THE CONTRIBUTION OF CHILD, FAMILY AND ENVIRONMENTAL FACTORS IN EXPLAINING THE PARTICIPATION OF SCHOOL-AGED CHILDREN WITH AUTISM SPECTRUM DISORDER IN HOME AND COMMUNITY

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CONTRIBUTION OF AUTHORS

All the work presented in this article was authored by myself in collaboration with my supervisor Dr. Dana Anaby. Listed below are the detailed contributions of each member to this manuscript-based thesis:

Ziru Wang collected the data and did the statistical analysis, designed the figures, interpreted the results, wrote, and arranged the thesis manuscript.

Dana Anaby contributed to conceiving the study design, checking the data analysis, revising of the present manuscript.

ABSTRACT

Background:

Participation, beneficial for children's development, well-being, and thriving, is one of the most important outcomes of rehabilitation interventions. Children with Autism Spectrum Disorder (ASD) face greater restrictions to participation in comparison to their typically developing peers. Generally, both personal (e.g., the severity of the child's condition) and environmental factors (e.g., barriers and supports) are significantly related to child participation. However, for school-aged children with ASD, little is known about the specific factors that explain their participation patterns, especially during the COVID-19 pandemic. Particularly, the impact of family aspects such as parental actual participation on child's participation is understudied.

Objectives:

This study aimed to estimate the extent to which complexity of child's condition, family income, mother's actual participation, and environmental barriers and supports, explain the frequency and involvement of children's participation in home and community activities, and the numbers of those activities in which their mothers wished to see change among school-aged children with ASD.

Methods and Analysis:

A cross-sectional design was employed. Mothers (n=130) of children with ASD aged 6-13 years (mean=9.09; SD=1.89) completed the *Participation and Environment Measurement for Children and Youth*-which measured participation patterns and environmental barriers/supports, the *Health Promoting Activities Scale* which measured mother's participation, a checklist of functional issues measured complexity of child's condition, and a socio-demographic questionnaire measured income and other family characteristics. Descriptive statistics and correlation between different variables. Multiple linear regressions were conducted and R^2 change was calculated to determine the unique contribution of explanatory variables (child's factors, family, environment) to the variance of the 3 participation outcomes: frequency, involvement, and desire for change in both home and community settings.

Results:

Children participated quite frequently at home (5.79 on a 7-point scale) and their participation was relatively lower in the community (4.32). Levels of involvement (3.5 on a 5-point scale) and number of activities in which change was desired (71%) were similar in both settings. In the home setting, mother's participation significantly explained child's participation frequency (β =0.24) and involvement (β =0.34), which accounted for 5.4% and 10.4% of their variances respectively. Child's age (β =-0.29), number of functional issues (β =-0.2), and environmental barriers (β =0.32), together explained 17.4% of the variance of desired change. In the community setting, the model of participation frequency had the highest explained variance (44.3%). Family income significantly explained child's participation frequency (β =-0.63) and involvement (β =0.29), accounting for 41.4% and 8.7% of their variances respectively. None of the explanatory factors affected numbers of community-based activities mothers desired to change. The impact of the COVID-19 pandemic, measured using a 7-point scale, was negatively associated with child's participation frequency in community activities (r=-0.51, p<.01), whereas at home, this association was positive (r=0.188, p<.05).

Conclusion:

Findings revealed the positive impact of mother's own participation on the participation of children with ASD, and thus can direct clinicians' attention towards improving mother participation in health-promoting activities when providing services to these families. Results of models for explaining participation in the community were somewhat unexpected, due in part to the pandemic. Future research is needed to discover additional factors and pathways to predict participation patterns of this population in times of crisis and beyond.

RÉSUMÉ

Contexte

La participation, bénéfique pour le développement, bien-être et prospérité des enfants, est l'un des résultats les plus importants eninterventions de réadaptation. Les enfantsavec troubles du spectre autistique (TSA) ontune participation plus restreinteque ceuxsans TSA. Généralement, les facteurs personnels (ex.gravité de l'état de l'enfant) et environnementaux (obstacles/soutiens) affectent significativement la participation infantile. Pourtant, on en sait peu sur les facteurs spécifiques expliquant la participation des enfants d'âge scolaire avec TSA, surtoutdurant COVID-19. Particulièrement, l'impact des aspects familiaux comme la participation réelledes parents sur celle de l'enfant est peu étudié.

Objectifs

Cette étude visait à estimer comment la complexité de l'état de l'enfant, revenu familial, participation réelle de la mère,obstacles/soutiens environnementaux expliquent la fréquence et l'implication de la participation des enfants d'âge scolaire avec TSA aux activités familiales et communautaires, et le nombre d'activités leurs mères désiraient changer.

Méthodes et analyse

Une étude transversale a été effectuée. Les mères (n=130) des enfants avec TSA âgés de 6-13 ans (moyenne=9.09; ÉT=1.89) ont rempli la *Mesure de la participation et de l'environnement pour les enfants et jeunes* mesurantles modèles de participation et obstacles/soutiens environnementaux, ainsi que l'*Échelle des activités de promotion de la santé* mesurant la participation maternelle, une liste de problèmes fonctionnels mesurant la complexité de l'état de l'enfant et un questionnaire sociodémographique mesurantle revenu et autres. Des statistiques descriptives et analyses de corrélation ont décrit la participation infantile et l'association entre les variables. Des régressions linéaires multiples et le changement R² ont été menéspour évaluer l'effet des variables explicatives (facteurs de l'enfant, famille, environnement) à la variance des 3 résultats de participation : fréquence, implication et désir de changement dans le cadre familial et communautaire.

Résultats

Les enfants participaient fréquemment à la maison (5.79 sur une échelle de 7) et leur

participation était relativement plus faible dans la communauté (4.32). Le niveau d'implication (3.5 sur une échelle de 5) et le nombre d'activités avec changements désirés(71%) étaient similaires dans les 2milieux. À la maison, la participation maternelle expliquait significativement la fréquence (β =0.24) et l'implication (β =0.34)departicipation infantile, représentant respectivement 5.4% et 10.4% de leurs variances. L'âge de l'enfant (β =-0.29), le nombre de problèmes fonctionnels (β =-0.2) et les barrières environnementales (β =0.32) expliquaient 17.4% de la variance du changement désiré. Dans la communauté, le modèle de fréquence de participation avait la variance expliquée la plus élevée (44.3%). Le revenu familial expliquait significativement la fréquence de participation infantile (β =-0.63) et l'implication (β =0.29), représentant respectivement 41.4% et 8.7% de leurs variances. Aucun facteur explicatif n'a affecté le nombre d'activités communautaires que les mères souhaitaient changer. L'impact de COVID-19, mesuré surune échelle de 7 points, était négativement associé à la fréquence de participation de l'enfant aux activités communautaires (r=-0.51;p<0.01), et positivement à domicile(r=0.188;p<0.05).

Conclusion

Les résultats ont révélé l'impact positif de la participation de la mère sur celle des enfants avec TSA, et peuvent encourager les cliniciens àfaciliter la participation des mère dans les activités de promotion de la santé lors de la prestation des services à ces familles. Les résultats des modèles expliquant la participation dans la communauté étaient inattendus, en partie à cause de la pandémie. Des recherches futures sont nécessaires pour trouver des facteurs et façons supplémentaires permettant de prédire les modèles de participation de ce groupe en temps de crise et au-delà.

PREFACE

The content of this thesis will include the following chapters:

Chapter 1: In this chapter, we present an overview of the importance of participation for children with ASD, and the potential factors that may impact child's participation patterns. It explores the literature gap and gives the rationale for the project, the resulting objectives and hypothesis.

Chapter 2: This chapter provides a description of the methodology for the study, including a detailed introduction of scales using for different factors and outcomes.

Chapter 3: The results of the project will be presented in this chapter.

Chapter 4: In this chapter, we provide a discussion of our findings and how they relate to other studies in the field.

Chapter 5: Here presented the final comments and future implications.

Chapter 6: List of references

Chapter 7: List of appendices

CHAPTER I | INTRODUCTION

BACKGROUND

Participation: how it is defined and why it is important

Participation, defined as involvement in a life situation (World Health Organization [WHO], 2001), involves engagement and inclusion in various activities, environments, and roles. The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), endorsed by the WHO (2007), has conceptualized participation as a multidimensional construct with objective (e.g., whether a child is regularly included in routine social activities in a setting) and subjective domains (e.g., a sense of belonging or satisfaction with the extent of one's involvement) (Coster & Khetani, 2008; McConachie et al., 2006). Similarly, a systematic review (Imms et al., 2016) revealed two important elements of participation: attendance ('being there') and involvement ('being in the moment'). Attendance level refers to the frequency and/or diversity of activities in which the person takes part, while involvement level could be described by the extent of motivation, persistence, social connection, and affect.

Participation is one of the most important outcomes of rehabilitation in social, medical, and educational interventions (Amini et al., 2014; Field et al., 2016; Golos et al., 2011; Law et al., 2015), and it can be used as an indicator of health and wellness. Participation for children usually takes place in a social context involving family members, peers, or other adults. Through participation in various activities, children can develop skills, establish interpersonal relationships, achieve self-satisfaction, and gain a sense of self-worth (Lim et al., 2016). Previous studies showed that participation is positively linked to development, mental and physical health, behavioral and emotional well-being, social relationships and self-efficacy for typically-developing children (Block et al., 2010; Fredricks & Eccles, 2006; Simeonsson et al., 2006; Watts & Caldwell, 2008). Moreover, for children with disabilities, evidence also shows that participation in different activities promotes their health and contributes to their development and quality of life (Anaby et al., 2012; Golos & Bedell, 2018; King et al., 2003b; Law et al., 2011). For instance, engaging in activities with others could help develop mutual relationships for children with disabilities (King et al., 2003b). Previous research has also

reported the supportive influence of participation on learning, independence, and social inclusion of children with disabilities (Guichard & Grande, 2019). By engaging in activities with others or alone, they could also develop their sense of identity and self-esteem throughout the process (Coster & Khetani, 2008; Holloway & Long, 2019).

In particular, participation in activities in the home and community settings (e.g., helping prepare meals, visiting neighbors) has proved to shape the everyday lives of children and to promote their development (Dunst et al., 2001; Humphry & Wakeford, 2006). Community participation has also been identified as a universal right for all children by UN General Assembly (2007), and has proved to be beneficial for the development of children's social, physical, and psychological skills (Howells et al., 2020; May et al., 2021). Specifically, participation in leisure community-based activities is considered to be one of the most important outcomes in pediatric rehabilitation (Larson & Verma, 1999; Mc Manus et al., 2008; Ullenhag et al., 2012). Participation in physical activities has proved to be associated with improved self-control skills, increased communication and cooperation skills, and improved quality of life for children with autism spectrum disorder (ASD) (Toscano et al., 2018; Zhao & Chen, 2018).

