<br>-Sources of stress: social isolation, difficulties accessing resources, geographic distance from family<br>-Mothers to adjust expectations regarding child’s academic achievement and future | 1. Beliefs about the etiology of ASD<br>2. Spouse & extended family |

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| | | | | | -Parents’ concerns for their child’s future when they are no longer around<br>-Mothers main hope for their children future is to be independent | |
| Lopez et al. (2018) | -Qualitative study<br>-Interviews | US | Latino and non-Latino white families<br>Latino mothers have lower education than the white mothers | To explore how Latino parents of children with ASD react to their children’s dx with ASD compared with white mothers | -White mother relieved with diagnosis; Latino mothers felt guilt<br>-White mothers expected the diagnosis and were ready to pursue treatment. Latino mothers felt an injustice and were less resolved<br>-Both White and Latino mothers had misinformation about ASD<br>-Latino mothers reported that their family did not accept the diagnosis; blaming mother for not raising the child properly<br>-Family looked for causes/cures for ASD<br>-Grandmothers for both groups were supportive and help caring for the child<br>-Extended family provided varied degree of support, however, Latino mothers reported not receiving | 1. Beliefs about the etiology of ASD<br>2. Lack of general knowledge about child development and impairments<br>3. Spouse & extended family<br>4. Community perception & societal acceptance |

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| | | | | | | help from family (potentially avoiding support seeking). | |
| Huang and Zhou (2016) | -Qualitative study<br>-Semi-structured interviews | 2–5 years | US | Chinese | To gain an in-depth understanding of ways that Chinese families cope with stress when they have a child diagnosed with ASD | -Confusion, and uncertainty about implications of ASD<br>-Guilt and regret not catching it earlier<br>-Had doubts about ASD diagnosis<br>-Understanding of ASD revolved around their child speech-language development<br>-View of ASD as a temporary/transient state of being<br>-Child problematic behaviors were major source of stress<br>-Isolation and social stigma are major stress<br>-Extended family could share burden<br>-Unprepared for diagnosis, strongly expressed lack of knowledge of ASD | 1. Lack of general knowledge about child development and impairments<br>2. Symptoms exhibited by the child<br>3. Community perception & societal acceptance<br>4. Spouse & extended family |
| Estrada and Deris (2014) | -Qualitative study<br>-Interviews, phenomenological study | | US | Hispanic parents speaking English, Spanish, or both | To describe and understand ASD as it relates to the effects it has on Hispanic families and treatment decisions made by them | -Professionals dismissed parents concern<br>-Hispanic preferred to work with Hispanics or someone understanding language and culture | 1. Challenges engaging with services<br>2. Lack of general knowledge about child development and impairments |

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| | | | | | | -Unsatisfied with knowledge or services received<br>-Unable to acquire information to assist child<br>-Distrust of professionals with care for their child<br>-Child's future is of concern to all parents and want their child to be independent<br>-Relies on other family for childcare<br>-Belief that God will help them and guide them to the right people to help their child | 3. Spouse & extended family<br>4. Beliefs about the etiology of ASD |
| Ravindran and Myers (2013) | -Qualitative study<br>-Web-based questionnaire | 3–15 years | US, Canada, & Kuwait | Indian (most were Hindu, one was Jain, and one was Christian) | To examine beliefs and practices about ASD in Indian families with a child on the autism spectrum who emigrated to other countries | -Vaccination as a cause of ASD<br>-Genetic and environmental factors<br>-Traditional Indian belief of ASD cause: Karma, /fate/destiny, parental mistakes in past life<br>-50% preferred both Western and Indian treatment<br>-Traditional Indian treatment include using Ayurveda or homeopathy<br>-Willing to use anything to help | 1. Beliefs about the etiology of ASD |

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| Jegatheesan et al. (2010) | Qualitative study | 5–6 years | US | Pakistan and Bangladesh (all participants were Muslim). Families speak at least three languages (Hindi, Urdu, & Arabic) | To explore the experience of Muslim Immigrant families of children with ASD in US | -Early signs consistent with western parents<br>-Did not seek immediate professional advice<br>-Preferred professionals who speak same language and cultural background<br>-Relatives expressed their beliefs about cause of ASD which focus on the mother<br>-Professionals used medical jargon, adding to confusion and stress<br>-Extended family not a source of support<br>-Parents sought more information after diagnosis<br>-Language was barrier to participate in support groups<br>-Parents unaware of have services led to delayed access<br>-Professionals advised against using more than one language at home<br>-Parents advised to "keep child life simple" and avoid interactions with family, (against their cultural values)<br>-Professional intervention goals | 1. Lack of general knowledge about child development and impairments<br>2. Challenges engaging with services<br>3. Spouse & extended family<br>4. Language barriers<br>5. Symptoms exhibited by the child |

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| | | | | | | differed from parents-family discontinued services | |
| Burkett et al. (2015) | Qualitative study | 3–8 years | US | African American Participants at least have high education | To explore the cultural values, beliefs and practices of African American families caring for their children with ASD | -Unequal treatment in health and community care and distrust clinical healthcare, resulting in delay in seeking ASD diagnosis and intervention<br>-Protecting child with ASD by pushing him to be independent in activities of daily living<br>-Treating the child as “normal” to avoid any further stigma toward a child who is Black<br>-Parents expressed first concerns to family<br>-Considered the internet as the most important sources for ASD resources<br>-Enrolled children in services post-diagnosis, but adapted recommendations to combine professional with traditional family care<br>-African American community does not believe that ASD happen in Black families<br>-Lack of acceptance of ASD diagnosis and lack | 1. Race/Ethnicity<br>2. Community perception & societal acceptance<br>3. Spouse & extended family<br>4. Lack of general knowledge about child development and impairments<br>5. Challenges engaging with services |

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| | | | | | | of ASD knowledge led to delayed diagnosis and enrollment in intervention<br>-Stigma in the black community against individual with disability make the family fail to accept ASD diagnosis | |
| Munroe et al. (2016) | Qualitative study | <13 years | UK | Africa (Sierra Leone Ethiopia, Nigeria, and Uganda)<br>Mothers were Christian, Jehovah's Witness, and Muslim | To investigate the experience of African immigrant mothers of children with ASD in the UK | -Stress from lack of social support because of migration and/or stigma toward child<br>-Preference to keep diagnosis private due to shame, embarrassment, and perceived stigma<br>-Felt had more support and acceptance from their family in Africa compared to the African community in UK<br>-Denial of diagnosis but accepted it with time to access services<br>-Experience of rejection from family, church, or local African community<br>-Isolated themselves to avoid judgment and stigma<br>-Felt guilt and shame because they have | 1. Community perception & societal acceptance<br>2. Spouse & extended family<br>3. Lack of general knowledge about child development and impairments<br>4. Beliefs about the etiolog of ASD |

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| | | | | | | been blamed for the diagnosis<br>-Mothers began looking for information from the internet, religion, and African culture<br>-Religion provided sense of meaning, and comfort; Family support fluctuated but God always there<br>-ASD is more challenging to be accepted by African because it is a hidden disability,<br>-Some mother belief that ASD is a curse | |
| Millau and Mello (2018) | Qualitative study | 2–6 years | Canada | Latin America, North Africa (Maghreb), Central and West Africa, Western Europe, Eastern Europe and Russia, Caribbean, Middle East, and East Asia | To describe immigrant families' perceptions of the causes, symptoms of ASD, and their treatment priorities | Causes of ASD were as follow: Environmental, unknown, pregnancy related, genetic, medical, spiritual or religious, and emotional.<br>-The most frequent symptom noticed by parents was speech delay, lack of non-verbal behavior (eye contact, gesture), and stereotypical behavior<br>-Lack of play was only mentioned by parents from Western Europe and Maghrib | 1. Beliefs about the etiology of ASD<br>2. Symptoms exhibited by the child |

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| | | | | | | -Only parents from Central and West African countries (100%) mentioned natural treatments | |
| Dababnah et al. (2018) | Qualitative study | ______ | US | African American nearly half of the participants reported education completion at or before high school graduation, while 50% had college or post-graduate degrees | To understand the perspective of parents and caregivers of black children with ASD on barriers and facilitators to ASD diagnosis and primary care referrals | -Primary health care providers listened to them and referred them to services<br>-Other caregivers reported that primary healthcare providers dismissed their concerns and did not provide referrals<br>-Caregivers who reported that their providers dismissed their concerns were from all SES and educational levels<br>-Majority of caregivers reported unease when interacting with their health care providers which they perceived as racism<br>-Health providers sometimes make negative (race) assumptions about caregivers<br>-Caregivers reported that stigma in the Black community made them reluctant to follow up or acknowledge developmental delays | 1. Challenges engaging with services<br>2. Race/ethnicity<br>3. Community perception & societal acceptance<br>4. Spousae & extended family<br>5. SES |

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| | | | | | | -Denial and shame common in Black community in having a child with disability<br>-Fathers are resistant to ASD “label”<br>-Older family insisted that prayers and discipline can address behaviors<br>-Caregivers across SES and education reported stigma as a barrier to ASD diagnosis<br>-Caregivers delayed seeking ASD diagnosis/follow up because of custodial arrangements<br>-Poverty-related stressors exacerbated legal or custodial issues and further delayed seeking ASD diagnosis | |
| Guler et al. (2018) | Qualitative study | <7 years | South Africa | Black African, white, Asian or Indian, and Colored (South African with mixed ethnic heritage)<br>There are 11 official language in South Africa | To explore the perspectives of South African caregivers of children with ASD on identifying the important contextual factors to consider for ASD early intervention | Factors relevant to early ASD intervention:<br>-Certain cultures in South Africa believe children with ASD is a curse—impacting on seeking a diagnosis and using traditional treatments<br>-Language was a barrier to ASD diagnosis<br>-Limit space at home, lack of resources, and home environments | 1. Beliefs about the etiology of ASD<br>2. Language barriers<br>3. Challenges engaging with services<br>4. SES<br>5. Lack of general knowledge about child |

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| are challenges to intervention<br>-Majority of participants preferred to receive intervention at home<br>-Cost related challenges included existing financial burden of raising a child with ASD, lack of governmental financial support, and little disposable income due to poverty and/or being a single parent<br>-Caregivers preferred to receive interventions from professionals. Majority do not want intervention from community health worker from same community<br>-Support related challenges including single parenting and co-parenting from different households, and low awareness of ASD<br>-Parents need to adapt their parenting style for their child with ASD<br>-Parents want therapist to acknowledge that they know their child best and to teach them | development and impairments<br>6. Community perception & societal acceptance<br>7. Spouse & extended Family |

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| | | | | | | how to improve their parenting approach<br>-Caregivers blamed for child behavior<br>-Experiencing stigma because of their Immigrant or refugee status<br>-Stigma led to isolation, secrecy, shame<br>-Sources of stigma are family, educators, health care professionals, and community | |
| Fox et al. (2017) | Qualitative study | 4–14 years | UK | Somali<br>Parents speak English, Somali, or both | To gain a better understanding of the perceptions, understanding, and support need of immigrant Somali parents of children with ASD | -Many parents have not heard the word autism before they received the diagnosis<br>-Somali language does not have a word for autism<br>-Because ASD is a hidden disability, it adds to the confusion for parents<br>-Child challenging behaviors are not tolerated in the local community<br>-The stigma led parents to hide their child and subsequently delayed seeking help<br>-Extended family believe “the child will grow out of it”, to disregard the diagnosis, | 1. Community perception & societal acceptance<br>2. Spouse & extended family<br>3. Lack of general knowledge about child development and impairments<br>4. Beliefs about the etiology of ASD<br>5. Challenges engaging with services<br>6. Language barriers |

and there is nothing wrong with the child
-Somali professionals “on Somali TV” advised that ASD is temporary for some children and they will grow out of it!
-Assessment and diagnosis delayed because challenging for parents to recognize ASD behaviors
-Some fathers did not accept dx or believe there was anything wrong with the child
-Faith played a crucial role in acceptance and hope that their child will improve
-Parents needed to learn more about ASD to be able to accept it
-Parents found information at diagnosis inadequate and difficult to understand
-uncertainty about the diagnosis that included unfamiliar cultural milestones
-Parents learned about ASD by looking online, from professionals, or support groups
-Accessing services was challenging for parents

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| | | | | | | unfamiliar with the system or where English is the second language<br>-The lack of familiarity, in combination with a fragmented system and the language barrier all contributed to delays for some families in accessing support for their child | |
| Studies of cultural differences “Between countries” | | | | | | | |
| Tait et al. (2016) | Mixed methods study | 3–17 years | China (Hong Kong) | | To understand the experience of Chinese parents of children diagnosed with ASD, and what influence their perceptions of their child disability | -Conflicted over obtaining more information for ASD diagnosis vs fear of cultural shame if a diagnosis was confirmed<br>-Teachers dismissed parent concern that there is a problem with their child<br>-Delayed seeking diagnosis until the child was formally enrolled in school<br>-Parent frustration upon discovering lack of information and limited diagnostic services<br>-Parent confused after diagnosis because they do not know what ASD mean | 1. Lack of general knowledge about child development and impairments<br>2. Community perception & societal acceptance<br>3. Challenges engaging with services |

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| | | | | | | -Culturally specific theme—children with ASD diagnosis were rejected by their family and put up for adoption<br>-Facing traditional shaming and discrimination—parent hid the diagnosis<br>-Parent belief that ASD can be cured | |
| Gona et al. (2015) | Qualitative study | ______ | Kenyan cost<br>Participants were Christians, Muslims, or Traditionalists<br>Education level varies from no formal education to secondary education | | To explore parents' and professionals' perceptions of ASD causes and treatment | -Perceived causes of ASD were two main types—preternatural and biomedical causes<br>-Preternatural causes involves external forces such as witchcraft, evil spirits, and curses<br>-Biomedical causes include genetics, malnutrition, inappropriate use of drugs (malaria drugs or family planning pills), infections, and birth complications<br>-Treatment either traditional or modern<br>-Traditional treatment involves consultations with traditional healers and spiritual prayers offered to God<br>-Modern treatment involves using therapy offered at health facilities | 1. Beliefs about the etiology of ASD<br>2. Challenges engaging with services |

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| Chamak and Bonniau (2013) | Qualitative study | 4–45 years | France | Participants were parents of adults with ASD and parents of children with ASD in France | To analyze the change and how parents have experienced the diagnostic process in France | -The main expectations for parents for ASD treatment was hope for cure of ASD<br>-Professionals sometimes dismissed parents concern, enhanced their feeling of guilt, or attributed child behaviors to inadequate parenting<br>-Both groups had trouble obtaining diagnosis and services<br>-Lack of diagnosis led to increase stigmatization<br>-For both parent groups, the words used to describe their children when they did not receive diagnosis were stressful for them<br>-Professionals recommended separation form the child, parents were blamed for their children situations, if did not comply they were excluded from services<br>-Parents of children with ASD refused to be treated as if they were guilty<br>-Access to internet, and learned about ASD and | 1. Challenges engaging with services<br>2. Community perception & societal acceptance<br>3. Lack of general knowledge about child development and impairments |

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| | | | | | | started parents' association<br>-Mothers experienced more stigma and therefore more open to medical label then fathers | |
| Sarrett (2015) | Mixed method | ______ | India (Kerala) | Kerala is a southwestern state with remarkably high access to health care and education. They have high access to Western medical care | To explore caregivers' explanatory models about children with ASD | -Parents believed the following to be cause of ASD—negative event in pregnancy, negative event in birth, Seizures, childhood accident, more than one language spoken at home, television watching, vaccine, or little interaction with parent at early age<br>-No mention of spiritual causes for ASD | 1. Beliefs about the etiology of ASD |
| Grinker and Cho (2013) | Qualitative study | _______ | South Korea | | To describe Korean mothers who are reluctant to accept ASD diagnosis for their child | -Parents had no intentions of embracing ASD diagnosis<br>-Mothers used the term "Border" rather than "autism" when challenged to explain their children behaviors<br>-In Korea, achieving academic excellence is a mean of prestige and social mobility, so mothers fear stigma at school and avoid revealing their children challenges, so they would not seek | 1. Community perception & societal acceptance<br>2. Lack of general knowledge about child development and impairments<br>3. Beliefs about the etiology of ASD |

specialized services or education
-As long as child is doing well academically, mothers would not seek help for behavioral challenges
-Korean schools have no official terminology to characterize high functioning children with a developmental disorder, and no system that offers services for them
-Mothers believed the cause of ASD is genetic
-Koreans view ASD as temporary symptoms that caused by environmental factors such as poor parenting or stressful prenatal environment such as the mother’s mood, loud verbal conflicts, excessive noise, or poor diet
-Mothers accept attachment diagnosis because it is not genetic, because genetic disorder runs in the family and threaten the marriage prospect of the relatives of the autistic person

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| | | | | | | -Mothers are in a hard place; either accept attachment disorder which blame them and increase their anxiety or accept autism which is genetic, permanent, and will stigmatize the family | |
| Liao, Dillenburger, and Buchanan (2018) | Qualitative study | _______ | UK & China | | To compare cultural differences in the UK and China in relation to ABA interventions for children with ASD | -In the UK, professionals such as nursery teachers were first to noticed developmental concerns<br>-In China, parents were first to notice such concerns<br>-Mothers are usually responsible for taking care of the child especially in China<br>-The internet was the first resource to look for intervention in both countries<br>-Parents tried educational and behavioral interventions, in addition to pharmaceutical or dietary interventions<br>-Professionals in both countries encouraged early intervention | 1. SES<br>2. Challenges engaging with services |

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| | | | | | | -In this study, UK children began intervention later<br>-In China, ABA was parent-focused training, while in the UK, parent cooperated but ABA therapist carried out most of the intervention<br>-Both China and the UK face the problem of shortage of qualified ABA therapists<br>-Lack of services in China, led mothers to start their own services | |
| Desai et al. (2012) | Qualitative study | 5–23 years | India (Goa) | Goa is different than other parts of India because of its Portuguese colonial heritage and relatively high educational and economic development<br>Participants were Hindu or Christian | To investigate the lived experience of parents of children with ASD in everyday cultural contexts in Goa, India | -Unexpected behaviors caught parents' attention because they disrupt everyday life<br>-Family members normalized the child behavior by mentioning similar behaviors in family members or cultural norm<br>-Parents thought the behaviors were temporary and were not indicating larger or ongoing issue<br>-When the term "autism" was introduced to parent it was not significant for parents because they did not understand it | 1. Symptoms exhibited by the child<br>2. Challenges engaging with services<br>3. Lack of general knowledge about child development and impairments<br>4. Beliefs about the etiology of ASD |

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| | | | | | | -Parents became concerned when the behaviors become socially problematic beyond the immediate family<br>-Allopathic and alternative healers were consulted looking for solutions<br>-Parents were learning the scientific and medical knowledge about ASD and their understanding of their child changed<br>-Parents accepting diagnosis based on causal explanations: genetic or chemical exposure, link to other children in the family with developmental disability, stressful experience during or after pregnancy, or mother did not take required medication or took too much medications during pregnancy | |
| Minhas et al. (2015) | Mixed methods | 7–16 years | India & Pakistan | | To explore existing parental beliefs and practices for children with ASD in India and Pakistan | -Family are responsible for providing care to the child with ASD<br>-State respite or remedial care are almost non-existent in | 1. Challenges engaging with services<br>2. SES<br>3. Spouse & extended family |

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| both urban and rural areas<br>-Small private facilities offer daycare services but can't be afforded by most families<br>-Parents are concerned for their children future<br>-Delay in recognizing the problem at home<br>-Family seek help outside the family when the child behavioral and social issues associate with ASD become visible and disrupt family life<br>-Parents have very limited information about ASD<br>-Rural parents described child condition as 'will of God' and 'a test by God'<br>-Parents separate communication and social issues from the behavioral issues<br>-Parents belief in supernatural causes of the condition, and belief that caring for the child will be rewarded in the afterlife<br>-Parents—especially who reside in rural | 4. Lack of general knowledge about child development and impairments<br>5. Symptoms exhibited by the child<br>6. Beliefs about the etiology of ASD<br>7. Community perception & societal acceptance |

areas-have difficulties accessing services
-Traditional healers are the first to be consulted by parents and they provide guidance and relief for parents
-if medical care is available parents move from one specialist to the other because they are looking for cure
-Some people in the community are intolerant of the children behavior
-Other are more understanding and know that the child has a special need and that they are “blessing from God”
-Parents are worried of stigma and that the child will be mistreated in the community
-As a result, children with ASD are socially isolated. Some parents did not send them to school because they fear they will be harmed
-Community lack of knowledge about ASD and the child disruptive behaviors led to parent

| | | | | | | | |
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| | | | | | | social isolation and embarrassment | |
| Alqahtani (2012) | Qualitative study | 3–15 years old | Saudi Arabia | Participants were Muslims<br>Fathers were highly educated while mothers have high school certificate or higher | To evaluate qualitatively the beliefs of parents of children with ASD in Saudi Arabia | -Parents reported their children were diagnosed between 17 months to 7 years<br>Beliefs of parents with autistic children about the causations:<br>-Medical investigations during pregnancy was the most suspected cause<br>-Vaccinations were believed to change children from normal to autistic<br>-Mothers felt guilty because they believed they may have contributed to causing ASD<br>-Emotional stress during early childhood was also another cause<br>-Some parents initially believed it was because of medical reasons, but they stopped to believe that when the treatment did not cure the problem<br>-Parents have cultural beliefs about the cause of ASD<br>-Three quarter of parents believed ASD to be because of evil eye | 1. Beliefs about the etiology of ASD |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | -Some parents believed it was because of black magic<br>-Cultural interventions were the most commonly reported by parents, e.g., reading Holy book or going to religious healers<br>-in addition to cultural interventions parents reported using autism-diet and the hyperbaric oxygen therapy<br>-Professionals offered medication but parents preferred religious and cultural interventions | |
| Ha et al. (2014) | Qualitative study | <17 years old | Vietnam | Study conducted in Hanoi, the capital city of Vietnam<br>One family was Christian, and all the others either were Buddhists or non-religious<br>Families have higher education than the overall population of Vietnam ranging from high school to undergraduate | To explore how ASD is represented and managed in Vietnam and to understand the experience of families with children with ASD | -Disability is perceived because of sins or immorality which led to stigma against people with disability<br>-Feeling ashamed, sad, and guilty because of their belief of Karma<br>-Individuals with ASD are viewed as burdensome and worthless for their family and the society<br>-Parents were advised by professionals to have another child because children with ASD are good for nothing | 1. Beliefs about the etiology of ASD<br>2. Community perception & societal acceptance<br>3. Challenges engaging with services<br>4. SES |

| | |
|---|---|
| level of education | -Feared stigma, because ASD is mistakenly associated with schizophrenia and healthcare providers believe the same<br>-Children with ASD experienced social exclusion—from education, institutional neglect, bullying and physical violence<br>-Diagnostic process in often rushed and the measures are inappropriate which provide parents with vague diagnosis and confusion<br>-The diagnostic measures are translated from other languages but have not been culturally validated because of resources restrains<br>-Families outside the major cities do not have access to any services and thus children may never receive a diagnosis<br>-Parents referred to ASD as a disease not a disorder because disease could be cured<br>-Some professionals advised that ASD is |

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| | | | | | | curable, and parents spend a lot of money and time looking for cure<br>-ASD not recognized as a disability, so ineligible for social payments<br>-Few public hospitals provide early intervention which only last for three weeks and each child has a limit of four courses of intervention<br>-Children outside Hanoi unable to attend because of the cost for accommodation, food, and travels<br>-Parents used a combination of interventions including biomedical medicine and traditional Vietnamese and Chinese medicine and spiritual practices | |
| Tilahun et al. (2016) | Mixed methods | <18 years | Ethiopia | Majority were Orthodox Christians, few were Protestant or Muslims. Education levels varies from no formal education to Diploma or above | To examine the stigma experiences, explanatory models, unmet needs, preferred interventions and coping mechanisms of caregivers of children with developmental | -High functioning cases of ASD are rarely diagnosed in Ethiopia<br>-45.1% of parents felt ashamed and embarrassed about their child condition<br>-26.4% felt the need to hide their child condition from people in the community | 1. Community perception & societal acceptance<br>2. Beliefs about the etiology of ASD<br>3. Spouse & extended family |

| | |
|---|---|
| disorders including ASD in Ethiopia | -26.7% made an effort to keep their child condition a secret<br>-24.7% worried that people would be reluctant to marry from their family<br>-39.3% worried about taking their child out of the house<br>-50.5% feel that their child problem is their fault<br>-The most common biomedical explanations were head injury, birth complications, epilepsy, pathogens and a family history<br>-Supernatural explanations included spirit possession, a sinful act<br>-92.2% believed that their child problem could be cured<br>-Parents reported using both traditional and biomedical interventions<br>-Traditional interventions included prayer, slaughtering a sheep, or fumigating (making excessive use of smoke by burning incense) |

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| | | | | | | -Few parents reported using beating or chaining to manage their children<br>-Source of support: Religion, talking to family or friend, or using drug or substance to cope with the emotional stress | |
| Al-Dababneh et al. (2017) | Qualitative study | 6–16 years | Jordan | Parents' education level varies from primary schools to college degrees | To understand the beliefs of Jordanian parents about the causes of their children disability and their progress | -Parents mentioned several causes for ASD including genetic, environmental, early childhood illness, events during pregnancy, premature birth, lack of oxygen after birth, immunisation, or injury<br>-Some parents blame themselves for the diagnosis<br>-Half of parents believes that disability is a gift from God<br>-Half of the parents felt proud and took pleasures in their child's performance<br>-Several parents believed that their children could make progress but not in an acceptable way<br>-Few parents have low expectations of their child progress | 1. Beliefs about the etiology of ASD |

especially when they
were first diagnosed

ASD, autism spectrum disorder; SES, socioeconomic status

**Table 2**

*Factors Identified from the Included Studies*

| Factor | Sub-codes | Within country | No. of articles | Between countries | No. of articles |
|---|---|---|---|---|---|
| 1. Lack of general knowledge on child development and impairments | 1. About ASD | ✓ | 14 | ✓ | 9 |
| | 2. About developmental milestones | ✓ | 2 | × | |
| 2. Beliefs about the etiology of ASD | 1. Cultural | ✓ | 6 | ✓ | 8 |
| | 2. Religious | ✓ | 8 | ✓ | 7 |
| | 3. Personal | ✓ | 3 | ✓ | 6 |
| 3. Symptoms exhibited by the child | | ✓ | 4 | ✓ | 2 |
| 4. Race/ethnicity | | ✓ | 3 | × | |
| 5. SES | | ✓ | 4 | ✓ | 3 |
| 6. Language barriers | 1. Difficulty expressing concern and navigating the diagnostic process | ✓ | 4 | × | |
| | 2. Incorrect translation of educational material | ✓ | 1 | × | |
| | 3. Conflict to use mother language at home | ✓ | 2 | × | |
| 7. Community perception & societal acceptance | 1. Stigma | ✓ | 11 | ✓ | 6 |
| | 2. Misconception about the child | ✓ | 9 | ✓ | 3 |
| | 3. Importance of academic achievements | ✓ | 2 | ✓ | 2 |
| 8. Spouse & extended family | 1. Source of support | ✓ | 6 | ✓ | 2 |
| | 2. Source of stress | ✓ | 7 | × | |
| 9. Challenges engaging with services | 1. Difficult to interact with a physician | ✓ | 3 | × | 0 |
| | 2. Physician dismissive of parents' concerns | ✓ | 2 | ✓ | 2 |
| | 3. Access to interpreter | ✓ | 2 | × | 0 |
| | 4. Challenges with access to services or lack of awareness of available services | ✓ | 5 | ✓ | 6 |
| | 5. Expectation of interventions' outcomes | ✓ | 1 | ✓ | 4 |

*Note.* ✓ = Factor was present, × = Factor was not present, ASD: autism spectrum disorder; SES: socioeconomic status

# Chapter 3

# Chapter 3

## Title: Exploring the Participation Patterns and Impact of Environment in Preschool Children with ASD

**Introduction to Chapter 3:** Chapter 2 described the cultural factors in a child's environment that could impact on parent behaviours in seeking and engaging in services for their child with ASD. Chapter 3 aims to look closely at the participation patterns of preschool children with ASD within different environmental contexts, to explore their engagement in home and community settings. It also explores the various factors associated with the participation of children in these different environmental contexts and the importance of considering social communication abilities.