However, the participation of children with disabilities in home-based, leisure and social activities is less frequent and less diverse, compared with typically developing children (Rosenberg et al., 2013). Children with developmental disabilities are usually at risk of experiencing more problems during participation compared to their age-matched peers without developmental problems (King et al., 2010; Law et al., 2013). Therefore, participation has a significant impact on the development of children with disabilities and it is important to further understand their participation patterns.

Participation patterns of children with ASD

With a prevalence of 1 in 66, Autism Spectrum Disorder (ASD) has been reported by the Public Health Agency of Canada as one of the most common developmental disorders affecting Canadian children aged 5 to 17 (Ofner et al., 2018). ASD is an increasingly prevalent neurodevelopmental disorder that includes deficits in social communication and interactions, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can

persist from early childhood (American Psychiatric Association, 2013). Due to their problems in social communication and challenges with controlled behavior, children with ASD are particularly at risk for limited activity participation.

Several studies have shown that children with ASD participate less frequently and in a limited variety of activities than children with other developmental disabilities (DD) as well as those with no disabilities (Huang & Kang, 2021; LaVesser & Berg, 2011; Rodger & Umaibalan, 2011). A key challenge for children with ASD is in social participation, i.e., engaging in activities that involve interactions with others (Bedell, 2012), and they often experience moderate to severe barriers in relation to the skills required for social participation (Ávila-Álvarez et al., 2020). Specifically, children with ASD participate less often in unstructured, social, and recreational activities (Hochhauser & Engel-Yeger, 2010; Reynolds et al., 2011) and they spend most of their leisure time at home with their family rather than with peers (Hilton et al., 2008; Potvin et al., 2013). Studies report their reduced participation in activities such as community events, organized physical activity, informal interaction with peers, overnight visits, and religious activities (Egilson et al., 2017; Hilton et al., 2008; Lee et al., 2008; May et al., 2021). Children with ASD are more likely to exhibit bizarre behaviors when involved in community activities, which always require higher social demands to interact with other people, and could therefore be more difficult for them to engage in (Carmen et al., 2020; LaVesser & Berg, 2011).

Benefits of regular participation in physical activities for children with ASD have been reported in several studies (Bremer et al., 2016; Healy et al., 2020), and have also been considered as target for interventions. However, restriction in physical activities was reported among this population across a range of age groups: primary-school age; aged 7 to 12; and adolescence (Jones et al., 2017; Potvin et al., 2013). In addition, it has been documented (Case et al., 2020; Stanish et al., 2019) that the majority of children with ASD actually do not meet the current guidelines of physical activity participation for health benefits, which in turn can lead to further health problems. Examples include significant higher risk of obesity and lower bone density compared with typically developing peers (Broder-Fingert et al., 2014).

These participation discrepancies may be associated with ASD-related symptoms that challenge their participation in different settings and may affect their quality of life. A long-term follow-up study (Billstedt et al., 2011) showed that engagement in different types of leisure activities was correlated with higher levels of quality of life (QOL) in individuals diagnosed with autism in their childhood. Thriving, as an important pursuing that reflects both wellbeing and an upward developmental trajectory, contributes to the human development (Benson & C. Scales, 2009). Using path analysis, Weiss and Riosa (2015) demonstrated that youth with ASD tend to thrive less and that their participation patterns mediate the relationship between ASD and thriving. Overall, the repercussions associated with limited participation are alarming. Thus, there is a significant need to focus on improving the engagement of children with ASD in home and community activities, with the purpose of promoting their well-being and quality of life.

Participation patterns in middle childhood (6 to 12 years old)

Participation patterns are known to change with age (Jarus et al., 2010; King et al., 2010), thus child's age is an important factor to consider when modeling participation. This shift occurs as individuals make the transition from childhood to adolescence around the age of 12. Specifically, a significant decline in participation intensity was observed among adolescents with disabilities, particularly in informal activities (Law et al., 2006; Ratcliff et al., 2018). Evidence also highlighted the importance of early intervention on participation in community activities for children with ASD to promote continued access to future participation opportunities, since their participation would decline further as they move into adolescence (Simpson et al., 2019). Similarly, the Canadian Council on Social Development (2001) revealed that as children become adolescents, participation in organized activities decreases. This shift can be linked to developmental stage theories that are closely related to the concept of participation. To illustrate, the task theory (Havighurst, 1948), a bio-psychosocial model of development, defined an age range between 6 and 12 (middle childhood) as one of the three developmental stages, which was based on task achievements that meet social expectations. Examples include learning physical skills to achieve competence and learning to be independent. Recent research (Gehricke et al., 2020) showed that boys with ASD between 6-11 years old engaged significantly less in physical activity than their peers in the general

population. Similar findings were reported in another study (Ismael et al., 2020), which indicated that children with ASD aged 6-12 have different participation patterns in the social and physical contexts compared with typically developing children. Examining participation within this important development stage of school-aged children from 6 to 12 years old can increase our understanding of participation prior to entering adolescence. Moreover, the majority of the studies (Bohnert et al., 2019; Krieger et al., 2018; Orsmond et al., 2004; Taheri et al., 2016) that examined participation were focused on adolescents with ASD. Thus, focusing on younger children is necessary.

Factors that influence participation for ASD children

Participation, as depicted by the ICF-CY, is a complex multi-dimensional concept that is influenced by a multitude of factors related to the child, their family, and their environment. Previous research suggests that among children with various types of disabilities, personal characteristics such as their age, the severity of their condition, and their functional abilities may influence their participation (Anaby et al., 2014; Anaby et al., 2012; King et al., 2009). Environment is also a key factor that influences the participation of children and youth with various types of disabilities, either positively or negatively (Anaby et al., 2013). Examples of environmental factors include physical accessibility, peer attitudes, availability of programs and social policies, among others. Optimal participation involves a dynamic interaction of dimensions (physical, social and self-engagement) and determinants (attributes of the child, family and environment) of participation for children with disabilities (Kang et al., 2014). A recent qualitative research study (Coussens et al., 2020a) also supports that participation should be regarded as an interrelationship of constructs including activity, body function, and environmental factors.

With regards to the ASD population, studies found that both children's personal factors (such as severity of the symptoms) and environmental factors were significantly related to their participation (Forsyth et al., 2007; Little et al., 2014; Shattuck et al., 2011). A scoping review (Askari et al., 2015)also highlighted the ICF-CY (factors associated with participation in this group. Examples include environmental factors (e.g., family and social support), body

functions (e.g., behavioral challenges), and activity limitations (e.g., inter-personal relationships). To further advance this body of knowledge, it is important to identify factors that can explain the outcomes of participation, especially those which are modifiable in nature and can be improved via appropriate interventions.

Guided by previous research findings and by the ICF-CY model, a range of potential explanatory variables that may influence child's participation were included in this study as follows:

a) Child's factors

i. Complexity of child's condition. ICF-CY views participation as the interaction between one's health condition and contextual factors (World Health Organization, 2002). As such, when considering participation as an outcome, it is important to consider the child's condition. Among children with disabilities, the severity of their condition as well as their functional abilities could influence changes in their participation over time (Anaby et al., 2014; 2012; King et al., 2009). Evidence also supports that children with severe or profound levels of severity tend to have lower diversity and intensity of participation (Kang et al., 2017). According to the American Psychiatric Association (2013), ASD is characterized by specific functional issues, including deficits in social communication and interactions, as well as the restricted repetitive patterns of language and behavior. These functional issues can cause difficulties in participation for children with ASD, especially in social activities that involve interacting with others and forming friendships (Carrington et al., 2003; Fein, 2015). Indeed, several studies have demonstrated that children with more severe aspects of ASD had lower community participation (Krieger et al., 2018; May et al., 2018).

The impairments in social-relatedness, often observed among children with ASD, could also strain parent-child relationships and interactions, which would cause transactional effects that impede development of these children (Crowell et al., 2019). Moreover, children with ASD aged 8-12 may experience greater stress in different social situations (Blythe A. Corbett et al., 2012; B. A. Corbett et al., 2010; Schupp et al., 2013), which can result in lower participation in social activities. Problem with sensory processing (e.g., higher sensitivity to sensory input) is another issue that can decrease participation for children with ASD (Lin, 2020; Piller & Pfeiffer, 2016). Thus, the complexity of children's conditions in terms of the number of functional issues they have is an important child factor in for explaining their participation patterns.

b) Family factors

i. Family social economic status (SES). The income level of parents has consistently been shown to affect participation of children with various disabilities (Andrews et al., 2014; Carr & Lord, 2016; Gregor et al., 2018; Krieger et al., 2018; Mandell et al., 2009). Families with higher incomes usually have the ability to offer greater opportunities and higher quality of activities for their children to engage in, and parents of children with ASD are no exception. To illustrate, a study by Shattuck et al.(2011) found that lower-income families raising a child with ASD had significantly higher odds of their child never being invited to activities, never seeing friends, or never being involved in any extracurricular activities, compared to their higher-income counterparts.

ii. Parental actual participation patterns. Several studies have indicated parental factors as playing an important role in children's participation. A systematic review (Arakelyan et al., 2019) revealed the significant impact of family on the participation of children with disabilities. Specifically for children with ASD, parents were viewed as active and quality facilitators for their child's development in many domains, including participation (Bar et al., 2016; Ghanouni et al., 2019; Mol et al., 2008). Parents' active lifestyle may influence their children's participation. For example, one study related to time usage showed a positive link between time parents spent in their physical activities, and the time spent by children with ASD in those activities (Ayvazoglu et al., 2015). Mothers were usually considered as the main caregivers for children, and a study has highlighted the greater influence of mothers on child's participation, particularly for children with development disabilities (Margalit & Kleitman, 2006). Evidence also supports the importance of paying close attention to the participation of mothers in a variety of everyday-life activities, as this likely increased the mother's satisfaction and enjoyment, and could predict their child's participation as well (Bar et al., 2016).