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*Environmental Research and Public Health*

*Article*

# Exploring the Participation Patterns and Impact of Environment in Preschool Children with ASD

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**Abstract:** Participation in everyday activities at home and in the community is essential for children's development and well-being. Limited information exists about participation patterns of preschool children with autism spectrum disorder (ASD). This study examines these participation patterns in both the home and community, and the extent to which environmental factors and social communication abilities are associated with participation. Fifty-four parents of preschool-aged children with ASD completed the Participation and Environment Measure for Young Children and the Autism Classification System of Functioning: Social Communication. The children had a mean age of 48.9 (8.4) months. Patterns of participation were studied using descriptive statistics, radar graphs, and Spearman correlations. Children with ASD participated in a variety of activities at home and in the community, but showed a higher participation frequency at home. Parents identified different barriers (e.g., social demands) and supports (e.g., attitudes) in both settings. There was a moderate positive association between children's social communication abilities and their levels of involvement during participation and the diversity of activities. This study highlights the importance of social communication abilities in the participation of preschool children with ASD, and the need to support parents while they work to improve their child's participation, especially within their communities.

**Keywords:** autism spectrum disorder; participation; environment; social communication; childhood

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## 1. Introduction

Participation is defined in the WHO's International Classification of Functioning, Disability, and Health (ICF) as "involvement in a life situation" [1]. Since the introduction of the ICF, this definition has evolved and has been given several meanings in the literature [2,3]. Participation has also been described as the intensity of engagement or being involved in a life situation [2], and as the experience of taking part in an everyday activity [4]. Participation has been defined as a multidimensional concept that includes two essential constructs: *Attendance* to an activity, and level of *involvement* [5,6]. *Attendance* is defined as "being there" and is measured by the frequency and/or diversity of activities in which the person takes part [5]. *Involvement* is defined as "the experience of participation while attending, including elements of motivation, persistence, social connection, and affect" [5]. The definition by Imms and colleagues [5] informed this study, as this multidimensional concept could be applied to any activity or setting, regardless of the ability of the individual [6].

It is believed that participation is a pre-requisite for human development [7] and an indicator of children's health and well-being [8,9]. According to Bandura's social learning theory [10], new skills are acquired by direct experience and engagement with and/or through the observation of others. Therefore, through participation in everyday activities, children develop cognitive, sensory, motor, and social skills [11], form friendships, and develop their sense of self-identity [7]. Overall, participation is associated with positive outcomes for all children, but it could have more significant impact on the development of children with disabilities. Participation has been reported to have an influence on learning, independence, and social inclusion of children with disabilities [9].

Over the last decade, the number of children diagnosed with autism spectrum disorder (ASD) has increased, with 1 in 54 children diagnosed with ASD in the US [12] and 1 in 66 in Canada [13]. Children receive an ASD diagnosis during the preschool years (median age of diagnosis is 4 years) [14]. Parents are usually stressed and overwhelmed following receiving an ASD diagnosis [15] and their children's participation might not be their priority. The preschool years are the period where children first start to learn their roles in a group, gain new skills, and practice these skills in their environments [16]. In addition, participation in the preschool years highly depends on the opportunities offered to children by adults in their everyday environment, typically their parents or caregivers [17,18]. The literature indicates that children with disabilities participate less frequently in domestic, educational, leisure, and social activities when compared to their typically developing peers [11]. Children with ASD are reported to have limited participation, as well as engaging less frequently and in fewer activities when compared to their typically developing peers [19,20]. They participate less frequently in activities of self-care, community mobility, and leisure activities [19]. Families of preschool children with ASD are reported to participate less in special event activities such as family vacations and birthday parties [20]. School-aged children with ASD are also reported to participate less than their typically developed peers in social activities, unstructured activities, and after school activities [21,22].

Many challenges associated with ASD, such as social communication deficits and/or repetitive behaviors, put children with ASD at risk of limited participation. Their social communication difficulties make it a challenge to be involved and engaged with others, which is required for many aspects of participation [19,23]. Furthermore, their restrictive and repetitive behaviors may set them apart from other children and further limit their participation in everyday activities [19]. In addition, parents of children with ASD indicate that their child's participation may also be impacted because parents may avoid participation outside their home due to fears of the negative perceptions of others [24,25].

As indicated above and in the literature, various aspects of the environment-the physical, social, or attitudinal—can have a significant impact on children's participation [1,4,26]. Bronfenbrenner's bioecological systems theory identified the different layers of the environment and their impact on child development [27]. Child development is affected by their interaction with the environment at various levels (directly and indirectly), including their immediate family, community, and society [27]. This emphasizes the need to look at the potential impact of various environments to understand children's development. Parents of children with disabilities consider the environment to be less supportive and believe that their children have more environmental barriers than typically developing children [9,28]. These barriers could relate to the physical, social, or attitudinal aspects of the environment. The environmental features may either support or hinder the participation of children with ASD. Some of these features include sensory issues, such as level of noise and lighting [29]; furthermore, the physical layout of the space, as well as the social and cognitive demands of some activities, may compromise social connections, such as interacting with others [29]. Availability of resources and services may also support participation of children with ASD [29].

Studies of the impact of the environment on participation with various populations of children with disabilities have shown inconsistent findings. In their study of participation of school-aged children with severe physical disabilities, King et al. [30] found that the environment indirectly impacted on participation. For example, unsupportive environments (e.g., inaccessible or less accommodating) were found to be related to a child's reduced functional ability and therefore were associated with limited participation [30]. A study of participation of children with cerebral palsy found that environmental factors failed to predict the child's participation diversity [31]. Moreover, for preschool children with mild developmental disabilities, environmental factors were found to be significant predictors of children's participation [11]. Studies of participation of school-aged children with ASD found the environment to be one of the factors that impacted their participation [26,28]. In their report, Askari and colleagues [26] reviewed the literature on the impact of the different aspect of the environment (i.e., physical, social, and attitudinal) on participation of children with ASD. In this work, social supports from parents, siblings, or friends were highlighted as important for participation, whereas negative attitudes in the community (e.g., church) presented as barriers for participation for children with ASD [26].

Few measures are designed to assess characteristics of the environment that impact participation in different settings. These include the Child and Family Follow-up Survey (CFFS) [32] and the Participation and Environment Measure (PEM) [33]. The CFFS is designed for children 5 years and older with traumatic brain injuries (TBIs) [32]. It has five sections, one of which is the Child and Adolescent Scale of Participation (CASP), to report on the participation of children with TBIs in the home, school, and community [32]. Another scale is the Child and Adolescent Scale of Environment (CASE), which measures the intensity of the physical, social, and attitudinal environment problems experienced by children with TBIs [32]. The PEM has two versions: The Young Children Participation and Environment Measure (YC-PEM) [34] for children aged 0–5 years, and the Participation and Environment Measure for Children and Youth (PEM-CY) for children and youth aged 5–17 years old [33]. They are used to report on participation and the quality of the environment in various activities in three contexts: At home, daycare/school, and community. PEM can be used with children with various disabilities, as well as children without disabilities.

Another factor that affects participation is the child's social functioning [35,36]. Social communication functioning is inconsistently defined in the literature [37]. New perspectives in the field are making the distinction between social deficits, impairment, functioning, and abilities [38]. In an extensive search of the literature, King and colleagues developed a conceptual model of factors affecting participation in recreational and leisure activities for children with disabilities [39]; the child's social functioning was one of the factors identified in this model. Evidence indicated that better-developed social functional ability was associated with better involvement when participating in activities [39]. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines social communication impairment as "deficits in social-emotional reciprocity, non-verbal behavior, and imitative and make-believe play" [40]. Although deficits in social functioning are one of the core symptoms of ASD [39,41], to our knowledge there is a paucity of research on the impact of social functioning on participation for children with ASD.

To date, studies on participation of children with disabilities have focused on school-aged children and adolescents and those with physical disabilities, while there is a lack of research on participation for young children with ASD [24]. A systematic review by Adair et al. [6] found that of the 394 articles on participation that they reviewed, 105 articles focused solely on cerebral palsy, while only 37 articles focused on ASD. Furthermore, these types of studies usually involve comparing a group of children with disabilities to a group of children without disabilities [29,42–45]. There is a need to study, in depth, the patterns of participation and the potential factors associated with participation amongst preschool children with ASD. The aims of this study were to explore the patterns of participation for preschool children with ASD (3–6 years old) and investigate the impact of different environmental and individual factors on their participation.

## 2. Methods

### 2.1. Participants and Procedures

This cross-sectional study investigated the patterns of participation in preschool children with ASD and the factors that are associated with them, including the environment and the social communication abilities of the child. The study involved analysis of data relating to a subsample of children who were recruited for a larger project (the Pediatric Autism Research Cohort (PARC) project-pilot phase). The subsample included children who have completed the YC-PEM, and therefore involved children who were 5 years and younger. PARC is a longitudinal inception cohort of children recently diagnosed with ASD from Hamilton, Ontario. The study was approved by the local research ethics board (Hamilton Integrated Research Ethics Board (HiREB)) and all families provided informed consent. The sample included 94 children diagnosed with ASD. The inclusion criteria for participants involved being under age 6 at enrollment and being enrolled in services at the regional autism program.

### *2.2. Assessment Measures*

Sociodemographic questionnaire: This questionnaire was created specifically for the PARC study and included questions about the child, such as their age, sex, and country of birth. It also asked questions concerning the family background, including their educational level and family income.

### *2.3. Participation and the Environment*

Participation and Environment Measure (Young children version—YC-PEM): YC-PEM was developed based on ICF concepts and is a parent- or caregiver-completed questionnaire. The current study explored participation at home and community settings only. Home and community are considered the natural learning environment of daily activities for young children [46]. For each activity, parents reported: (i) Frequency of participation on an 8-point scale from never (0) to daily (7) for 13 age-appropriate activity items at home and 11 items in the community; (ii) level of involvement in specified activities (5-point scale from minimally involved (1) to very involved (5)); and (iii) whether caregiver/parent would like to see changes in their child's participation in this type of activity (yes or no question). For each setting, parents reported on various features of the environment or resources and their impact on their children's participation, such as the sensory qualities of the environment or the cognitive demands of an activity. For each item in the environment, parents chose one of the following: Whether it has no impact, usually helps, sometimes helps, sometimes makes harder, or usually makes harder. Since the study aim was to explore the pattern of participation, questions on caregivers' desire to change participation were not considered.

The YC-PEM has shown sound psychometric properties with children with different disabilities. It has an acceptable internal consistency (>0.70) for three scales: Frequency ($\alpha = 0.72$); Involvement ($\alpha = 0.80$); and Environmental Support ($\alpha = 0.92$) [47]. The test–retest reliability for the frequency scale was fair to good for home (ICC = 0.61–0.63) and community (ICC = 0.55–0.63), and for the level of involvement scale reliability was good to excellent for the home (ICC = 0.79–0.93) and good for the community (ICC = 0.71–0.97). The reliability for the environment scale was good for the home and community (ICC = 0.91–0.94) [47]. PEM-CY/YC-PEM has been used to investigate the pattern of participation for children with ASD in different settings, but mostly for school-aged children [29,42,48].

### *2.4. Social Communication Functioning*

The construct of social communication was explored using the Autism Classification System of Functioning: Social Communication (ACSF:SC) [49]. The ACSF:SC is a strength-based tool that aims to categorize children with ASD who are between 3 to 6 years old into one of five levels of functioning based on their social communication abilities. This descriptive tool was developed by CanChild researchers based on ICF concepts. The social communication abilities range from level V (lowest ability) through level I (highest ability). This classification tool is not meant to replace any diagnostic or assessment tools, but rather provides a simple standardized method to classify the child's social communication abilities in a consistent manner among the health provider teams, teachers, and parents [50]. A rater who is familiar with the child is asked to provide two ratings: The child's capacity level (what the child can do at their best) and the child's typical performance level (what the child can do on a day-to-day basis). The ACSF:SC demonstrates good intra-rater agreement for parents ($k_w = 0.61$–$0.69$) and good to very good for professionals ($k_w = 0.71$–$0.95$) [50].

The inter-rater agreement among parents and professionals ranges from fair to moderate agreement ($k_w = 0.33$–$0.53$) [50].

### *2.5. Data Analysis*

The data for the current analysis were drawn from the initial time point from the larger PARC study. Data were analyzed using STATA software, version 13 (StataCorp LLC, Texas, TX, USA), and an effect was considered statistically significant at $\alpha = 0.05$.