To date, studies have mostly focused on parental perspectives and beliefs about participation (Coussens et al., 2020b; Egilson et al., 2018; Healy et al., 2018), the contribution of the familial environment to participation (Orsmond et al., 2004; Petalas et al., 2015), family

self-perceived orientations towards leisure activities participation (Baixauli et al., 2019; King et al., 2003a; Krieger et al., 2018; Law et al., 2006) and the challenges parents faced in their everyday lives when raising their children (Altiere & Kluge, 2009; DePape & Lindsay, 2015; Dieleman et al., 2018; Hayes, 2013; Safe et al., 2012). However, little is known about the impact of parents' actual participation on the participation patterns of their school-aged children with ASD across different settings. In other words, the impacts of parents' actual participation patterns, particularly in non-parenting activities that are leisure-oriented and health-promoting, on their child's engagement remain unclear. To our knowledge, only two studies examined mother participation among younger children focused on these factors, one for Canadian children (with a mean age of 3.5 years) with various types of disabilities (n=236) (Williams et al., 2019), the other one for children (mean age of 4.98 years) with ASD (n=30) living in Israel (Bar et al., 2016). Their findings indicated that higher levels of mother participation in health-promoting recreational activities were significantly associated with their child's participation (Williams et al., 2019), and mothers' participation could explain a notable proportion of child's participation (Bar et al., 2016). Thus, there is a strong need to explore mother's actual participation and to discover its relationship with child participation for children in a wider and older age range. Examining both parents' participation would be ideal, however, given the scarcity of evidence on the topic, it is important as a first step to better understand the participation of one parent, i.e., mothers, and how it affects their child's participation. Mothers' participation patterns therefore in this study served as another family-related explanatory factor to impact participation of children with ASD, addressing current gaps in research.

c) Environmental barriers and supports.

The ICF-CY places importance on the interplay between the environment and participation. All aspects of the environment identified by the ICF model can serve as a barrier, a support, or both, for participation of children and youth with various types of disabilities (Anaby et al., 2013) including ASD (Askari et al., 2015). Participation levels of children with ASD are context specific (Rios & Scharoun Benson, 2020), and it is important for them to participate in supportive environments during the early years of their life as this optimizes the

child's and the family's outcomes (Healy et al., 2020; National Research Council, 2000).

Studies have highlighted the unique role of the environment as a mediator between child factors and participation (Anaby et al., 2014). In other words, the environment as a mediating factor consistently alleviates or intensifies the impact of a child's condition on their participation levels across different settings: at home, school and in the community (Anaby et al., 2014). In addition, several studies (Egilson et al., 2018; Simpson et al., 2018) and scoping reviews (Askari et al., 2015; Krieger et al., 2018) have identified specific environmental factors that could affect the participation of children and youth with ASD. These included attitudes, social support, parental time, access to information, availability of resources and services, physical accessibility/layout, and social/cognitive demands of the activities, among others. A recent study (Fiscella et al., 2021) also found an association between the safety of the neighborhood environment and the engagement in physical activities for children with ASD. Another recent study (Devenish et al., 2020) found that lower perceived levels of community supportiveness could reduce the involvement of children with ASD in community activities, emphasizing the importance of environmental supports for participation. The sensory quality of the environment (e.g., noise, crowds, light) is another environmental feature that is important to consider, given the prevalence of sensory processing issues among children with ASD (Ausderau et al., 2014).

The setting in which participation occurs is also important to consider when investigating patterns of participation. The participation frequency levels of school-aged children with ASD have been proven to be lower at home, and much lower in community settings (Lamash et al., 2020; Simpson et al., 2019). While evidence showed that environmental barriers/supports had a direct impact on participation across all settings (home, school, community), the community setting poses the greatest challenge as it is often difficult to control (Bedell et al., 2011). Building supports in the home setting is often a more attainable goal for families. Thus, considering the setting where participation occurs is important when exploring patterns of participation. This study therefore focused on two main environments, i.e., home and the community (excluding the school context), which were settings parents were most implicated in.

d) Impact of COVID-19

The World Health Organization has declared a worldwide pandemic situation of corona-virus disease 2019 (COVID-19) since March 2020 (Sohrabi et al., 2020). This pandemic induced greater challenges on the wellbeing of children with disabilities and their mental and social health because of the lockdown and other restrictions (Cacioppo et al., 2021). Due to the significant and abrupt changes in their daily lives, families of children with neuro-developmental conditions, such as attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and intellectual disability, could have been particularly vulnerable during such adverse times. Children with developmental disabilities and their caregivers rely especially on continued systems of support; however, routine essential services for child health and psychosocial development were interrupted during the pandemic. Residents in Canada and other countries have been required to stay at home and follow social distancing rules. The wellbeing of these vulnerable groups of children was therefore affected in many domains. Examples include exacerbated mental health symptoms (Masi et al., 2021), greater barriers in accessing healthcare services (Eapen et al., 2021), lack of the cognitive flexibility (Aishworiya & Kang, 2021), experiencing greater loss and feeling overwhelmed(Asbury et al., 2020). Promoting social interactions has always been a challenge for children with ASD, and the limited social activities further increased their communication challenges and negatively impacted their development (Patel, 2020). Thus, it is also important to consider this exceptional global situation when investigating the participation patterns of children with ASD and interpreting the findings.

RATIONALE

Participation is an important outcome of rehabilitation intervention among children with

ASD that can have a positive impact on their well-being. Since participation is a complex phenomenon, factors relating to the child, the environment and the family are important to consider when explaining the participation of children with ASD. However, little is known about the unique contribution of each factor, in the presence of other relevant factors in this population. More specifically, the extent to which parental actual participation (rather than parents' perception towards participation) could explain children's participation in the presence/context of other factors known to be influential (environmental barriers/supports, income, complexity of child's condition, age), remains unknown. To address these gaps in knowledge, it is imperative to discover the impact of these factors, especially in the context of the COVID-19 pandemic.

The participation patterns of children in this research were studied based on mothers' report. The upper limit of 12/13 years old was selected because previous studies (Jarus et al., 2010; Law et al., 2006; Ratcliff et al., 2018) have shown that participation patterns change as children move to adolescence (at around age 12). Furthermore, this age range could represent an important development stage- middle childhood, according to Havighurst's developmental task theory (1948) as aforementioned. Other developmental theories also considered this age range as important and unique, such as Erikson's developmental psychosocial theory(1968), which frames this phase as a competence stage. Understanding middle childhood participation before entering the challenging phase of adolescence can set the stage for early intervention and prevention.

Specifically, knowledge of parental participation and environmental contextual factors that may promote participation among school-aged children with ASD could redirect therapists' attention to factors that are potentially modifiable. This redirected attention can serve to enhance participation in home and community-based activities, and to inform the development of participation-fostering interventions. Therefore, developing and testing a comprehensive model that includes a range of factors explaining participation is required to enhance the understanding of phenomenon.

OBJECTIVES

This study aimed to estimate the extent to which complexity of a child's condition, parents' income/education, parents' actual participation, and environmental barriers/supports, can explain frequency and involvement of the child's participation in home and community activities, as well as the number of those activities their parents would like to see change, among school-aged children with Autism Spectrum Disorder (ASD).

HYPOTHESES

Primary hypothesis: Children with lower number of functional issues, higher family income level, higher levels of mother's participation, fewer environmental barriers, and more environmental supports, would have increased levels of participation frequency and involvement,

Secondary hypothesis: Children with lower number of functional issues, higher family income level, higher levels of mother's participation, fewer environmental barriers, and more environmental supports, would have fewer number of activities in which change is desired in the home and community settings

CHAPTER II | METHODOLOGY

STUDY DESIGN

A cross-sectional design was used to describe participation patterns in terms of frequency and involvement in home and community activities. Within this design, all the explanatory variables and outcomes were measured at the same time, assessed using questionnaires and surveys. Cross-sectional studies are observational studies that provide a description of a population at a given time, and are useful in testing for associations (Leeuw et al., 2008). As such, this design is appropriate for the aim of this study. Frequency and involvement of the child's participation were treated as the main outcomes. Mean percentage of activities in which parents wish to see change (i.e., 'desire for change') was treated as the secondary outcome. This is because the 'desire for change' scale has seldom been studied as a participation outcome and hence was analyzed in an exploratory fashion.

For each of the two settings (home, community), three models were tested: one for explaining participation frequency, one for participation involvement, and one for desire for change. Thus, a total of 6 models were tested: 3 participation outcomes (frequency, involvement, desire for change) *2 settings (home and community).

The proposed model described below (**Figure 1**) serves as the overall hypothesis of the study and illustrates how factors related to the child, the environment and the family, might affect participation outcomes. It was replicated and tested in two settings: home and community.



Figure 1 The proposed model for explaining participation

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STUDY PARTICIPANTS

The target population under the study was school-aged children with ASD. One hundred and thirty mothers were included in this study as participants based on the following eligibility criteria: a) they had a child with a diagnosis of ASD by a physician or a psychologist with expertise (any level of function and across the entire spectrum) to include Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) or Asperger Disorder b) their child's age ranged between 6 to 12 years old when entering the study (maximum 13 if just past 12 birthday) c) they can understand English or French to complete the questionnaires independently and d) had access to an electronic device and internet.

Mother-participants were excluded if: a) they had a major health condition based on their own report b) their child had an additional complex neurodevelopmental diagnosis such as cerebral palsy(CP) or Down syndrome. Co-occurrence of such complex conditions (CP 18%, Down syndrome 9%) may have an effect on participation patterns (Mammad et al., 2019; Marie Moore et al., 2015), thus children with such co-occurrences were excluded. Children with ASD who also encountered other conditions such as attention deficit hyperactivity disorder (ADHD) and intellectual disability(ID) were included as these are more common in this population (McClain et al., 2017; Påhlman et al., 2020).

MEASUREMENTS

Outcomes Measures: frequency, involvement, and desire for change

The Participation and Environment Measurement for Children and Youth (PEM-CY) (Coster et al., 2011)was used to measure all three participation outcomes in this study. These include participation frequency, involvement and percentage of activities parents want to change, in both home and community settings respectively.

The PEM-CY is a parent-report assessment that includes 25 sets of activities across three different settings: home (10 items), school (5 items) and community (10 items). This present study did not examine participation in the school setting since parental participation patterns, one of the explanatory variables, may not impact children's participation at school. Thus, only the home and community settings of the PEM-CY were included in this study. Parents were

asked to rate their child's participation using 3 scales: frequency of participation (how often) using an 8-point scale, from never (0) to daily (7); level of involvement in activities rated on a 5-point scale, from minimally involved (1) to very involved (5); and whether parents wanted to see a change in their child participation ('desire for change') using 'Yes' or 'No' along with additional 5 options to clarify the types of change desired. A summary group score for each setting and for specific item level were obtained. The PEM-CY's scales and scoring is described in further detail in **Table 1**.

The PEM-CY was selected as an outcome measure because it is a unique and comprehensive measure that considers both the environment and participation domains in the same instrument. As such, it is well aligned with our study objectives. It has good reliability and validity with internal consistency ranging from 0.59 to 0.91, test-retest reliability ranging from 0.70-0.95, and has been successfully used among parents of children with ASD (Egilson et al., 2018; Simpson et al., 2019). In order to measure participation of children with ASD, the experience/ involvement of our target subjects is equally important as the number and frequency of those activities (attendance). PEM-CY was developed to explicitly capture the child's experience and assess the extent to which they immersed (or focused) in a specific type of activity. This aligns with current operational definitions of participation (i.e., attendance and involvement) (Imms et al., 2017), making the PEM-CY most appropriate tool for our research question. A French-Canadian version of the PEM-CY is available.

Outcomes	# of items	Scale	Score	Meaning
Average	Home-10;	8-point scale	Individual score: sum	On average, how often the
Frequency	Community-10	(0='never' to of all the frequency		child participates in all the
		7='daily')	responses within the	activities within each
		Range 0-7	setting, divided by the	setting. Higher scores
			number of activities	indicate greater frequency.
			that were rated 0-7 in	
			each setting.	
Average	Home-10;	5-point scale	Individual score: sum	On average, how involved
Involvement	Community-10	(1='minimally	of all the involvement	or engaged the child is in
		involved' to	responses within the	the activities. Higher
		5='very	setting, divided by the	scores indicate greater
		involved')	number of activities	involvement across
		Range 1-5	that were rated in	activities within a given

Table 1. Detailed description table of the outcome measure- PEM-CY

				each setting.	setting
Desire	for	Home-10;	% yes responses	Individual score:	This score represents
change		Community-10	Range 0-100%	number of divided by	average percentage of
(number	of			total number of items	activities in which parents
activities	in			rated 'yes, change is	want to see change. Higher
which par	ents			desired' responses.	percentages suggest less
would see	like			Multiply by 100.	satisfaction with the
to see chan	ge)				child's participation within
					the setting.

Explanatory Variables Measures

Child's factors

The complexity of the child's condition was measured by a checklist of functional issues completed by the parents. This checklist included 12 functional issues (e.g., difficulty paying attention or concentrating; communicating with others; socializing with other children). Each item/functional issue was rated on a 3-point scale: No problem, Little problem, Big problem. The number of functions rated as "little problem" or "big problem" were counted, ranging from 0 to 12 for each child. This checklist, which covered multiple domains of functional issues, is easy to complete and feasible. It has consistently shown the ability to explain participation levels in previous studies (Anaby et al., 2014). Parents were also asked to report about their child's health condition (e.g., developmental delay, intellectual disability, attention deficit disorder). Specifically, they were asked to check off up to 3 health conditions using a list of 13 health conditions.

Family factors

Mother actual participation in health-promoting activities was measured by the Health Promoting Activity Scale (HPAS) (Bourke-Taylor et al., 2013). The HPAS is a brief and psychometrically sound instrument that measures the frequency of participation in self-selected leisure activities that promote health (e.g., 'social activities with people who are important and supportive towards you'). The HPAS includes 8 items (or activities) rated on a 7-point response scale from 1 (never) to 7 (once or more every day). A sum score is generated ranging from 8 to 56 where a higher score indicates more frequent participation. The HPAS has good internal consistency (0.78), excellent intra-class correlation (0.9), and its construct validity has been demonstrated in several studies (Bourke-Taylor et al., 2013; 2012a; Muskett et al., 2017). It was also effectively used among mothers of school-aged children with developmental disabilities (Bourke-Taylor et al., 2012b). HPAS was developed for parents of children of any age with any kinds of disabilities. Compared to other existing similar tools that measure adult participation such as ASAP (Adults Subjective Assessment of Participation) (Barnea et al., 2004) or LPP (Life Participation for Parents) (Fingerhut, 2013), HPAS is shorter in length and is easier to complete.

Parental socioeconomic status was measured by a demographic questionnaire which collected data regarding family characteristics in terms of family annual income and education. There are 12 response options about income levels (ranging from 'less than \$10,000' to 'more than \$100,000') and four options about educational levels (i.e., 'high school or less', 'some college/university', 'graduated college/university', 'graduate degree'). First three digits of mothers' postal code have been also collected to document the geographical region/borough in which they lived.

Environmental factors

Environmental barriers and supports were measured using the environmental scales of PEM-CY. It includes a separate section that measures the environmental factors that support or hinder participation in the home (13 items) and in the community (16 items). Examples of environment items include physical accessibility, social support, attitudes of others, as well as the demands of the activity (physical, cognitive, and social). To calculate the average environmental supports score for each setting (i.e., home, community), we counted the environmental items rated as "usually helps" or "usually yes". To calculate the average environmental items rated as "usually makes harder" or "usually no". First, we counted the number of barriers and number of supports for each individual score by setting, and then, we calculated the mean by dividing these count numbers by all the number of environmental items within each setting. Scores were then presented in percentages. For the group scores by setting, the total score of individuals' supports/ barriers was divided by the number of children whose

score is included. Please see Table 2 for further information

Explanatory factor	Name	# of items	Scale	Score	Rationale
Parental (mother's) participation	HPAS (health promoting activities scale)	8	7-point Likert response scale (1 = never, 2 = 1-3 times per year, 3 = once a month, 4 = $2-3$ times a month, 5= once per week, 6 = $2-3$ times per week, and 7 = once or more every day).	The total HPAS score of each individual is obtained by summing the eight items. Range from 8 to 56	Addressmothers'frequencyofparticipationinhealth-promotingleisure activities. Higherscoreindicatesfrequent participation.
Environment al barriers	PEM-CY (All environment questions)	Home-12; Communit y-16	4-point scale ('Not an issue'/'Not needed'=4, 'Usually helps' /'Usually yes' =3, 'Sometimes helps, sometimes makes harder'/'Sometimes yes, sometimes no'=2, 'Usually makes harder'/'Usually no'=1)	For each child: Count the number of environmental items rated as "usually makes harder" or "usually no". Divide by the number of items within the setting. Multiply by 100. 0-100%	The percentage of environmental items that parents see as barriers to their children's participation. Higher percentages indicate a greater number of environment features perceived as <i>barriers</i> within a setting.
Environment al supports	PEM-CY (All environment questions)	Home-12; Communit y-16	4-point scale ('Not an issue'/'Not needed'=4, 'Usually helps' /'Usually yes' =3, 'Sometimes helps, sometimes makes harder'/'Sometimes yes, sometimes no'=2, 'Usually makes harder'/'Usually no'=1)	For each child: Count the number of environmental items rated as "usually helps" or "usually, yes". Divide by the number of items within the setting. Multiply by 100. 0-100%	The percentage of environmental items that parents see as supports to their child's participation. Higher percentages indicate a greater number of environment features perceived as <i>supports</i> within a setting.
Complexity of child's condition checklist	Checklist of children functional issues	12	"no problem" =0; "little problem" or "big problem" =1.	The total number of items that parents rate either "little problem" or "big problem". Range from 0-12	Higher score indicates a greater complexity level of functional condition.
Income	Demographic questionnaire	12	12 income level choices	Rank order 1-12	Higher rank indicates higher income level

 Table 2. Description of the measures of explanatory factors

Other demographic variables

Demographic variables such as age and gender, family makeup, type of community area, language spoken at home etc., were collected using a demographic questionnaire. We also added one question, rated on an 8-point scale, to assess the extent to which the COVID-19 pandemic affected child's participation at home and in the community, ranging from 0 (not at all affected) to 7 (to a very great extent). Mothers were also encouraged to elaborate what specific challenges they and their children were facing during the pandemic.

PROCEDURES

Ethical approval has been obtained from both McGill University Research Ethics Board and CIUSSS Centre Ouest de l'île de Montréal (the Integrated Health and Social Services University Network for West-Central Montreal). Mothers of children with ASD were invited to participate in the study, and were recruited from ASD related organizations, special schools (both public and private), associations, and research networks. This included the Miriam Home (a medical clinic that provides specialized rehabilitation services for people with intellectual disabilities or ASD), the Summit Centre for Education, Research and Training – SCERT (a multidisciplinary research facility of Summit School), and Giant steps (a private school for children with autism). Additional recruitment strategies included approaching research networks such as Transforming Autism Care Consortium (TACC) and the CHILD-BRIGHT in order to reach our sample size.

The local responsible and authorized research coordinator of Summit School helped screen families who meet our inclusion criteria using existing lists of school-aged children with ASD in their site. Then, recruitment material including a link to the online survey was shared with eligible families through organization's network. For participants in Miriam Home, the clinical research coordinator in the CIUSSS West-Central facilitated the recruitment collaboratively with the Agent de planification, programmation et recherche to identify potential participants through the organization's list of clients. Potential participants at their site were contacted by phone call or texts to receive more information about the study and to ensure eligibility criteria were met. As per the other participating sites, advertisements explaining the key information of this study and a link directing participants to the survey were also posted on relevant platforms and were circulated through email and regular newsletters. Detailed instructions about how to complete the online questionnaires were provided, and each mother had the opportunity to ask the research team any questions they may have through email. Formal consent of the mothers for participating in the research study was first introduced and then signed electronically using the online platform, i.e., LimeSurvey, by each eligible participant before starting the survey.

Mother-participants who agreed to participate in the study by providing their consent were automatically directed to the completion of the online questionnaires (PEM-CY; HPAS; demographic questionnaire) in their preferred language (English or French). Participants were asked to complete the questionnaires within the scheduled time period- up to 4 weeks upon receipt of the LimeSurvey link by email. To ensure confidentiality and anonymity, participants were assigned a random ID number. Response data including the score of participation outcomes (frequency, involvement, desire for change), score of mother participation, number of child functional issues, score of environmental features, and demographic information were compiled and analyzed after all data was collected and validated. A token of appreciation, in a form of a \$15 gift-card, was provided to each mother-participant upon the completion of the survey.

DATA ANALYSIS

Descriptive statistics were used to characterize the patterns of participation of children with ASD in the home and community activities, as well as to describe the specific activity items and environment features in each setting. Scores of frequency, involvement and desire for change as well as environmental supports and barriers were calculated as specified in the PEM-CY's manual (Coster et al., 2014). Multiple linear regressions were used to examine our hypotheses because we had multiple explanatory variables, and each outcome variable (frequency, involvement and desire for change) was treated as a continuous variable. SPSS 27 and R studio were used. The level of significance was set to 0.05 for all statistical tests. All available responses were organized and were validated. Missing data was calculated for:

frequency, involvement, desire for change and environmental scores within each setting. Specifically, the 80% rule was applied to each score to exclude data that had less than 80% valid response (Tabachnick & Fidell, 2013).