Descriptive statistics, including the means, standard deviations, and percentages of child characteristics and their family's sociodemographic information were first calculated for the participants. The distribution of the sample among the five levels of the ACSF:SC was obtained for the best capacity and typical performance scales. To understand the pattern of participation for our sample, the mean and standard deviation were calculated for the frequency and level of involvement scales of the YC-PEM. The percentages of activities in which the children participated were also calculated. Radar graphs were obtained to illustrate the distribution of scores across items. Radar graphs are used to represent the data visually in order to examine patterns of activity and are shaped like histograms. The radar graphs have multiple spokes spreading from the center of the graph, and the longer the spoke, the higher the magnitude of the variable represented by this spoke [51].

To explore the relationships between the ACSF:SC levels and YC-PEM-reported frequency, level of involvement, and the percentage of activity for both settings, scatter plots were created to visualize the data, followed by Spearman's correlation analysis. The same procedure was done to explore the relationships among the ACSF:SC levels and the environmental scales of the YC-PEM, followed by analysis of variance (ANOVA). ANOVA was conducted to explore whether the size of the differences between best capacity and typical performance levels was associated with the presence of environmental supports or barriers.

## 3. Results

Descriptive statistics: 54 children completed the ACSF:SC and were included in the analysis. Socio-demographic information of the parents, their household, and their child with ASD is summarized in Table 1.

**Table 1.** Descriptive statistics and sociodemographic features of the sample.

| Demographic Variables | (*n* = 54) |
|---|---|
| **Child Gender** | |
| Boys | 45 (83.3%) |
| Girls | 9 (16.7%) |
| **Child Age** (in months) | |
| Mean (SD) | 48.9 (8.4) |
| **Language Spoken at Home** | |
| English | 53 (98.2%) |
| **Caregiver's Highest Level of Education** | |
| High School | 9 (17%) |
| Secondary education | 44 (83%) |
| **Spouse Highest Level of Education** | |
| High School | 11 (23.9%) |
| Secondary education | 35 (76.1%) |
| **Family Annual Income** | |
| <$30,000 | 9 (17.6%) |
| $30,001–$60,000 | 14 (27.5%) |
| $60,001–$80,000 | 5 (9.8%) |
| >$80,000 | 23 (45.1%) |

Non-respondent analysis: Six participants did not complete the ACSF:SC and were excluded from the study. There were no significant differences between the respondent and non-respondent children in terms of their age (t (58) = 0.15, $p = 0.9$), gender (Pearson $X^2$ (1) = 1.0, $p = 0.3$), or language spoken at home (Pearson $X^2$ (1) = 0.36 $p = 0.6$).

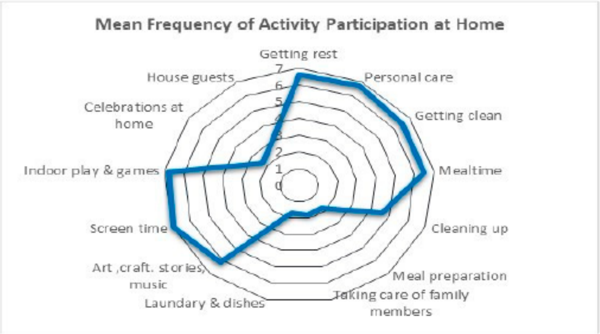
ACSF:SC best capacity and typical performance scores: Parents of 50% of the participants rated their child the same for typical performance and best capacity, and 44.4% of parents judged their children to have lower typical performance abilities than their best capacity ability. Parents of only 5.6% of the participants judged their children to have higher typical performance abilities than their best capacity (Table 2). A total of 46.3% of participants had a ±1-level difference, while only 2% had a 2-level difference.

**Table 2.** Autism Classification System of Functioning: Social Communication (ACSF:SC) best capacity and typical performance ratings. Agreement between best capacity and typical performance is highlighted.

| **Best Capacity** | **Typical Performance** | | | | | |
|---|---|---|---|---|---|---|
| | **I** | **II** | **III** | **IV** | **V** | **Total** |
| **I** | 2<br>3.7% | 4<br>7.4% | 0<br>0.0 | 0<br>0.0 | 0<br>0.0 | 6<br>11.1% |
| **II** | 1<br>1.9% | 4<br>7.4% | 7<br>12.9% | 0<br>0.0 | 0<br>0.0 | 12<br>22.2% |
| **III** | 0<br>0.0 | 0<br>0.0 | 10<br>18.5% | 8<br>14.8% | 1<br>1.9% | 19<br>35.2% |
| **IV** | 0<br>0.0 | 0<br>0.0 | 1<br>1.9% | 6<br>11.1% | 4<br>7.4% | 11<br>20.4% |
| **V** | 0<br>0.0 | 0<br>0.0 | 0<br>0.0 | 1<br>1.9% | 5<br>9.3% | 6<br>11.1 |
| **Total** | 3<br>5.6% | 8<br>14.8% | 18<br>33.3% | 15<br>27.8% | 10<br>18.5% | 54<br>100 |

*YC-PEM*

Participation: Overall, parents reported their children as participating in a variety of activities at home and in the community. Frequency and level of involvement are demonstrated in the radar graphs to depict the activities in which children engaged within the home and community settings (Figures 1 and 2).

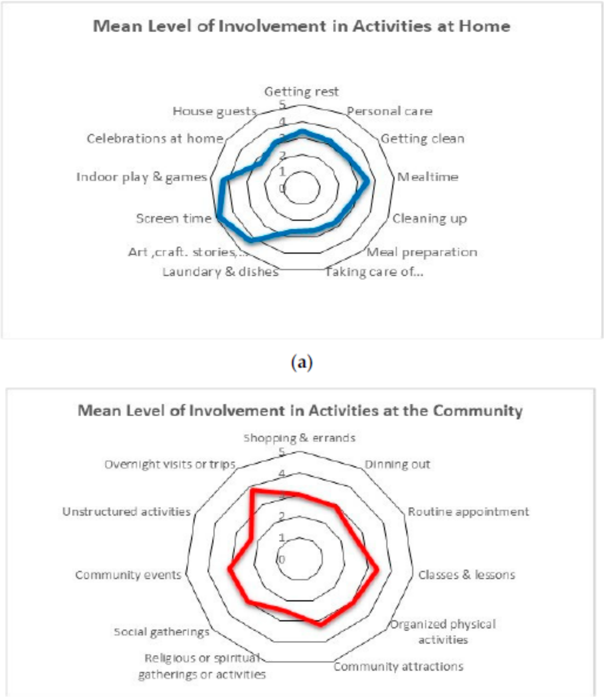


(a)

**Figure 1.** *Cont.*

**(b)**

**Figure 1.** (**a**) Mean frequency of activity participation at home, (**b**) mean frequency of activity participation in the community.



**(a)**

**(b)**

**Figure 2.** (**a**) Mean level of involvement in activities at home, (**b**) mean level of involvement in activities in the Community.

## 4. Home Setting

Activity frequency and level of involvement: The majority of our sample (>73%) were reported to participate most frequently in basic care routine activities (mean = 6.6) (Figure 1a); 50% were reported to be "somewhat involved" in these activities (Figure 2a). Household chores were reported to have the lowest frequency in the home setting with a mean of 1.8 ("few times in the last four months") in three out of four activities. Participants were reported to have different levels of involvement ranging from "not very involved" to "very involved". Furthermore, up to 65% of the participants were reported to have never participated in these chores. Participants showed high frequency rates in the interactive and organized play with the majority (98%) participating daily in these activities and being very involved. Socializing with friends and family was also reported to have low frequency from "few times in the last four months" (44%) to "a few times a month" (up to 27%). The level of involvement ranged from not very involved to very involved (Supplementary Table S1).

Environmental supports and barriers: Half of the parents reported that the physical layout of their houses supported their children's participation, as shown in Table 3. Sensory qualities were perceived as a support for 37.7% of the parents. Cognitive and social demands were reported to support children's participation for 22.6% and 26.4%, respectively, with a further 24.5% and 30.2% parents considering them as barriers. The attitudes of family were reported as supportive for 34.7% of parents. A total of 46.7% of parents considered money and time to support their children's participation.

Relationship between social communication and participation: Spearman's correlation analyses provided the same correlations for best capacity and typical performance levels and participation. Therefore, we decided to use the typical performance levels as they represent everyday functional performance. There was very low correlation between participation *frequency* and the ACSF:SC (typical performance level) ($r = -0.02$, $p = 0.9$). However, the Spearman's rank correlation showed a low negative correlation between the *level of involvement* and the ACSF:SC ($r = -0.32$, $p < 0.01$), and a moderate negative correlation between the *percentage of activity participation* and the ACSF:SC ($r = -0.42$, $p < 0.01$). Because of the scaling of the ACSF:SC, the correlation was negative, but there was a positive association between the level of involvement, percentage of activity participation, and social communication (i.e., the better the social communication ability on the ACSF:SC, the higher the level of involvement and the wider the variety of activities in which the child participates).

**Table 3.** Environmental features as perceived by parents at home.

| Environmental Features | Home Setting | | | |
|---|---|---|---|---|
| | % Supports | % Barriers | % No Impact | % Sometime Helps/Sometime Make Harder |
| Physical Layout | 55.0 | 0.0 | 25.0 | 21.0 |
| Sensory Qualities | 37.7 | 1.8 | 37.7 | 22.6 |
| Physical Demands | 30.2 | 9.4 | 39.6 | 20.8 |
| Cognitive Demands | 22.6 | 24.5 | 20.8 | 32.1 |
| Social Demands | 26.4 | 30.2 | 20.8 | 20.8 |
| Relationships with Family Members | 51.9 | 3.8 | 5.8 | 38.5 |
| Attitudes | 34.7 | 4.1 | 26.5 | 32.7 |
| Policies | 25.5 | 17.6 | 35.3 | 21.6 |
| Services | 25.5 | 27.5 | 13.7 | 31.4 |
| Supplies | 97.7 | 0.0 | 0.0 | 2.2 |
| Information | 50.0 | 2.3 | 0.0 | 47.7 |
| Time | 46.7 | 11.1 | 0.0 | 42.2 |
| Money | 46.7 | 4.4 | 0.0 | 48.9 |

## 5. Community Setting

Activity frequency and level of involvement: Overall, the frequency of participation in the community activities was lower than those in the home setting (Figure 1b). Children were reported to participate most frequently in shopping and errands (once a week), followed by unstructured physical activities (a few times a month). The lowest frequency observed was 1 (once in the last four months) for classes and lessons, organized physical activities and overnight trips, vacations and visits. However, even with the low frequency, children were reported as being involved when doing these activities. In all of the activities, there were parents who reported that their children never participated in these activities. For example, 73.4% of parents reported that their children never participated in an organized physical activity.

*Environmental supports and barriers*: The sensory quality of the environment was reported by parents as a barrier for 23.1% of the participants (Table 4). Cognitive and social demands were reported by parents as supportive for 22% and 11.8% of the participants, respectively, while reported as barriers for 24% and 35.3% of the participants, respectively. Parents reported attitudes and relationships with friends to be supportive for 25% and 24% of the participants, respectively. Personal transportation, equipment, and supplies were reported as supports for more than 60% of participants. Time and money to support their children's participation at the community were also reported by 40% of the parents.

Relationship between social communication level and participation: There was very low correlation between the ACSF:SC (typical performance) level and the participation *frequency* or the percentage of activity participation. There was a moderate negative correlation between the ACSF:SC (typical performance) level and the *level of involvement* ($r = -0.41$, $p = < 0.01$). Once again, although the correlation was negative, there was a positive association between the level of involvement and social communication abilities (i.e., the better the social communication ability on the ACSF:SC, the higher the level of involvement when children participate in activities).

ACSF:SC and the environmental supports and barriers: The Spearman's analysis showed very low correlation ($r \leq 0.03$) between the ACSF:SC levels and the environmental supports or barriers for both the home and community settings.

The sample was then divided into three groups based on the size of differences between the best capacity and typical performance levels of the ACSF:SC. In group 1, differences were $\leq -1$, in group 2 there were no differences, and in group 3 the differences were $\geq +1$. The ANOVA showed no difference between the groups in terms of home environmental support ($F(2, 50) = 0.08$, $p = 0.9$). Since the environmental barriers at home, as well as environmental supports and barriers in the community were not normally distributed, the Kruskal–Wallis tank test was conducted but no difference was found between groups ($p > 0.05$).

**Table 4.** Environmental features as perceived by parents in the community.

| Environmental Features | Community Setting | | | |
|---|---|---|---|---|
| | % Support | % Barrier | % No Impact | % Sometime Helps/Sometime Make Harder |
| Physical Layout | 30.8 | 5.8 | 42.3 | 21.2 |
| Sensory Qualities | 11.5 | 23.1 | 19.2 | 44.2 |
| Physical Demands | 19.2 | 7.8 | 32.7 | 38.5 |
| Cognitive Demands | 22.0 | 24.0 | 16.0 | 38.0 |
| Social Demands | 11.8 | 35.3 | 13.7 | 37.3 |
| Attitudes | 25.0 | 11.5 | 15.4 | 48.1 |
| Relationship with Peers | 24.0 | 16.0 | 18.0 | 42.0 |
| Weather | 7.7 | 11.5 | 30.8 | 50.0 |
| Safety | 30.8 | 9.6 | 36.5 | 23.1 |
| Policies | 26.0 | 6.0 | 34.0 | 34.0 |
| Personal Transportations | 76.5 | 5.9 | 11.8 | 5.9 |
| Public Transportations | 21.6 | 5.9 | 66.7 | 5.9 |
| Program & Services | 35.3 | 9.8 | 5.9 | 49.0 |
| Equipment or Supplies | 86.8 | 0.0 | 2.6 | 10.5 |
| Information | 43.6 | 5.0 | 0.0 | 51.3 |
| Time | 46.2 | 7.7 | 0.0 | 46.2 |
| Money | 43.6 | 5.0 | 0.0 | 51.3 |

## 6. Discussion

This descriptive study explored participation patterns of preschool children with ASD and factors associated with participation, including the environment and the social communication abilities of the child.