Distribution of the potential explanatory variables and outcome variables were examined by using histograms and normal curves. Multi-collinearity was firstly tested to examine the inter-correlation between explanatory variables by using Pearson correlation coefficient and the VIF (variance inflation factor) values. If the estimated correlations are lower than 0.5 (Domholdt, 2000) and VIF values are closer to 1, there is no concern for multi-collinearity (Tabachnick & Fidell, 2013).

Explanatory variables were entered to each model in 'blocks' allowing us to test the unique contribution of each factor to the explained variance of participation outcomes. Specifically, in block 1 income was entered; block 2 included numbers of functional issues and age; block 3 comprised of environment barriers and supports; and in block 4 mother participation (measured by the HPAS) was entered. The order of the block is important. As income and child's factors (age, functional issues) have been previously found to impact child's participation, they were entered in the first two blocks. Environmental factors may mediate the relation between child's condition and participation, as aforementioned; thereby entered in the third block. Finally, mother participation was added in the last block which allowed us to test if this variable had a unique contribution over or above other factors already known to be important. Both R^2 and the change of R^2 were reported (in percentage) to evaluate the extent to which each block contributes to the overall variance of participation outcomes. Histogram plots and description analysis of the residuals were also examined to assess their independence and normal distribution, to ensure they did not violate the assumption of the linear regression. These were conducted separately for each the 3 outcomes: average frequency scores, average involvement scores, and percentage of activities in which change is desired in home and community settings. A sample of 130 mother-participants of children with ASD provided enough power to model up to 6 explanatory variables at a conservative effect size (F square 0.15) with a power of 0.80 when α =0.05 (Erdfelder et al., 1996; Green, 1991).

CHAPTER III | RESULTS
SAMPLE CHARACTERISTICS

Out of 171 mothers having given consent and completed the survey, 130 families met all the eligibility requirements and were included in the study. Among all the participants, the age of their children ranged from 6-13 years old, and most of them were male (61%). The mean number of health conditions of the children reported by their mothers was 2.4 (SD=0.96) and ranged from 1 to 4, where 44.6% of them had a total of 3 health conditions. Specifically, all of the mothers had reported their children were diagnosed with ASD, and 29.2% of these children were also diagnosed with Attention Deficit Disorder, followed by Developmental Delay (20%) and serious emotional disturbance (20%). The number of child's functional issues reported ranged from 2 to 12 with a mean of 7.48 (SD=1.84) and the median was 8 issues. Specifically, the most common issues reported were socializing with other children (80.8%), followed by controlling behavior (77.7%), communicating with others (74.6%), paying attention (73.1%), and managing emotions (71.5%). Compared with other functional issues, moving around (45.4%) and using hands to do activities (46.2%) were the only two issues that reported by less than 50% of the mothers.

When looking at the occupation status of the mothers, most of them were working (66.2%). This included working in part-time/seasonal (36.2%), closely followed by working full time (30%). The remaining of the mothers were caring for family full time (16.9%) and pursuing other occupations such as going to school or looking for work (16.9%). In terms of family income, the median income level fell into a range of \$30,000-40,000/year (Canadian dollars). As shown in **Figure 2**, the participants lived in various geographic locations, including 8 different provinces in Canada (68.5%), mostly living in Quebec (39.2%), followed by Ontario (11.5%), whereas some families were residing in the US (26.2%). In addition, when looking at the family makeup, on average those families had 2 children and 2 adults living at home, and there were approximately 4 rooms in their household (mean 3.82). Further demographic characteristics of the included sample are presented in **Table 3**.



Figure 2 Distribution of provinces participants lived in

Variable		n(%) or mean± SD
Child Sex		
	Male	82(63.1%)
	Female	48(36.9%)
Child age, Years		9.09 ± 1.89
Type of class attend at school		
	Regular classroom	13(10%)
	Both a regular and special classroom	52(40%)
	Special education class	59(45.4%)
	Not in school	3(2.3%)
	Other	3(2.3%)
Language spoken at home		
	English	94(72.3%)
	French	33(25.4%)
	Other	3(2.3%)
Community type		
	Major urban (population over 100,000)	45(34.6%)
	Suburban (population between 20,000-99,000)	62(47.7%)
	Small town (population between 3,000-20,000)	20(15.4%)
	Rural (population less than 3,000)	3(2.3%)
Mother age, Years		
	Under 20	2(1.5%)
	20-29	33(25.4%)
	30-39	59(45.4%)

 Table 3 Sample characteristics

	40-49	32(24.6%)
	50-59	3(2.3%)
	60 or over	1(0.8%)
Mother's education level		
	Graduate degree	17(13.1%)
	Graduated college/University	68(52.3%)
	Some college/University or technical training (at	42(32.3%)
	least 1 year)	
	High school or less	3(2.3%)
Family annual income		
	Less than \$10,000	5(3.9%)
	\$10,000-\$19,999	24(18.9%)
	\$20,000-\$29,999	24(18.9%)
	\$30,000-\$39,999	26(20.5%)
	\$40,000-\$49,999	20(15.7%)
	\$50,000-\$59,999	7(5.5%)
	\$60,000-\$69,999	5(3.9%)
	\$70,000-\$79,999	5(3.9%)
	\$80,000-\$89,999	2(1.6%)
	\$90,000-\$99,999	2(1.6)
	More than \$100,000	7(5.5)
	Unknown/Missing	3

Note. N=130

PARTICIPATION PATTERNS

As described in **Table 4**, the children of this study participated quite frequently in the home setting (5.79 on a 7-point scale, between 'once a week' and 'a few times a week'), and in the community setting their participation was relatively lower (4.32, between 'a few times a month' to 'once a week'). The diversity of activities in which they participated was relatively high in the home setting (94% out of all listed activities on average; ranging from 5 to 10 activities) whereas in the community children took part in 81.6% out of all activities (ranging from 2 to 10 activities). The levels of participation involvement (approximately on average 3.5 on a 5-point scale, indicating 'somewhat involved') as well as the numbers of activities mothers desired to change (on average around 71% of the listed activities), were similar in both home and community settings. In addition, the average percentage of environmental features that mothers perceived as supports to their children's participation were similar (35%) within the home and community settings, while that of environmental

features perceived as barriers within the home setting (13.33%) was slightly lower than in the community setting (14.81%).

When looking at the specific activity item in each setting, all of the 10 home-based activities were above a mean frequency score of 4.5 (indicating more than 'few times a month') and ranged from 4.56 to 6.30 (on a 7-point scale) (see **Table 5** and **Figure 3**). Concurrently, the frequency of community-based activities score varied with a range of 1.77 to 4.76, and only 4 out of 10 activities were above a mean frequently score of 4 ('few times a month') (see **Table 6** and **Figure 4**).

More specifically, in the home setting as shown in **Table 5**, children participated most frequently in watching TV/videos/DVDs (mean 6.30, between 'few times a week' and 'daily') and personal care management (mean 6.27), while the activity with the lowest frequency score was household chores (mean 4.56, between 'once a week' and 'few times a month'). 14.6% of the mothers have reported socialized using technology as 'never participated', followed by indoor play and games (12.3%). In terms of levels of involvement, the mean scores of each home-based activity ranged from 3.15 to 3.83 (on a 5-point scale), where computer/video games and watching TV had the highest mean value (3.8). In addition, most mothers wished to see their child's participation change in personal care (81.5%) followed by doing homework (78.5%). The activity types where desired for change was reported less often (yet still substantial) included indoor play and games (53.1%) and socializing using technology (56.9%).

In the community setting as shown in **Table 6**, children most frequently participated in religious or spiritual gatherings (mean score 4.76, between 'few times a month' to 'once a week') and neighborhood outings (mean score 4.58, between 'few times a month' to 'once a week'). Relatively lower levels of frequency were evident in organizations/groups/clubs activities (mean 2.68, slightly less than 'once a month') and 53.1% of children rarely participated in working for pay (mean 1.77, between 'few times in last four months' and 'once in last four months'). With respect to the involvement level, the mean scores of each community-based activity ranged from 2.89 to 3.72 (on a 5-point scale). Among the included activities listed in the PEM-CY, children had greater level of involvement in 'religious or spiritual activity' (mean score 3.72) and in 'not school-sponsored classes and lessons' (mean

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score 3.68). These two activities were also rated with the highest score on the involvement scale (5= 'very involved') by 29.4% and 20.4% of the participants, respectively. With regards to types of activities to which mother wished to see changed, more than80% of mothers indicated that they would like their children to change their participation in 4 out of the 10 listed activities. This included neighborhood outings (82.3%), getting together with other children in the community (81.5%), community events (80.8%), and organized physical activities (80.8%).

Setting	Scale	Group setting Scores				
		Mean	Median	Standard	Minimum	Maximum
				Deviation		
Home	Frequency (all listed activities)	5.42	5.45	0.74	2.90	6.90
	Frequency (actually activities	5.79	5.90	0.69	3.20	6.90
	done)					
	Number of activities children	9.40	10.00	0.94	5.00	10.00
	participated (%)					
	Involvement	3.52	3.56	0.47	2.00	4.80
	Desire for change (%)	71.31	70.00	20.21	10.00	100.00
	Environmental supports (%)	35.90	33.33	13.99	8.33	83.33
	Environmental barriers (%)	13.33	8.33	11.86	0.00	75.00
Community	Frequency (all activities)	3.57	3.90	1.22	0.50	5.30
	Frequency (actually activities	4.33	4.42	0.79	1.80	6.25
	done)					
	Number of activities children	8.16	9.00	2.24	2.00	10.00
	participated (%)					
	Involvement	3.40	3.44	0.53	1.57	4.80
	Desire for change (%)	71.54	70.00	19.11	0.00	100.00
	Environmental supports (%)	34.95	31.25	12.90	0.00	75.00
	Environmental barriers (%)	14.81	12.5	12.16	0.00	62.50
Mother	HPAS sum score	35.67	36.00	9.22	11.00	53.00
narticination						

Table 4 Group setting scores of participation scales for each setting

Note: N=130. Frequency - measured on a 7-point scale; Involvement - measured on a 5-point scale

^a refers to on average parents' perception of how helpful the environment is in supporting participation in that setting; ^b refers to on average parents' perception of the availability of environment resources to support participation in that setting; ^c refers to on average parents' overall perception of how the environment supports their children's participation in that setting.

Items	HOME setting				
	Mean frequency	Mean involvement	% Desired change		
Computer and video games	5.79	3.83	72.3		
Indoor play and games	4.78	3.34	53.1		
Art/crafts/music and hobbies	5.29	3.69	73.1		
Watching TV/videos	6.30	3.82	74.6		
Getting together with others	5.44	3.29	74.6		
Socializing using technology	4.85	3.39	56.9		
Household chores	4.56	3.15	72.3		
Personal care	6.27	3.75	81.5		
School preparation	5.12	3.45	76.2		
Homework	5.82	3.34	78.5		

Table 5 Mean participation scores of specific activity item at home

Note: N=130.Frequency - measured on a 7-point scale; Involvement - measured on a 5-point scale

Table 6 Mean participation scores of specific activity item in community

Items	COMMUNITY setting			
	Mean frequency	Mean involvement	% Desired change	
Neighborhood outings	4.58	3.38	82.3	
Community events	3.43	3.34	80.8	
Organized physical activities	3.94	3.50	80.8	
Unstructured physical activities	3.68	3.35	73.1	
Classes and lessons	4.52	3.68	68.5	
Organization, clubs and volunteer activities	2.68	3.15	73.1	
Religious or spiritual gatherings	4.76	3.72	60	
Getting together with other children	4.43	3.36	81.5	
Working for pay	1.77	2.89	48.5	
Overnight visits or trips	1.90	2.90	66.9	

Note: N=130. Frequency - measured on a 7-point scale; Involvement - measured on a 5-point scale



Figure 3 (a) Mean participation frequency in each of the home-based activities, (b) Mean participation frequency in each of the community-based activities.

Legend: 0 – never; 1 – Once in the last four months; 2 – Few times in the last four months; 3 – Once a month; 4 – Few times a month; 5 – Once a week; 6 – Few times a week; 7 – Daily



Figure 4 (a) Mean level of involvement in each of the home-based activities, (b) Mean level of involvement in each of the community-based activities

Legend: 1 – Minimally involved; 2 – 2; 3 – Somewhat involved; 4 – 4; 5 – Very involved



Figure 5 (a) Mean level of desired change in each of the home-based activities, (b) Mean level of desired change in each of the community activities

(b)

Legend: percentage of activities parents want to change, 0-100%.

ENVIRONMENTAL BARRIERS AND SUPPORTS

Results of the specific environmental features at home and in the community are presented in **Table 7 and Table 8** respectively and illustrated in **Figure 6**. When evaluation their child's participation, mothers tend to consider the environment items as supports rather than barriers in both settings. For the home environmental items, having enough resources

such as time (44.6%) and money (44.6%) to support children's participation were perceived as the most common environmental supports, while attitudes and actions of others who care for their child at home (18.5%) was the most common barrier. In the community setting, environmental features such as having access to personal transportation (42.3%) was perceived as the most common support, while availability of equipment or supplies in the community (23.1%) was reported as the most common barrier. Physical layout or amount of space has the highest mean score (3 in a 4-point scale, 'usually helps') among all the items in both home and community settings. Information about services or programs was with the lowest mean score in the home environment (2.19, 'sometimes available/adequate, sometimes no'), while in the community setting, equipment or supplies has the lowest mean score (2.12, 'sometimes available/adequate, sometimes no').

MOTHER'S PARTICIPATION

The mean sum score of participation frequency in health-promoting activities of mothers who has a child with ASD was 35.67 ± 9.22 (out of 56, equal to an average of 4.46 on a 7-point scale, more than '2-3 times a month' but less than 'once a week'). Specifically, as shown in **Figure 7**, mothers in this study most frequently participated in quiet and physically inactive leisure activities done alone, with a mean frequency score of 5 (i.e., 'once a week') on a 7-point scale. Activities in which mothers participated less often, around '2-3 times a month', included spiritual personal time (4.19), physically active recreational pursuit with others (4.25), and social activities with important others (4.27). The most common activity in which mothers participated 'once or more every day' (score of 7) was quiet inactive pursuits with others (25.4%) followed by personal health care tasks (22.3%), and quiet inactive pursuits alone (21.5%). The most often reported activity in which these mothers never took part was spiritual or rejuvenating personal time (15.4%), followed by personal health care tasks (10%) and physically active recreational pursuit with others (9.2%).

Items		HOME setting	
	% Support ^a	% Barrier ^b	Mean Score ^c
Physical layout	35.4	6.9	3.01
Sensory Qualities	33.1	5.4	2.97
Physical Demands	27.7	14.6	2.72
Cognitive Demands	34.6	14.6	2.57
Social Demands	33.1	16.2	2.58
Relationships with family members	35.4	10	2.81
Attitudes and actions	28.5	18.5	2.59
Services	37.7	13.1	2.63
Supplies	40	16.9	2.23
Information	36.2	16.9	2.19
Time	44.6	16.2	2.28
Money	44.6	10.8	2.34

Table 7 Environmental features at home as perceived by mothers

Note: N=130. a refers to percentage of parents who perceive the item as a support, b refers to percentage of parents who perceive the item as a barrier, ^c refers to the mean score (out of 4) of each environmental item.

Items		COMMUNITY setting				
	% Support ^a	% Barrier ^b	Mean Score ^c			
Physical layout	39.2	7.7	3.07			
Sensory Qualities	31.5	20	2.62			
Physical Demands	32.3	9.2	2.77			
Cognitive Demands	28.5	21.5	2.50			
Social Demands	27.7	16.2	2.61			
Relationships with family members	37.7	16.2	2.52			
Attitudes and actions	32.3	13.1	2.76			
Outside weather	26.2	15.4	2.54			
Safety of community	36.2	17.7	2.77			
Access to personal transportation	42.3	10	2.85			
Access to public transportation	40.8	10	2.85			
Programs and services	36.9	15.4	2.58			
Information	36.9	16.9	2.20			
Equipment and Supplies	34.6	23.1	2.12			
Time	38.5	11.5	2.27			
Money	37.7	13.1	2.25			

Table 8 Environmental features in community as perceived by mothers

Note: N=130. ^a refers to percentage of parents who perceive the item as a support, ^b refers to percentage of parents who perceive the item as a barrier, ^c refers to the mean score (out of 4) of each environmental item.

Figure 6 (a) Mean level of environment supports at home in each of the items (b) Mean level of environment barriers at home in each of the items (c) Mean level of environment supports in the communityin each of items (d) Mean level of environment barriers in the community in each of the items





(d)

Legend: percentage of parents who perceived the environment item as support/ barrier, 0-100%

Figure 7 Mean participation frequency in each of the health-promoting activities in which mothers participated



Legend: 1 = never, 2 = 1-3 times per year, 3 = once a month, 4 = 2-3 times a month, 5 = once per week, 6 = 2-3 times per week, and 7 = once or more every day

IMPACT OF COVID-19

The mean level of the impact of COVID-19 reported was 2.65 ± 1.77 (on a 7-point scale between 'some extent' to 'neutral extent'). The median level was 3 ('neutral effect') and its interquartile range was 3(1-4). The majority of the families (89.2%) indicated that the pandemic had at least a small effect on their children's participation at home and in the community (sees **Table 9**).

1 J		
Impact level	Frequency (%)	
Not at all affected (0)	10.8	
To a small extent (1)	23.1	
To some extent (2)	15.4	
Neutral(3)	16.2	
To a moderate extent (4)	17.7	
To a great extent (5)	10.0	
To a very great extent (6)	6.9	
N=130		

 Table 9 Impact of COVID

CORRELATION TEST RESULT:

Correlations between explanatory variables and outcomes

Home setting

As seen in **Table 10**, level of mother participation (measured by the HPAS) was significantly and positively correlated with both participation frequency (r=0.24, p<.01) and involvement (r=0.39, p<.01) at the home setting. In addition, child's age was positively and significantly associated with levels of involvement (r=0.29, p<.01). There was also a significant positive correlation (r=0.19, p<.05) between number of environment barriers and number of activities in which parents wished to see changed (desire for change) at home. When looking at additional outcomes of participation, i.e., frequency of activities done and diversity of activities done, the results showed that higher level of mother participation and higher family income were associated with more frequent (r=0.40, p<.05; r=0.27, p<.01, respectively) but less diverse participation (r=-0.18, p<.05; r=-0.36, p<.01, respectively).

Community setting

As seen in **Table 11**, higher income level was significantly correlated with lower levels of participation frequency in the community (r=-0.64, p<.01), but was related to higher level of child's involvement in community activities (r=0.30, p<.01). None of the predictive/explanatory variables was significantly correlated with number of activities to which parents desired change. When looking at activities actually done, family income was negatively associated with frequency (r=-0.25, p<.05) and diversity (r=-0.64, p<.01) of actual participation in the community.

Relationships between predictors/explanatory variables

Table 12 presents the Pearson correlations between all the explanatory variables. Overall, their correlations, based on Pearson coefficients, were non-significant to relatively weak (with the exception of the correlation between environment barriers and supports), reducing a concern for multi-collinearity. To illustrate, mother participation was positively correlated with child's age (r=0.27, p<.01) and number of environment supports in the community

(r=0.26, p<.01); the income level was positively correlated with home environment support (r=0.23, p<0.05) and community environment barriers (r=0.17, p<0.05); greater number of child's functional issues was associated with higher numbers of environment barriers at home (r=0.22, p<0.05).

Correlations between explanatory variables and outcomes across groups

To further investigate the association between those variables, specific groups were created based on the median: child's age (2 groups; younger children aged 6-9 and older children above 9 years), income level (2 groups; below/above \$39,999), functional issues (2 groups below/above 8 issues), and health conditions (3 groups; child with ASD only, ASD and one other condition, ASD and two/three other conditions). Under each group, Pearson correlations between explanatory variables and the outcomes were tested. The relations that proved to be significant are reported below.

Home setting

Levels of child's frequency of participation at home was significantly associated with levels of mother participation in the younger age group aged6 to 9 (r=0.27, p<.05); among families with lower income (<=339,999) (r=0.37, p<.01); among those with less number of functional issues (8 issues or less) (r=0.23, p<.05); and those with 3-4 health conditions (r=0.39, p<.01). Considering child's levels of involvement, it had a moderate correlation with mother participation for younger children (r=0.53, p<.01); those with lower family income (r=0.57, p<.01); and children with higher number of health conditions (2-4 health conditions) (r=0.39~0.55, p<.05). With respect to number of activities to which change desired, it was significantly correlated with home environment supports (r=-0.35, p<.05) and environment barriers (r=0.35, p<.05) for children with more functional issues (9-12 issues). In addition, higher number of activities desired change was related to higher number of home environment barriers in the younger age group aged 6-9 (r=0.24, p<.05).