Participation pattern for preschoolers with ASD in different settings: Overall, preschool children with ASD participated in a variety of activities at home. Organized play activities, such as screen time, indoor play, and games, were reported to have the highest frequency, which was also reported in other studies [19,29,42,52]. In fact, in one study, children with ASD had a higher frequency of participation than their typically developed peers in activities such as watching TV and screen time [29]. These activities usually do not involve socializing or engaging with others. Previous studies found that children with ASD usually participate in activities alone or with few people—usually their families [22,42].

Children in this study were also reported to have the lowest frequency of participation in household chores. For example, the mean frequency of participation in meal preparation was 1.8 (out of 7), for taking care of family members was 1.8, and for laundry and dishes was 1.7. These findings were also evident in the literature with preschool and school-aged children with ASD [19,53]. When asked, parents revealed that they did not consider assigning chores to their children with ASD [19]. Parents reported that offering chores to their children with ASD would require a lot of energy to accommodate their children's behaviors and needs, and therefore they chose not to engage them in these activities [19]. Participating in chores could provide children with ASD with the opportunity to practice their problem-solving skills, increase family socializing, teach them to take responsibilities, and prepare them to take care of themselves and others [54,55].

Our findings also indicated that children with ASD generally have lower rates of participation in community settings (mean = 2.9) when compared to a home setting (mean = 5.9). The same findings were reported for children with various disabilities [56,57]. Parents of children with ASD reported having less control over the environment in the community [11,53]. It is more challenging for parents to manage their children's behavior in the community due to the unpredictability of the situations and sensory stimulation. As such, families reported that their energy is spent trying to think about the environment—what to expect and how their child may react [19]. The whole process is exhausting for them and consequently they avoid participating in activities in the community [53]. When considering participation for children with ASD in the community, this highlights the importance of taking the whole family into consideration as a unit, rather than only focusing on the child and their capabilities. These findings are consistent with Bronfenbrenner's Ecological Theory of Human Development [27], in which the child's developmental outcome is influenced by their interactions with different levels of the environment. At the level of the microsystem, child development is influenced by their immediate environment, which typically includes the family [27]. Parents are responsible for offering opportunities for their children to participate [19,53]. In one study, parents reported avoiding dining out or taking their child to grocery stores because of their risk of a behavioral meltdown [53]. This is supported by our findings that even though these children have generally lower frequency of participation in the community, some were reported to have a high level of involvement of participation in activities in the community. For example, participating in overnight trips and vacations had the lowest frequency (1 out of 7) in the community; however, children who participated had the highest level of involvement (3.8 out of 5) compared to all other community activities. Although there were no control groups in the current study to see how patterns of participation in this cohort compare to those of children without ASD, other studies have reported common findings that children with disabilities have lower participation frequency and involvement than children without disabilities [26,28]. Even when children with and without disabilities participated in the same activities, their levels of involvement are different [26].

Environmental barriers and supports: Parents reported a variety of environmental supports and barriers. However, in some cases what was reported as a support for some parents was considered as a barrier for others. For example, 22% of parents considered the cognitive demands of an activity as a support to their child's participation at home; however, the same percentage of parents considered it as a barrier. The same applies for social demands of the activity and the availability of services, where similar percentages of parents had considered it as either a support or a barrier. This underscores the importance of taking into consideration the individual variations among children with ASD and how the needs of each child vary in different contexts [28]. Furthermore, sensory qualities of the environment were considered mainly as a support at the home, while a higher percentage considered it as a barrier in the community. This lends further support to the fact that parents' lack control over the community environment and its impact on their children's participation. It also supports the findings of another study where atypical sensory processing, such as hyper-responsiveness, was associated with lower frequency of activity participation in the community [58].

Relationship between social communication and participation: Our findings indicated that better social communication abilities were associated with a wider variety of activities in which the child participated at home, and higher levels of involvement when participating in these activities. However, in the community, better social communication abilities were only associated with higher level of involvement, which aligns with the findings that identify the complexity of participation in the community and the different factors that impact it.

### *Clinical Implications*

The study findings provide some insights for clinicians who work with children with ASD and their families. One important implication for service providers is actively to encourage parents of preschoolers to involve their children in as wide a range of daily activities and recreational opportunities as possible from a very young age, so that "participation" becomes part of daily life and is not then seen as a prescribed "add-on". Young children's participation in activities is a reflection of their family choices, available opportunities, as well as their abilities and interest. Whereas typically-developing children often take the initiative to be involved in activities, families of children with ASD need to be supported and encouraged to see opportunities to help improve their children's participation at home and in the community. Considering each child's individual needs, clinicians could provide some strategies to improve their participation. For example, household chores could be modified and broken down into several steps that the child could follow to improve various skills, such as their problem-solving skills. Clinicians could also provide some strategies to manage children's behavior in the community to increase their participation. When recommending interventions, clinicians need to take into consideration the family as a whole and any special situations they might have. Clinicians should also be aware of the community with regard to sensitivities, needs, and vulnerabilities of children with ASD.

## 7. Limitations and Future Research

Results of this study should be considered in light of possible sampling and data limitations, including the small sample size and the study design. Cross sectional data limits our ability to identify whether social communication ability increases participation or whether the opposite is true. However, the PARC study continues to collect longitudinal data, which will provide the opportunity to further examine this in the future. In addition, only families who are enrolled in ASD services were included, which could be a potential source for sample selection bias (access to service bias). For example, children being seen could have complex issues while children with higher cognitive abilities may not be seen within the clinical setting. Furthermore, this study was based on parents' recall and no direct observation of children's participation was conducted. Future studies could include a qualitative dimension for a deeper understanding of children's participation from parents' perspectives. Other factors that may impact on participation, such as socioeconomic status and maternal education, could also be investigated in future studies. Participation patterns could also be investigated longitudinally in future studies. Simpson and colleagues (2019) studied longitudinally the participation pattern of children with ASD who are transitioning to adolescents (age 9 and 10 years old) [48]. Over three years, they found a trend regarding socializing and participating in physical activities (participation declined as children's ages increased) [48]. Similar studies with different age groups are essential and would highlight the important factors to consider for intervention planning to improve or maintain their participation in various activities.

## 8. Conclusions

This study adds to the emerging body of literature on participation patterns for preschool-aged children with ASD. In addition, it explores the relationship between social communication and participation, which is a key factor central to ASD. Preschool children with ASD participated in various activities at home and in the community, which are the main environments for participation for this age group. However, parents need support to facilitate and improve their children's participation in both settings. Furthermore, for interventions to be successful, especially those intended to modify the environment, the individuality of children with ASD, with variable abilities, should be acknowledged and considered when planning intervention goals. In addition, interventions should go beyond modifying the environment around the children and consider the environments that support them, including their family.

**Supplementary Materials:** The following are available online at http://www.mdpi.com/1660-4601/17/16/5677/s1, Table S1: Percentage of children participation frequency and level of involvement.

**Author Contributions:** G.K. and B.D.R. conceptualized the idea and methodology for this study. Data curation, investigation, and formal analysis of the data were conducted by G.K. and validated by E.D., G.K. was responsible for the original draft preparation. B.D.R., P.R., K.G., and E.D. were responsible for reviewing and editing the manuscript, and B.D.R. supervised the project. All authors have read and agreed to the published version of the manuscript.

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Supplementary material, table S1:

**Table S1.** Percentage of children's participation frequency and level of involvement

| | **Type of Activity** | | **Frequency** | **Level of involvement** |
|---|---|---|---|---|
| **Home** | **Basic care routines** | Getting rest | 82.7% participate daily | 56% somewhat involved<br>30% very involved |
| | | Personal care management | 86.5% participate daily | 56.9% somewhat involved<br>19.6% very involved |
| | | Getting clean | 73.1% participate daily<br>21.1% a few times a week | 18% not very involved<br>52% somewhat involved<br>18% very involved |
| | | Mealtime | 84.6% participate daily | 44.9% somewhat involved<br>36.7% very involved |
| | **Household chores** | Cleaning up | 15.4% never participated<br>38.5% a few times a week<br>21.2% participate daily | 20.9% not very involved<br>55.8% somewhat involved<br>11.6% very involved |
| | | Meal preparation | 58.8% never participated<br>11.8% once a week | 39.3% not very involved<br>21.4% somewhat involved<br>28.6% very involved |
| | | Taking care of other family members | 64.7% never participated<br>11.8% once a week | 36% not very involved<br>40% somewhat involved |
| | | Laundry & dishes | 62.8% never participated<br>11.8% once a week | 38.5%not very involved<br>30.8% very involved |
| | **Interactive & organized play** | Art, craft, stories, music | 63.5% daily | 26% somewhat involved<br>62% very involved |
| | | Screen time | 98%daily | 88.2% very involved |
| | | Indoor play & games | 88.5% daily | 30.8%somewhat involved<br>65.4% very involved |

| | | | | |
|---|---|---|---|---|
| | **Socializing with friends & family** | Celebrations at home | 44.2% a few times in the last four months<br>19.2%few times in the last month | 31.4% not very involved<br>37.3% somewhat involved |
| | | Houseguests | 19.2% never participated<br>26.9% a few times in the last month | 23.9% not very involved<br>37% somewhat involved<br>26.1% very involved |
| **Community** | **Neighborhood & community outings** | Shopping & errands | 32.1% once a week<br>34% a few times a week | 22% not very involved<br>56% somewhat involved<br>16% very involved |
| | | Dining out | 20.8% never<br>24.5% a few times in the last month | 25.6% not very involved<br>51.2% somewhat involved |
| | | Routine appointments | 7.5% never<br>24.5%once in the last four months<br>26.4%few times in the last four months | 35.4% not very involved<br>45.8% somewhat involved |
| | **Classes & groups** | Classes & lessons | 64.7%never<br>13.7%once a week | 42.9% somewhat involved<br>33.3% very involved |
| | | Organized physical activities | 73.4%never<br>12.2%once a week | 27.8% not very involved<br>44.4%very involved |
| | **Community-sponsored activities** | Community attractions | 21.2%never<br>21.2%few times in the last four months<br>17.3%once in the last month | 48.7% somewhat involved<br>20.5% very involved |
| | | Religious or spiritual gatherings or activities | 82.7%never<br>9.6%once a week | 38.5% not very involved<br>30.8% somewhat involved<br>23.1%very involved |
| | | Social gatherings | 7.8%never<br>29.4% a few times in the last four months | 27.5% not very involved<br>40% somewhat involved |

| | | | | |
|---|---|---|---|---|
| | | | 25.5% a few times in the last month | 27.5% very involved |
| | | Community events | 29.4% never<br>23.5%once in the last four months<br>21.6%few times in the last four months | 26.5% not very involved<br>35.3% somewhat involved<br>26.5% very involved |
| | **Recreational activities & trips** | Unstructured activities | 26.9%few times in the last month<br>32.7%few times a week | 32.7%somewhat involved<br>65.3%very involved |
| | | Overnight visits or trips | 42.3% never<br>32.7%once in the last four months<br>13.5% a few times in the last four months | 42.9%somewhat involved<br>39.3%very involved |

# Chapter 4

# Chapter 4

## Title: Stability of the Autism Classification System of Functioning: Social Communication and associated factors

**Introduction to Chapter 4:** This chapter contributes to this thesis by examining the patterns of social communication functioning over the course of six months for preschool children with ASD. Using a novel tool, the ACSF:SC, this study also considered the association with the environment on children's social communication abilities, which is central to an ASD diagnosis, and explored factors that might be associated with social communication stability. This chapter also highlighted the complexity of examining the functioning of children with ASD and the different factors that impact it.

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## Abstract

**Aim:** To assess the stability of the 5-level parent-reported Autism Classification System of Functioning: Social Communication (ACSF:SC) over six months.

**Methods:** This prospective study involved preschool children recently diagnosed with autism spectrum disorder (ASD) who were recruited from a children's hospital as part of a longitudinal study. The ACSF:SC data were collected at two time-points six months apart. Data analyses for the stability of the ACSF:SC were assessed using transition tables and Kappa coefficients (quadratic-weight).

**Results:** We studied 47 children with a mean age of 49.3 months; 44.6% of these children maintained their ACSF:SC level of functioning for their typical performance level, and 51% maintained their best capacity level. Weighted Kappa values ranged from 0.56 to 0.65 indicating fair to good chance-corrected agreement. Children classified in level III showed the highest stability over time.

**Interpretation:** The use of the ACSF:SC provides a common language to communicate the abilities of children with ASD. However, a frequent re-rating is recommended for accurate classification of a child's current level due to the relative instability of classification in young children.

**What this paper adds**

- **Preschool children with ASD classified using the ACSF:SC have a 50% chance of being classified differently at six months.**
- **Frequent rating using ACSF:SC is recommended for accurate and current classification due to the variability in social communication functioning in preschoolers.**
- **The typical performance level has a higher parent-reported agreement than the best capacity level.**

## Stability of the Autism Classification System of Functioning: Social Communication and associated factors

The number of children being diagnosed with Autism Spectrum Disorder (ASD) has increased over the last decade[1]. It is estimated that 1 in 54 children in the United States of America[2] and 1 in 66 in Canada[1] is diagnosed with ASD. ASD diagnosis is associated with social, language, cognitive, and/or behavioural challenges[3,4,5].

Children with ASD vary widely in their functional abilities in everyday life[6]. Research has suggested that it is important to describe children's functional abilities positively using a function-based approach to identify their skills, abilities, as well as their needs[7]. Using a function-based approach helps to reduce parents' stress and improve the relationship between parents and professionals and potentially improve children's outcomes while utilizing child abilities to guide goal setting and intervention planning[7,8]. Steiner (2011) compared the impact of therapists using statements that highlight children's deficits versus statements that emphasized their abilities when commenting on the behaviours of children with ASD during parent-education sessions[8]. The study found that using strengths or abilities-based approaches increased parents' affection toward their child and improved the parent-child interaction[8].