Community setting

Levels of child's frequency of participation in the community was significantly and strongly associated with income level for children with lower number of functional issues (r=-0.72, p<.01); and with number of community environment supports among families with lower income (r=0.26, p<.05). In terms of child's levels of involvement, it has significant correlation with income for younger children (r=0.39, p<.01) and for children with less functional issues (r=0.37, p<.01). Considering the number of activities to which change desired, it was negatively correlated with income for older children (r=-0.32, p<.05). Participation frequency of children with more health conditions was further impacted by community environment barriers (r=-0.41, p<.01).

Relationships between COVID-19 and other variables

In the home setting, higher impact levels of COVID-19 reported by mothers was significantly yet weakly correlated with higher participation frequency (r=0.19, p<.05) and greater number of activities at home parents wanted to change (r=0.20, p<.05), but it had no significant association with levels of involvement at home. In the community, the association between participation frequency and reported impact of COVID-19 was moderate and negative (r=-0.51, p<.01), and it was positively (yet weakly) associated with levels of involvement in the community (r=0.18, p<.05). When looking at activities actually done in the community, higher impact of COVID-19 was associated with lower levels of frequency(r=-0.35, p<.01) and diversity (r=-0.43, p<.01).

The reported impact of COVID-19 also had a positive and significant correlation with the income level (r=0.39, p<.01), which means families with higher income tend to report greater impact of the pandemic on their child's participation.

Differences in tested variables between groups

To have a better understanding of the data, difference between groups were also tested using T-test and ANOVA. Results showed that there were significant differences in several variables across the groups. To illustrate, children of families with higher income had significant higher score of involvement in community activities (t=-3.30, mean difference=-0.29, p=0.001) and lower score of community frequency (t=7.15, mean difference=11.34, p<.001). Moreover, older children (aged 9 to 13) had higher levels of involvement at home (t=-3.12, mean difference=-0.25, p=0.002) and their mothers had higher level of participation (t=-2.52, mean difference=-4.03, p=0.013). Significant higher levels of mother participation (F=7.91, p=0.001) and community involvement (F=5.83, p=0.004) were also seen in the group of children with ASD only. Children with greater number of functional issues (>8 issues) had more environmental barriers at home (t=-2.01, mean difference=-4.61, p=0.047).

Variable	M(SD)	1	2	3
1. Frequency	5.42(0.74)			
2. Involvement	3.52(0.47)	.18*		
		[.01, .34]		
3. Desired change	71.31(20.21)	.26**	.13	
		[.09, .41]	[04, .30]	
4. COVID impact	2.65(1.77)	.19*	.15	.20*
		[.02, .35]	[02, .31]	[.03, .36]
5. Income	4.42(2.49)	01	.02	.12
		[18, .16]	[16, .19]	[05, .29]
6. Mother's participation	35.67(9.22)	.24**	.39**	.09
		[.07, .40]	[.24, .53]	[08, .26]
7. Number of function issue	7.48(1.84)	15	09	16
		[32, .02]	[25, .09]	[33, .01]
8. Child age	9.09(1.89)	.05	.29**	17
		[12, .22]	[.12, .44]	[33, .01]
9. Environment supports	35.90(13.99)	04	.13	06
		[21, .14]	[04, .30]	[23, .11]
10.Environment barriers	13.33(11.86)	04	06	.19*
		[21, .14]	[23, .12]	[.02, .35]

 Table 10 Correlations between participation outcomes and explanatory variables at home

Note. M and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. * indicates p < .05. ** indicates p < .01.

Table 11 Correlations between participation outcomes and explanatory variables in the community

Variable	M(SD)	1	2	3
1. Frequency	3.57(1.22)			
2. Involvement	3.40(0.53)	34**		
		[48,17]		
3. Desired change	71.54(19.11)	.14	17	

		[03, .31]	[33, .00]	
4. COVID impact	2.65(1.77)	51**	.18*	08
		[62,37]	[.01, .34]	[25, .09]
5. Income	4.42(2.49)	64**	.30**	14
		[74,53]	[.13, .45]	[30, .04]
6. Mother's participation	35.67(9.22)	09	04	.00
		[26, .08]	[21, .13]	[17, .17]
7. Number of function issue	7.48(1.84)	.08	16	.06
		[09, .25]	[33, .01]	[11, .23]
8. Child age	9.09(1.89)	03	13	.07
		[20, .14]	[30, .04]	[10, .24]
9. Environment supports	34.95(12.90)	.13	09	.01
		[04, .30]	[26, .08]	[17, .18]
10. Environment barriers	14.81(12.16)	15	.06	.00
		[31, .02]	[12, .23]	[17, .18]

Note. M and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. * indicates p < .05. ** indicates p < .01.

Table 12 Correlations between predictors/explanatory variables

Variable	M(SD)	1	2	3	4	5	6	8
1. COVID impact	2.65(1.77)							
2. Income	4.42(2.49)	.39**						
		[.23, .52]						
3. Mother's participation	35.67(9.22)	.16	.14					
		[01, .33]	[03, .31]					
4. Number of function issue	7.48(1.84)	05	12	07				
		[22, .12]	[29, .06]	[24, .11]				
5. Child age	9.09(1.89)	06	.01	.26**	.06			
		[23, .11]	[17, .18]	[.10, .42]	[11, .23]			
6. Home environment supports	35.90(13.99)	.04	.23*	01	06	02		
		[13, .21]	[.05, .39]	[18, .16]	[23, .11]	[19, .15]		
7. Home environment barriers	13.33(11.86)	03	.01	01	.22*	.18*	44**	
		[20, .14]	[17, .18]	[18, .16]	[.05, .38]	[.00, .34]	[57,29]	
8. Community environment supports	34.95(12.90)	03	04	.26**	02	01		
		[20, .14]	[22, .13]	[.09, .41]	[19, .15]	[18, .16]		
9. Community environment barriers	14.81(12.16)	.09	.17*	08	.12	.07		41**
		[09, .26]	[.00, .34]	[25, .09]	[05, .29]	[10, .24]		[55,26]

Note. M and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation.

* indicates p < .05. ** indicates p < .01

REGRESSION ANALYSES

Multiple linear regressions were used where explanatory variables were entered into the model in blocks. This allowed us to analyze the unique contribution of explanatory variables to the variance of the following outcomes: 1) participation frequency, 2) involvement and 3) desire for change in each of the settings, i.e., the home and the community. In both settings, VIF (variance inflation factor) of these explanatory variables were all around value of 1, and the correlation coefficients value were all below 0.45. Such results alleviated the concern of multi-collinearity. Explanatory variables including level of income (block 1), child's factors in terms of age and number of functional issues (block 2), environmental support and barrier (block 3), and mother participation (block 4) were then entered in specific order as described in the data analysis section (see **Table 13** and **Table 14**).

Models of home participation outcomes

When examining levels of child's **frequency** at home, the last block which included all the factors was not significant (F=1.65, p>.05, R²=0.076), but the unique contribution of mother participation to the variance explained at block 4 was significant (R² change=5.4%, p<.01). The beta coefficient (0.24, 95% CI [0.06, 0.43]) of mother participation indicated that score of mother participation was positively associated with child participation frequency at home when accounting for other relevant variables. Income, child's functional issues and age, and environment supports/barriers did not explain any significant amount of variance at all four blocks.

When examining child's levels of **involvement** at home, the last block was significant (F=5.27, p<0.001) explaining nearly 21% of the variance. Child's age served as a significant contributing variable explaining 8.2% (p=0.005) of the variance at block 2, and the unique contribution of mother participation explained an additional 10.4% (p<.001) to the variance explained at block 4. Overall, mother participation and child age together explained 20.9% (p<.001) of the variance of child involvement in the presence of other variables. Based on the beta coefficients, mother participation (0.34, 95%CI [0.17, 0.51]) has a stronger effect on child's involvement in home-based activities in comparisons to child's age (0.20, 95% CI [0.03, 0.51])

0.37]).

When modeling levels of **desire for change** at the home setting, the last block was significant (F=4.22, p=0.001) and explained 17.4% of the variance. Child's age and number of functional issues, entered in block 2, significantly explained 6.6% of the variance (p<.05), and number of environmental barriers added an additional 7.9% (p<.01) to the variance explained at block 3. Based on the beta coefficients, child's age (-0.29, 95%CI [-0.47, -0.12]) and environmental barriers (0.32, 95%CI [0.12, 0.51]) had a similar magnitude of effect on desire for change, whereas functional issues had a relatively lower effect (-0.2, 95%CI [-0.37, -0.03]).

In summary, when modeling participation outcomes in the home setting, involvement and desire for change had the highest variance explained (20.9% and 17.4%, respectively) and participation frequency had the lowest level of explained variance (7.6%). Mother's participation significantly explained child participation frequency and involvement (but did not explain desire for change) where the effect of mother participation was more pronounced in the model for explaining levels of <u>involvement</u>. Child's age served as a significant contributor for explaining levels of involvement and desire for change whereas environmental barriers could explain levels of desire for change only. Specifically, the older the child, the higher the home involvement level and the lower number of home-based activities in which change is desired. In addition, the more barriers encountered in the home environment, the higher the number of activities parents wish to see change.