The Autism Classification System of Functioning: Social Communication (ACSF:SC)[9] is a function-based classification system that categorizes children with ASD into one of five levels of functioning based on their social communication abilities. A classification is made by determining which level corresponds to the child's social communication ability at their best (best capacity level) and in their average day (typical performance level)[9]. Research supports the reliability[9] and validity[10,11] of the ACSF:SC ratings in preschool children with ASD.

Classification systems are useful tools for effective communication, goal setting, and intervention planning[5,12]. For a classification system to be helpful in clinical practice, its stability must be established[13]. Stability means the extent to which children remain in the same level of function over a period of time[12,14,15]. Determining the stability of a classification system is important for parent counseling as well as decision-making[12]. Stability is also crucial for predicting future social communication abilities[13,15]. This study aimed to examine the patterns of social communication functioning using the ACSF:SC with a sample of preschool children diagnosed with ASD. The study addresses two objectives: (i) to investigate the stability of children's ACSF:SC prospectively over a 6-month period, and (ii) to examine factors associated with the stability of the ACSF:SC classification over time.

## Methods:

### *Participants:*

This study followed a group of preschool children with ASD for six months. Data were collected at two time- points: baseline (i.e., recently diagnosed with ASD) and six months after baseline. This study involves the analysis of a subsample of children who were recruited for an observational study (the Pediatric Autism Research Cohort (PARC) project-pilot phase). PARC is a longitudinal inception cohort of recently diagnosed children with ASD from Hamilton, Ontario. The study was approved by the local research ethics board (the Hamilton Integrated Research Ethics Board (HiREB)), and all families provided informed consent. The sample includes 94 children diagnosed with ASD. The PARC inclusion criteria for participants were being under age six at enrollment and being enrolled in services at the regional autism program.

### *Measures:*

Self-report measures were completed by parents at multiple time- points in approximately six-month intervals. At each time point, parents received a package of self-completed parent/guardian questionnaires reporting on the target child and family.

*Sociodemographic questionnaire:* This questionnaire included questions about the child such as their age, sex, and country of birth. It also asked questions concerning the family background including parental educational level and family income.

*ACSF: SC[9] [Appendix 1]:* The ACSF:SC was developed to describe the social communication abilities of preschool children with ASD in one of five levels. Social communication abilities range from level V (lowest ability) to level I (highest ability). The rater had to be familiar with the child and was asked to provide two ratings: the child's *capacity* level (what the child can do at their best) and the child's typical *performance* level (what the child can do on a day-to-day basis). A user guide is available with a clear explanation of each level and how to distinguish between them. Examples of different types of communications are also included (e.g., facial expression, body language, and sign language)[16]. For this study, parents were asked to complete these ratings at two time-points.

*Short Sensory Profile 2 (SSP-2)*[17]*:* SSP-2 is a parent/caregiver questionnaire with 34 items to measure behaviours associated with atypical responses to sensory stimuli. The SSP-2 was completed at baseline only. It is standardized for children 3 -14 years old and shows high validity. The questionnaire uses a 5-point Likert-type scale for parents to report how frequently their children respond to stimuli in their everyday activities.

### *Data analysis:*

Descriptive statistics including mean, standard deviations, and percentages of children's characteristics were prepared along with the family's sociodemographic information. A non-respondent analysis was conducted to investigate if there were differences between children who had ACSF:SC ratings at two time- points and children who had only one timepoint in terms of age, gender, ACSF:SC level, and their SSP-2 scores using either independent sample t-tests or Chi-square analysis.

The data for the following analysis were drawn from baseline (T1) and six-month follow-up (T2). Data were analyzed using STATA software version 13[18]. To account for the multiple testing of each objective, an effect was considered statistically significant at $\alpha = 0.01$. Analyses for each research objective are outlined separately.

*Objective 1:* The stability of the ACSF:SC was examined using several metrics. 1) Transition tables evaluated how much movement occurred between categories. These transition tables included the counts and the percentage of children who stayed at the same level or moved to another level. 2) Chance-corrected measure of agreement (Kappa) used quadratic weight for ratings at T1 and T2. Quadratic weighting accounts for the magnitude of disagreement between ratings; disagreement by one classification level is less severe than disagreement by two or more levels[19]. 3) Specific positive (SPA) and specific negative (SNA) agreements were calculated to complement Kappa to better understand the results and the direction of the agreement[20]; therefore, both SPA and SNA were calculated for each ACSF:SC level. SPA and SNA represent inconsistencies in the observers' agreement for positive and negative ratings[20]. In this context, positive agreement represents stable ACSF:SC ratings while negative agreement represents unstable ACSF:SC ratings (see supplementary file for the formula and a working example (appendix 2)). 4) While Kappa examines inter-rater agreement, the McNemar-Bowker exact test of symmetry examines test/retest agreement. Therefore, the McNemar-Bowker exact test of symmetry, applying STATA's symmetry/exact command, was conducted to test for consistency (or change) in parents' responses at baseline and six months later.

*Objective 2:* An exploratory objective of our study was to identify factors associated with the stability of the ACSF:SC classification levels over time. We studied the influence of these factors at baseline on our outcome (stability of the ACSF:SC six months later): A new variable was created for the stability of ACSF:SC ratings and defined as follows: (a) stable = no change between T1 and T2 and (b) not stable = any change from T1 to T2. Changes in social communication abilities are expected[21], but we do not know if these changes are enough to warrant change in ACSF:SC ratings six months later. 1) Pearson's Chi-Square test was used to test for association between ACSF:SC stability and child's sex, caregiver's education, and enrollment in services. 2) One-way analysis of variance (ANOVA) was used to test for an association for age and short sensory profile scores with ACSF:SC as the independent variable, using Omega squared. 3) Binary logistic regression was performed for the factors that had a significant association with the stability of ACSF:SC ratings.

## Results

A total of 64 children with ASD participated in the study of which 47 had complete data at two time- points. The majority were boys (n= 41 (87.2%)) with a mean age (SD) of 49.3 (9.4) months. Table 1 provides a summary of the socio-demographic information of the children in the final analytic sample.

*Non-respondent analysis:* Seventeen children within the sample have one missing data point. Non-respondent Chi-squared analysis revealed no significant differences between participants who were included versus those who were excluded in our analyses based on child age, gender, baseline ACSF:SC levels, and SSP-2 scores.

| **Demographic variables** | **(n=47)** |
|---|---|
| **Language spoken at home** | |
| English | 46 (97.9%) |
| **Caregiver's highest level of education** | |
| High School | 8 (17.39%) |
| Secondary Education | 38 (82.6%) |

| | |
|---|---|
| **Spouse highest level of education** | |
| High School | 12 (30%) |
| Secondary Education | 28 (70%) |
| **Family annual income** | |
| < $30,000 | 7 (15.6%) |
| $30,001-$60,000 | 12 (26.7%) |
| $60,001-$80,000 | 5 (11.11) |
| >$80,000 | 21 (46.7%) |

**Table 1.** Descriptive statistics and sociodemographic features of the participants.

*Stability of the ACSF:SC:*

For the ACSF:SC **typical performance (TP)** rating, the transition table shows that 44.6% of the children remained in their initial ACSF level six months later [Table 2]. The percentage of children who stayed at the same level both times is as follows: Level 1 1/3, Level II 4/7, Level III 8/16, Level IV 7/12, and Level V 1/9. After six months, 44.8% of children were reclassified into plus or minus one level; 36.1% of them were rated at a higher ability level of the ACSF:SC (better ability) while 19.3% of them were rated by their parents at a lower ACSF:SC ability six months later.

| **Typical performance at t1** | **Typical performance at t2** | | | | | |
|---|---|---|---|---|---|---|
| | I | II | III | IV | V | Total |
| I | 1<br>2.1% | 2<br>4.3% | 0<br>0.0 | 0<br>0.00 | 0<br>0.00 | 3<br>6.4% |
| II | 1<br>2.1% | 4<br>8.5% | 0<br>0.00 | 2<br>4.3% | 0<br>0.00 | 7<br>15% |
| III | 1<br>2.1% | 4<br>8.5% | 8<br>17% | 2<br>4.3% | 1<br>2.1% | 16<br>34% |
| IV | 0<br>0.00 | 0<br>0.00 | 3<br>6.4% | 7<br>14.9% | 2<br>4.3% | 12<br>25.5% |
| V | 0<br>0.00 | 0<br>0.00 | 1<br>2.1% | 7<br>14.9% | 1<br>2.1% | 9<br>19% |
| Total | 3<br>6.3% | 10<br>21.3% | 12<br>25.5% | 18<br>38.3% | 4<br>8.5% | 47<br>100 |

**Table 2.** Transition table for TP at baseline and six months later. Agreements for t1 and t2 are highlighted in Yellow (entries are n and % of total N).

For the ACSF:SC **best capacity (BC)** rating, the transition table shows that 51% of the children remained in the same ACSF:SC level six months later. Table 2 shows that 4/7 of children were rated at level I both times, 5/9 at level II, 10/16 at level III, 5/9 at level IV, and 0/6 at level V. After six months, 34% of the children were rated by their parents at a higher ability level of the ACSF:SC (better ability) while 14.4% of them were rated at a lower ACSF:SC ability six months later.

| **Best capacity at t1** | **Best capacity at t2** | | | | | |
|---|---|---|---|---|---|---|
| | I | II | III | IV | V | Total |
| I | 4<br>8.5% | 1<br>2% | 0<br>0.00 | 1<br>2% | 1<br>2% | 7<br>15% |
| II | 4<br>8.5% | 5<br>10.6% | 0<br>0.00 | 0<br>0.00 | 0<br>0.00 | 9<br>19% |
| III | 0<br>0.00 | 2<br>4.3% | 10<br>21.3% | 3<br>6.4% | 1<br>2% | 16<br>34% |
| IV | 1<br>2% | 0<br>0.00 | 3<br>6.4% | 5<br>10.6% | 0<br>0.00 | 9<br>19.2% |
| V | 0<br>0.00 | 0<br>0.00 | 1<br>2% | 5<br>10.6% | 0<br>0.00 | 6<br>12.8% |
| Total | 9<br>19% | 8<br>17% | 14<br>30% | 14<br>30% | 2<br>4% | 47<br>100 |

**Table 3.** Transition table for BC at baseline and six months later. Agreements for t1 and t2 are highlighted in Yellow (entries are n and % of the total N).

Quadratic weighted kappa for **TP** was $k_w$= 0.65 with a bias-corrected confidence interval (CI= 0.48 – 0.79). The McNemar-Bowker $\chi2$ test for symmetry was not significant ($\chi2_M$(7)= 10.3, p=0.2). For **BC**, a quadratic-weighted kappa was kw= 0.56 with a bias-corrected confidence interval (CI= 0.23 – 0.78). McNemar-Bowker $\chi2$ test for symmetry was not significant ($\chi2_M$(7)= 9.80, p=0.2). The p-value associated with McNemar-Bowker test is not significant, which indicates that there is no evidence that parents likely will change their response when they rated their children six months apart.

SPA and SNA for **TP** and **BC** (Table 4) are presented below:

| **TP** | SPA | SNA | Kappa | **BC** | SPA | SNA | Kappa |
|---|---|---|---|---|---|---|---|
| ACSF:SC Level 1 | 0.3333 | 0.954 | 0.288 | ACSF:SC Level 1 | 0.5 | 0.9 | 0.399 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| ACSF:SC Level 2 | 0.471 | 0.883 | 0.358 | ACSF:SC Level 2 | 0.59 | 0.91 | 0.498 |
| ACSF:SC Level 3 | 0.571 | 0.818 | 0.395 | ACSF:SC Level 3 | 0.67 | 0.84 | 0.511 |
| ACSF:SC Level 4 | 0.467 | 0.750 | 0.231 | ACSF:SC Level 4 | 0.43 | 0.82 | 0.263 |
| ACSF:SC Level 5 | 0.154 | 0.864 | 0.041 | ACSF:SC Level 5 | 0 | 0.91 | -0.068 |

**Table 4.** SPA, SNA, & Kappa statistics for each level of **TP** and **BC**.

### *Factors associated with ACSF:SC stability*

For TP, 42.5% of our sample were classified as stable, with 57.5% as not stable. For BC, 51.1% were classified as stable with 48.9% as not stable. Several factors were explored, but no significant associations were found with ACSF:SC (TP and BC), including sex of the child, being enrolled in services, caregiver's education, age, or sensory score of the SSP-2. However, a weak association was found between ACSF:SC (TP) and the behavioural score of the SSP-2 (($\omega 2$) =0.11). The results of the binary logistic regression for the behaviour score showed that there is a reduced odds of the parents' ACSF:SC classification being stable over time (OR=0.94. 95%CI=0.88 to 0.99, p<0.01) for every unit increase in behaviour score.

## Discussion

This study aimed to investigate the stability of the ACSF:SC over a six-month interval and explore factors that could potentially influence social communication functioning. By comparing ACSF:SC levels at two time-points (6 months apart), this study was able to examine the subsequent ratings and the extent to which children were maintaining their level of social communication. Establishing the stability of the ACSF:SC would be beneficial for parents and professionals to anticipate the potential changes in social skill abilities and make informed decisions for intervention planning. In our sample, 44.6% of children maintained their level of functioning for their typical performance level and 51% for their best capacity level; children were more likely to move to a higher ability level (more functional) six months later. Weighted Kappa values ranged from 0.56 to 0.65 indicating fair to good chance-corrected agreement.

Previous stability studies have used various statistical tests to investigate the stability of several classification systems. A novel approach was introduced by Burgess and colleagues in their study of the stability of the Manual Ability Classification System (MACS)[15]. They calculated the SPA as an indicator of stability. However, from a commentary on Burgess's paper, one of the additional analyses that could have been conducted was SNA[22]. SNA is needed to understand the agreement in a specific context[22]. SPA and SNA are affected in opposite directions[22]. Therefore, both SPA and SNA were reported in this study; however, they are both affected by the distribution of the classification in the sample[22]. Thus, the SPA increases when the marginal prevalence of a category increases[22]. For example, level III in the TP table has the highest prevalence as well as the highest SPA compared to the other levels. Given that our sample size is small, SPA and SNA calculations were affected, as is highlighted in Table 4 where the chance-corrected agreement "unweighted Kappa" for each level was lower than the raw agreement indices (SPA and SNA). Therefore, additional statistical tests were also considered in this paper, including transition tables, weighted Kappa, and McNemar-Bowker $\chi 2$ test for symmetry.

The results of parent ratings on the ACSF:SC demonstrated that parents had higher agreement for TP levels when compared to BC as reflected by the higher weighted Kappa (TP $k_w$ =0.65 and BC $k_w$=0.56) and narrower confidence interval range (CI for TP =0.48-0.79 and BC= 0.23-0.78). This could be because TP is an indicator of everyday performance while BC is an indicator of a moment that might have happened once or twice over the last month. Another interpretation could be that parents rarely have the opportunity to reflect on their children's abilities or strengths[8]; therefore, it may be more difficult to recall what they "can do" if their focus has been on reporting deficits and challenging behaviours.

The ACSF:SC $k_w$ for both TP and BC indicated a fair to good chance-corrected agreement, which is comparable to the stability of other classification systems[12]. The Kappa coefficient was used as the primary stability indicator in a study of the stability of several classification systems[12]. For example, the linear Kappa coefficient for MACS was 0.59 to 0.73, and $K_w$= 0.57 to 0.77 for the Communication Function Classification System (CFCS)[12]. Furthermore, at the one-year visit for children younger than four years old, only 39.3% maintained their level of function on the CFCS while 55% of children four years and older maintained their level of function[12]. The investigators of the CFCS stability attributed these findings to the fact that distinguishing between levels of communication function at a young age could be challenging for parents and professionals when compared to distinguishing between levels of gross motor function[12]. They also expected that reclassification in communication levels could be influenced by personal and environmental factors[12]. The same justification could also be applied to the stability of the ACSF:SC. A study on the pattern of growth of social skills in children with ASD over 11 years found that the majority of children showed a steady pattern with little improvement; others showed a dramatic increase in their social skills[21]. Both child development and environmental factors impacted these patterns[21]. These included children's cognitive abilities, language skills, and the availability of environmental resources such as early intervention programs[21]. Also, a study of the interrater reliability of the MACS found it to be lower when parents received the instructions by mail, as in this study, versus receiving verbal instructions[23,24]. Given that the ACSF:SC is a new tool and parents may not have heard about it before, they may need extra information and instructions to understand the ACSF:SC and the concept behind it[24].

Transition tables in the current study indicated that clinicians should be aware that there is about a 50% chance of reclassification to another level on the next visit. Using the ACSF:SC would help provide a positive and standard language to communicate the child's current ability among the treating team including parents. However, to make sure that the child's current functioning level is being communicated accurately, we recommend regular ratings for accurate presentation of the child's current ability because, there is a chance that the child's level will be different over time.

The factors that were explored in this study did not appear to influence the stability of the ratings except for the behavioural scores of the SSP-2 for the TP levels. A behavioural raw score ranges from 60 to 100 indicates that children's emotional and behavioural responses in everyday life are much more than others. This preliminary data suggests that children with behavioural issues are more likely to have unstable ACSF:SC ratings over time.

This study has several limitations. First, the distribution of the study sample was not equal across ACSF:SC levels, with level III having the highest number. This, in turn, had an influence on the SPA and SNA results and the interpretation of these findings. This study still utilized the SNA analysis as a unique methodological contribution to explore the measurement of the agreement for clinical evaluations at two time- points. A second limitation was the small sample size used to examine the factors that potentially influenced the stability. However, the current study could be used to determine the appropriate sample size required for future studies. A third limitation is the relatively short period of observation (only six months) and included only two time- points.

Future research should expand upon the findings in this study by using a larger sample of participants and by analyzing multiple time- points.

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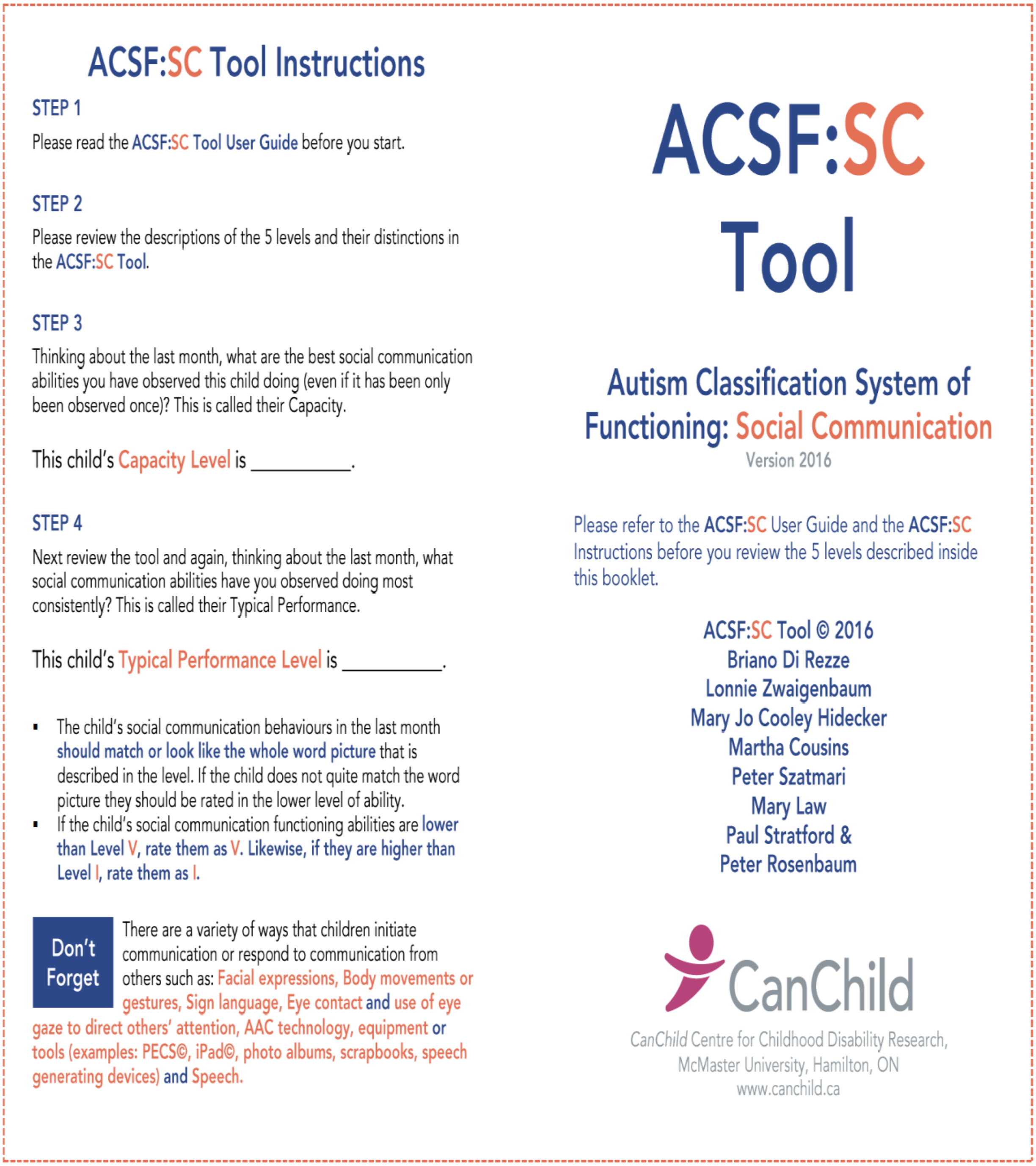
## Appendix 1: The ACSF:SC



### ACSF:SC Tool Instructions

**STEP 1**

Please read the **ACSF:SC Tool User Guide** before you start.

**STEP 2**

Please review the descriptions of the 5 levels and their distinctions in the **ACSF:SC Tool**.

**STEP 3**

Thinking about the last month, what are the best social communication abilities you have observed this child doing (even if it has been only been observed once)? This is called their Capacity.

This child's Capacity Level is __________.

**STEP 4**

Next review the tool and again, thinking about the last month, what social communication abilities have you observed doing most consistently? This is called their Typical Performance.

This child's Typical Performance Level is __________.

- The child's social communication behaviours in the last month **should match or look like the whole word picture** that is described in the level. If the child does not quite match the word picture they should be rated in the lower level of ability.
- If the child's social communication functioning abilities are **lower than Level V, rate them as V. Likewise, if they are higher than Level I, rate them as I.**

**Don't Forget**

There are a variety of ways that children initiate communication or respond to communication from others such as: Facial expressions, Body movements or gestures, Sign language, Eye contact **and** use of eye gaze to direct others' attention, AAC technology, equipment **or** tools (examples: PECS©, iPad©, photo albums, scrapbooks, speech generating devices) **and** Speech.

# ACSF:SC Tool

## Autism Classification System of Functioning: Social Communication

Version 2016

Please refer to the **ACSF:SC** User Guide and the **ACSF:SC** Instructions before you review the 5 levels described inside this booklet.

ACSF:SC Tool © 2016
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**Level V - In the last month, a Child in Level V may be observed...**

Playing with objects or talking to themselves.

Trying to initiate or react to other people's specific words or physical actions. The purpose of their communication may only be understood by their primary caregiver or highly experienced teacher/therapist.

**Level IV - In the last month, a Child in Level IV has been observed...**

Trying to initiate communication with their primary caregiver(s) by requesting to have their needs met.

Trying to respond to communication initiated by people they know (could be as simple as the use of a facial expression) but may not be responding to people they don't know.

**Level III - In the last month, a Child in Level III has been observed...**

Initiating communication with people they know, mostly to request having their needs met.

Trying to initiate communication for social purposes using simple, practiced or scripted requests (verbally or non-verbally) about their preferred interests/activities.

Responding to communication from others (such as when asked simple questions like 'What's that?') but the communication is not sustained.

**Level II - In the last month, a Child in Level II has been observed...**

Initiating and responding to communicate for social purposes about their preferred interests/activities with most people.

Sustaining communication until the other person changes the topic/activity or they are not being understood.

**Level I - In the last month, a Child in Level I has been observed...**

Initiating and responding to communicate for social purposes about more than just their preferred interests/activities with most people.

Sustaining communication with most people. Although they may have some difficulty, they will try to respond to the change in topic/activity or use effective communication strategies to be understood.

## Distinction between Levels

### Distinctions between Level V and IV

*A child in Level V is simply REACTING to communication from others & the PURPOSE of their communication is at best only known by their primary caregiver or highly experienced teacher/therapist,*
*whereas a child in Level IV is TRYING to initiate for their needs and TRYING to respond with people they know.*

### Distinctions between Level IV and III

*A child in Level IV may be TRYING to initiate and respond to people they know to have their needs met,*
*whereas a child in Level III is doing those things for their own needs as well as TRYING to initiate to communicate for social purposes about their preferred interests. They may respond to requests of others, but communication is scripted and not easily sustained.*

### Distinctions between Level III and II

*A child in Level III is TRYING to initiate and respond for social purposes about their preferred interests/activities,*
*whereas a child in Level II is initiating and responding to most people for social purposes, which may continue the interaction. However, if anything changes or they aren't understood the communication doesn't last.*

### Distinctions between Level II and I

*A child in Level II is communicating with others for social purposes but has problems sustaining the interaction if there are changes,*
*whereas although the interaction may not look perfect, a child in Level I attempts to sustain the interaction by using effective communication strategies to be understood and adapt to changes.*

ACSF:SC © Di Rezze, Zwaigenbaum, Cooley Hidecker, et al., 2016
www.canchild.ca

## Appendix 2:

**Table S1:** Worked example of specific positive agreement (SPA) and specific negative agreement (SNA) using a 2X2 table.

The circumstance of two time- points (e.g. baseline and 6 months) and two categories (e.g. ACSF:SC I and not ACSF:SC I) results in a two-by-two table.

| **a** | **b** |
|---|---|
| **c** | d |

SPA formula: 2a/(2a+b+c)

SNA formula: 2d/(2d+b+c)

| | **ACSF=1 at T2** | **Not ACSF=1 at T2** |
|---|---|---|
| **ACSF=1 at T1** | 1 | 2 |
| **Not ACSF=1 at T1** | 2 | 42 |

SPA = 2/(2+2+2)= 0.3333

SNA = 84/84+2+2) = 0.954

# Chapter 5

# Chapter 5. Discussion and Conclusion

This thesis includes three manuscripts that aimed to advance the field of ASD to better understand the social communication abilities of preschool children with ASD, their patterns of participation, and the factors associated with their functioning using novel tools and analysis. A brief synopsis of the findings of each chapter, what has been gained, clinical and research implications, and future directions are summarized below.

## Summary of findings by chapter

**Chapter 2** identified cultural factors associated with parents' decision to seek help and engage their children in health services. Qualitative studies identified nine factors related to parents' decisions on whether to seek health care for their child, including: 1) lack of general knowledge about child development and impairments, 2) beliefs about the causes of ASD, 3) the child's symptoms, 4) race/ ethnicity, 5) socioeconomic status, 6) language barrier, 7) community perception and societal acceptance, 8) extended family, and 9) challenges engaging with services. These factors were common among parents from various cultural backgrounds. Race and language barriers were unique for parents of a cultural minority. This study emphasized the need to further examine these factors for culturally competent practices to develop a positive therapeutic relationship between families and practitioners. Clinicians need to be aware of potential cultural differences and the challenges these families are facing in their journey throughout health care.

**Chapter 3** aimed to explore the participation patterns of preschool children with ASD at home and in the community. Environmental factors and social communication abilities were also investigated with regards to their association with participation. Preschool children with ASD were found to be participating in a variety of activities, though more at home than in the community. Parents identified several environmental supports and barriers that contributed to their children's participation. Social communication abilities based on the ACSF:SC were found to have a moderate correlation with the diversity of activities at home and with the level of involvement both at home and in the community. This study was the first to explore the association between social communication abilities and children's participation. It also highlighted the importance of supporting families to help them improve their children's participation, as well as the need for community accommodations to encourage their participation.

**Chapter 4** was the first study we know of to examine the stability of the *Autism Classification System of Functioning: Social Communication* (ACSF:SC). ACSF:SC is a function-based categorization system that aims to classify the social communication abilities of children with ASD into five levels of functioning. Examining stability is important for decision-making and parent counselling. It is also important for predicting future social communication abilities. Data for this study were collected at two time-points approximately six months apart. The findings indicated that for children classified using the ACSF:SC, there is a 50% chance to be classified differently after six months. On average, children were more likely to be re-classified to a higher ability level (more function) six months later. This highlighted how variable their social communication abilities can be over six months, especially at this young age. It also indicated how contexts can have an influence on social communication abilities over the preschool years. For this reason, frequent ratings are recommended for accurate presentation of children's social communication functioning.

## What has been learned over the course of the three chapters

### I. *The association of environmental contexts with everyday functioning*

The findings from this thesis indicated that the social environment, including those of the family, community, and culture, is associated with the daily functioning of children with ASD. Chapter 2 explored the effect of culture and emphasized its importance. Culture has a strong influence not only on parents' decisions in service engagement, but also on what kind of activities they will choose for their children to participate in. In Bronfenbrenner's Ecological Systems Theory (1977), culture is the most distal system, at the macrosystem level. However, this current review (Chapter 2) supports the idea that culture is at the core of the family (microsystem level), and guides the rituals and routines to which any child will be exposed in their daily life. The same findings are reported in recent literature where culture was not considered separate from the individual/child, and is part of what is directly impacting on everyday practices, activities, and routines (Vélez-Agosto, Soto-Crespo, Vizcarrondo-Oppenheimer, Vega-Molina & García Coll, 2017). The same observations can be concluded for children with ASD (Chapter 2).

Acknowledging and respecting the family's cultural individuality is essential for effective family-centred care. Parents who are from a particular cultural background cannot automatically be assumed to have the same beliefs and attitudes as others from the same cultural group. These findings emphasize the need to remember that each child's needs and circumstances are unique. It also underscores the importance of an individualized approach to care, where the various personal, family, and cultural factors are taken into consideration for a successful intervention.

For a positive relationship with families, clinicians need to ask what ASD means to the family, what are their beliefs and attitudes toward ASD, and who else is involved in the care of the child (i.e., grandparents, siblings). Clinicians and parents need to find a middle ground between what the child needs in an intervention and what the family's cultures and beliefs are, to avoid negatively impacting the child's outcome. Studies have shown that when there is a mismatch between what parents and professionals believe the child needs, there is a significant possibility that parents will not adhere to the interventions and recommendations (Dunst & Leet, 1987).

Canada is a multicultural country that provides a unique opportunity to further our understanding of cultural influences on help- seeking behaviours and how to improve and integrate culture into our interventions. This study has explored the influence of culture with regards to families' diagnosis- and intervention-seeking activities. However, it is imperative to understand the role of culture across age groups. Parents of various cultural backgrounds are different on what they value most and what they expect from their adolescent children (Friedman, 1999). Future studies could examine the impact of culture on the transition to adolescence and adulthood, the expectations of individuals with ASD as they grow up, and how culture alters these expectations. Subsequent research could involve qualitative inquiry with adolescents and adults from various cultural backgrounds. Their parents should be involved as well, to help us understand their perspectives and concerns. Such studies would be beneficial to provide important points to include in transition services that otherwise might not be considered, and reduce potential conflicts for adolescents that might stem from different cultural norms between their culture (minority culture) and the host country culture.

### ***II. Participation and missed opportunities***

It is well documented in the literature that participation for individuals with disabilities is influenced by a variety of factors internal and external to the individual (Askari, Anaby, Bergthorson, Majnemer, Elsabbagh, & Zwaigenbaum, 2015; Guichard & Grande, 2019). These same findings were echoed in the results for preschool children with ASD (Chapter 3). Another key point is that parents often have limited engagement or do not think to engage their children in a variety of activities that occur regularly in their immediate everyday environment (e.g., chores) (LaVesser & Berg, 2011). Several explanations could be considered and need to be explored in future studies. For example, it could be that parents may not know how to break up these chores into several steps that can be followed by these children; they may not be aware of their benefits for their children's development of new skills; parents may be underestimating their children's abilities and do not think they can complete such tasks. Another possible explanatory reason could be that the healthcare and educational settings are lacking the supports and accommodations that are needed to facilitate these children's participation. These findings call for future qualitative research to further examine parents' (and professionals') perspectives and collaborate with them on how to integrate these activities into their children's intervention. Generalizability of skills happens more successfully when activities that occur in the natural environment are used as learning opportunities (Cherylin, 2010; Kellegrew, 1998; Simpson, 2015). Educators are another important group of stakeholders who should be included in research and intervention planning to facilitate children's participation in daycares and schools as well.

Since parents get to decide what, when, and how to engage their children in activities, parent coaching could be used as a strategy to collaborate with parents and teach them the importance of participation and the various activities that their children could participate in that occur in their everyday routines and environments. Virtual coaching could be our future reality (Snodgrass, Chung, Biller, Appel, Meadan & Halle, 2017), especially in the time of COVID-19 (Degli Espinosa, Metko, Raimondi, Impenna & Scognamiglio, 2020; Narzisi, 2020). However, although some families have found online coaching to be beneficial, and reduce the time and expenses associated with travel (Snodgrass et al., 2017), it should be noted that in some circumstances, in-person interventions are preferred and work better for some families (i.e. families with no access to technology) (Degli Espinosa et al., 2020). Having said this, it is also essential to recognize that parents need to find a balance between teaching skills and having quality time with their children without thinking about how to make it about 'therapy'.

### *III. Classification systems and function-based approaches*

It has already been established that the ACSF:SC is a function-based tool validated for preschool children with ASD. In this thesis, the ACSF:SC was examined at two time-points over a 6-month period to examine the stability of a child’s level. The ACSF:SC is different from other classification tools of functioning (such as the Gross Motor Function Classification System (GMFCS) for cerebral palsy, and the Manual Ability Classification System (MACS)), because its construct of social communication is a complex construct that may be influenced by various contexts and environments. The work reported in this thesis provides a starting point for understanding social communication abilities across age groups in ASD, especially with the development of the integrated version of the ACSF:SC, now completed, that targets children and youth of all ages. Future studies should explore the development of social communication abilities over a longer timeframe and the applicability of the ACSF:SC to an expanded age-range. In this thesis, social communication abilities changed over six months for half of the sample. It would be important to observe the stability and change in the development of social communication over longer periods of time. Such studies would provide us with the ability to understand the patterns of change and the rate of progress of social communication over time, which can then be used to develop growth curves of social communication skills (Anderson, Oti, Lord, & Welch, 2009; Cunningham, Hanna, Oddson, Thomas-Stonell, & Rosenbaum, 2017).

Future studies could also compare the changes over time in ratings of the ACSF:SC to the changes in the outcome of the Brief Observation of Social Communication Change (BOSCC) (Grzadzinski et al., 2016). BOSCC was developed and validated to measure subtle changes in social communication over a short period (Grzadzinski et al., 2016). Such a study would shed light on whether changes in ACSF:SC ratings are actually due to changes in social communication abilities or if there are other explanations for observed changes (i.e. other sources of variations, whether related to the rater or the tool itself).

In addition, one of the reported benefits of involving parents in interventions is that they become aware of their children’s strengths and needs (Kemp & Turnbull, 2014), which prompts the need for future studies to explore the impact of using the ACSF:SC on parents’ view of their children’s functioning, especially in the preschool years, where parents usually are stressed and overwhelmed after recently receiving the diagnosis (McMillin, Bultas, Wilmott, Grafeman, & Zand, 2015).

## Implications and future considerations

The factors identified in Chapter 2 emphasized the importance of prioritizing providing family- and child-centred care that is culturally competent. Children's development is impacted by their physical, social, and attitudinal environment (Dunst, Bruder, Trivette, & Hamby, 2006). The social environment and family routines are basic aspect of the culture (Engel-Yeger, Jarus & Law, 2007). Cultures differ in their expectations of children as well as their attitudes toward the skills and behaviours that are expected to be developed and encouraged in children (Engel-Yeger, Jarus & Law, 2007). In family-centred care, clinicians build trusting relationship with families, so families feel safe to share their understanding and how they are perceiving ASD and any challenges they might be facing. Moreover, clinician awareness and acceptance of cultural differences will provide a deeper understanding of the needs of families, which will further strengthen clinician-family relationships and improve child outcomes.

Based on findings from Chapter 2, participation of children with ASD from different cultural backgrounds could be at risk for further limitations due to various factors such as stigma against children with disabilities. For example, some parents of children with ASD avoid seeking health-related services due to their fear of stigma and being shamed within their communities. The same fear could also impact their child's participation in variety of activities, especially in the community. A study that compared the participation in activities outside the school in Israel for typically developing children found that cultural background is associated with participation patterns (Engel-Yeger, Jarus & Law, 2007). In this study, Jewish children who part are of the cultural majority were compared to Druze children who are members of a cultural minority. Jewish children were found to participate more frequently in a variety of activities and have higher level of enjoyment (Engel-Yeger, Jarus & Law, 2007). The authors suggested that those findings could be related to the conservative nature of the Druze community, where children are exposed to fewer Western activities that were assessed in the tool. In addition, for Druze children, parents make the decisions on what activities they should be participating in, and that may explain their lower level of enjoyment (Engel-Yeger, Jarus & Law, 2007). Educating parents about ASD and the importance of participation in child development is crucial to improve their goals concerning children's development and consequently increase these children's participation.

One possible way to address this challenge is to use function-based approaches and tools that may change parents' perspectives of the condition. Spouses and extended families in some of the identified studies in Chapter 2 were reluctant to accept the ASD diagnosis. Using a function-based approach that looks at what children can do might encourage them to be more cooperative and accepting of the child and their abilities. Therefore, future studies are required to explore the impact of using function- and strengths-based approaches and whether that would facilitate better uptake and use of diagnostic and related services.

Another important point that warrants further investigation in future studies is to consider how representative current study samples are of children with different cultural backgrounds and how to include them in future research. If families are having a hard time to access ASD services due to, for example, a language barrier, then one would assume that the same barrier exists and prevents them from participating in research. This could be further illustrated by the current PARC sample where only 15% (11 out of 75) of the sample were of different cultural backgrounds. Most of the time, research studies require participants to be able to read and understand the local language (in our case English) to be included. Consequently, families who are not fluent in English are excluded. Excluding these families from participating in research might very well remove those who are most vulnerable and those who might have different or additional challenges that we are not aware of.

### Knowledge translation opportunities

This work highlights the need to share research findings and accurate information to stakeholders, especially parents. Following a diagnosis of ASD, parents of children with ASD face many uncertainties related to services that are accessible to best meet the needs of their child. Parents are using the Internet to find information for their children with special needs (Knapp, Madden, Wang, Sloyer, & Shenkman, 2011; Zeng & Cheatham, 2017); however, they reported not being able to distinguish between high and low quality information (Knapp et al., 2011). Parents of different language and cultural backgrounds face more challenges, because in addition to the language barriers, they also have different values and communication styles (Zeng & Cheatham, 2017). In addition, when families are new to the country, or there is a lack of available evidence in their language, parents' experience is further complicated.

Findings from this thesis could be beneficial for the diverse populations within Western countries as well as for countries that are starting to establish their ASD services. The concepts of participation and function-based approach should be easily translated in any language, and are important to better meet the needs of children with ASD and therefore improve their outcomes. Such concepts need to be communicated within the context of cultural and/or language differences. As noted in Chapter 2, lack of available knowledge about ASD was a common barrier among parents regardless of their country of residence and not necessarily due to a lack of resources within the country. For example, in the Eastern Mediterranean region, home of some of the world's wealthiest countries (in the Arab Gulf region), the use of information and communication technology (ICT) in the healthcare sector is new and still developing (Al Shorbaji, 2008). However, regardless of the availability of resources, it is still hard to find reliable and valid health information in Arabic (Altuwaijri, 2011; Weber, Verjee, Rahman, Ameerudeen, & Al Baz, 2014) as medical information and research are usually published in English (Weber et al., 2014). Thus, parents not only need to understand English to be able to learn about ASD, they also need to figure out the medical jargon that is usually included in research reports (AlSaadi, 2012). One step in the direct of knowledge translation in function-based care in ASD could be to translate the ACSF:SC to different languages with growing populations in the world and to disseminate the ACSF:SC to stakeholders, including parents, clinicians, and researchers.

## Conclusion

In summary, this thesis advanced knowledge focused on functioning and participation for preschool children with ASD and the environmental factors that influence it. This thesis revealed the complexity of examining the functioning of children with ASD and the association of factors, such as participation and the environment. Future studies could employ qualitative methodology to continue to explore and understand parents' and professionals' perspectives and collaborate with them for better outcomes for their children.

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