Outcome	Block	Predictor	β Block1	β Block2	β Block3	β Block4
Frequency	1	Income	-0.01	-0.03	-0.02	-0.05
			[-0.19, 0.17]	[-0.20, 0.15]	[-0.20, 0.17]	[-0.24, 0.13]
	2	Functional issue		-0.14	-0.14	-0.13
				[-0.32, 0.04]	[-0.32, 0.05]	[-0.31, 0.05]
		Child age		0.04	0.04	0.02
				[-0.14, 0.22]	[-0.14, 0.22]	[-0.21, 0.16]
	3	Environment support			-0.05	-0.03
					[-0.25, 0.16]	[-0.23, 0.17]
		Environment barrier			-0.03	-0.01
					[-0.24, 0.18]	[-0.21, 0.19]
	4	Mother participation				0.24**

Table 13 Multiple regression analyses for participation outcomes at home

						[0.06, 0.43]
ΔR^2			0.000	0.020	0.002	0.054**
R^2			0.000	0.020	0.022	0.076
Involvement	1	Income	0.02	0.01	-0.02	-0.07
			[-0.16, 0.20]	[-0.16, 0.18]	[-0.20, 0.16]	[-0.24, 0.10]
	2	Functional issue		-0.04	-0.03	-0.02
				[-0.22, 0.13]	[-0.21, 0.14]	[-0.19, 0.14]
		Child age		0.29**	0.29**	0.20*
				[0.12, 0.46]	[0.12, 0.47]	[0.03, 0.37]
	3	Environment support			0.14	0.17
					[-0.06, 0.34]	[-0.02, 0.35]
		Environment barrier			-0.02	0.01
					[-0.22, 0.18]	[-0.18, 0.20]
	4	Mother participation				0.34***
						[0.17, 0.51]
ΔR^2			0.000	0.082**	0.021	0.104***
R^2			0.000	0.083*	0.104*	0.209***
Desire change	1	Income	0.12	0.11	0.09	0.07
			[-0.05, 0.30]	[-0.07, 0.28]	[-0.08, 0.26]	[-0.10, 0.25]
	2	Functional issue	[-0.05, 0.30]	[-0.07, 0.28] -0.14	[-0.08, 0.26] - 0.20*	[-0.10, 0.25] - 0.20*
	2	Functional issue	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03]	[-0.10, 0.25] -0.20* [-0.37, -0.03]
	2	Functional issue Child age	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] - 0.21 *	[-0.08, 0.26] - 0.20* [-0.37, -0.03] - 0.26**	[-0.10, 0.25] - 0.20* [-0.37, -0.03] - 0.29**
	2	Functional issue Child age	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09]	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12]
	2 3	Functional issue Child age Environment support	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09] 0.03	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12] 0.04
	2 3	Functional issue Child age Environment support	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09] 0.03 [-0.16, 0.22]	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12] 0.04 [-0.15, 0.23]
	2 3	Functional issue Child age Environment support Environment barrier	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09] 0.03 [-0.16, 0.22] 0.31**	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12] 0.04 [-0.15, 0.23] 0.32**
	2	Functional issue Child age Environment support Environment barrier	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09] 0.03 [-0.16, 0.22] 0.31** [0.11, 0.50]	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12] 0.04 [-0.15, 0.23] 0.32** [0.12, 0.51]
	2 3 4	Functional issue Child age Environment support Environment barrier Mother participation	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09] 0.03 [-0.16, 0.22] 0.31** [0.11, 0.50]	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12] 0.04 [-0.15, 0.23] 0.32** [0.12, 0.51] 0.13
	2 3	Functional issue Child age Environment support Environment barrier Mother participation	[-0.05, 0.30]	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09] 0.03 [-0.16, 0.22] 0.31** [0.11, 0.50]	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12] 0.04 [-0.15, 0.23] 0.32** [0.12, 0.51] 0.13 [-0.05, 0.30]
ΔR^2	2 3 4	Functional issue Child age Environment support Environment barrier Mother participation	[-0.05, 0.30] 0.015	[-0.07, 0.28] -0.14 [-0.31, 0.03] -0.21* [-0.38, -0.03]	[-0.08, 0.26] -0.20* [-0.37, -0.03] -0.26** [-0.43, -0.09] 0.03 [-0.16, 0.22] 0.31** [0.11, 0.50] 0.079**	[-0.10, 0.25] -0.20* [-0.37, -0.03] -0.29** [-0.47, -0.12] 0.04 [-0.15, 0.23] 0.32** [0.12, 0.51] 0.13 [-0.05, 0.30] 0.015

*p<.05; **p<.01; ***p<.001

Models of community participation outcomes

When examining levels of child's **frequency** in community activities, the overall model at the last block was significant (F=15.88, p<0.001, R²=0.443), where income and environment supports were the only two significant variables to explain its variance. Specifically, levels of income accounted for 41.4% (p<.001) of the variance, while environment supports had a negligible and insignificant addition contribution of 2.7% (p>.05) to the variance. Child's factors (i.e., age and number of functional issues), community barriers and mother

participation did not have any significant contribution to the explained variance of participation frequency. Based on the beta coefficients, income (β =-0.63, 95%CI [-0.77, -0.49]) had a stronger and negative effect on child's participation in the community setting in comparisons to environmental support (β =0.18, 95%CI [0.03, 0.33]), and they together significantly explained 44.3% (p<.001) of the overall variance in the presence of other variables in the block 4. Specifically, community participation frequency score increased by 0.63 units as a result of one unit decrease in income level, whereas increased by 0.18 units as a result of one unit increase in environment support.

When examining child's levels of **involvement** in community-based activities, the last block was significant (F=2.87, p=0.012, R^2 =0.125). Income served as the only significant contributor, which uniquely explained 8.7% (p<.01) of the variance. The beta coefficient (0.30, 95% CI [0.13, 0.46]) of the income was positive indicated that increase in the income level could positively predict increase in mean score of participation involvement in community when accounting for other variables.

Results of the model for explaining **desire for change** in the community setting indicated that all the included variables in the last block explained a negligible non-significant percent of the variance (F=0.46, p=0.84, R^2 =0.022).

In summary, in the community setting, modeling the outcome of participation frequency had the highest explained variance (44.3%). Family income significantly explained child's participation frequency and involvement (but did not explain desire for change) in the community where the effect of income was more pronounced in the <u>frequency</u> model. Interestingly, family income has a negative effect on participation frequency and a positive effect on participation involvement.

Outcome	Block	Predictor	β Block1	β Block2	β Block3	β Block4
Frequency	1	Income	-0.64***	-0.64***	-0.64***	-0.63***
			[-0.78, -0.51]	[-0.78, -0.51]	[-0.78, -0.50]	[-0.77, -0.49]
	2	Functional issue		-0.00	-0.00	-0.00
				[-0.14, 0.14]	[-0.14, 0.13]	[-0.14, 0.13]
		Child age		0.02	0.03	0.04
				[-0.12, 0.16]	[-0.10, 0.17]	[-0.10, 0.18]

Table 14 Multiple regression analyses for participation outcomes in the community

	3	Environment support			0.17*	0.18*
					[0.02, 0.32]	[0.03, 0.33]
		Environment barrier			0.01	0.01
					[-0.14, 0.16]	[-0.14, 0.16]
	4	Mother participation				-0.04
						[-0.18, 0.11]
ΔR^2			0.414***	0.00	0.027	0.001
R^2			0.414***	0.415***	0.442***	0.443***
Involvement	1	Income	0.30**	0.29**	0.28**	0.29**
			[0.13, 0.46]	[0.12, 0.46]	[0.10, 0.45]	[0.11, 0.46]
	2	Functional issue		-0.03	-0.04	-0.04
				[-0.20, 0.14]	[-0.21, 0.13]	[-0.21, 0.13]
		Child age		-0.11	-0.12	-0.10
				[-0.28, 0.06]	[-0.29, 0.05]	[-0.28, 0.08]
	3	Environment support			-0.10	-0.08
					[-0.29, 0.08]	[-0.27, 0.11]
		Environment barrier			0.07	0.07
					[-0.12, 0.25]	[-0.12, 0.25]
	4	Mother participation				-0.08
						[-0.26, 0.11]
ΔR^2			0.087**	0.013	0.020	0.005
R^2			0.087**	0.100**	0.120**	0.125*
Desire	1		0.14	0.12	0.12	0.12
change	1	Income	-0.14	-0.13	-0.13	-0.13
			[-0.31, 0.04]	[-0.31, 0.05]	[-0.32, 0.05]	[-0.32, 0.05]
	2	Functional issue		0.04	0.04	0.04
				[-0.14, 0.22]	[-0.14, 0.22]	[-0.14, 0.22]
		Child age		0.03	0.02	0.02
				[-0.15, 0.20]	[-0.15, 0.20]	[-0.17, 0.21]
	3	Environment support			-0.04	-0.04
					[-0.23, 0.16]	[-0.24, 0.16]
		Environment barrier			0.00	0.00
					[-0.19, 0.20]	[-0.20, 0.20]
	4	Mother participation				0.01
						[-0.18, 0.20]
ΔR^2			0.018	0.003	0.001	0.000
R^2			0.018	0.021	0.022	0.022

*p<.05; **p<.01; ***p<.001

CHAPTER IV | DISCUSSION

This study revealed the participation patterns of school-aged children with ASD in the home and community settings during the COVID-19 pandemic period. The findings of the study describe the unique and significant contribution of multiple factors on child's participation, including family factors (mother participation and income), child factors (age and number of functional issues), and environment factors (supports and barriers).

PARTICIPATION PATTERNS

The data collection phase of this study took place during the period of the COVID-19 pandemic (Dec 2020 to May 2021). As a result of the pandemic, children and their families had to endure strict social restrictions, and these interruptions to daily routines could have affected children with ASD in many ways (Narzisi, 2020); and thus, can serve as one of the explanations of our findings.

Descriptive results of the present study reveal a relatively higher level of participation outcomes in home-based activities (e.g., more frequent and a greater number of activities actually done). The average participation frequency of children at home in our study was more than 'once a week' but less than 'few times a week', which showed a similar result to a recent study among a similar population (Ambrose et al., 2021). Specifically, for home-based activities, watching TV/videos/DVDs and personal care management were the ones children most frequently participated in, and the most common activities child never participated at home were socializing using technology and indoor play. Similar findings have been reported in a recent study (Kaya Kara et al., 2021) comparing participation at home before and during the pandemic, which indicated that school-aged children with attention-deficit/hyperactivity disorder were participating more frequently in specific home-related activities (e.g., computer and video games, getting together with other people at home and household chores) during the COVID-19 pandemic, but were participating less in socializing using technology and school preparation. A study in Turkey (Esentürk, 2020) investigating the impact of COVID-19 on physical activity of children with ASD also highlighted several themes to consider during the pandemic (e.g., insufficient distance towards education infrastructure). Further studies in different nations (e.g., Canada) asking parents of children with ASD to

reflect on their child's participation during the pandemic in comparison to their current participation are needed.

Average child participation frequency in the community was less than 'few times a month'. This finding is not surprising and is consistent with previous research, which states that children with ASD or any other disabilities prefer home-based activities and have higher participation levels than in the community setting regardless of pandemic (Bedell et al., 2011; Hilton et al., 2008; Khalifa et al., 2020; Potvin et al., 2013; Tonkin et al., 2014). At the same time, the pandemic may have intensified these patterns as families needed to spend more time at home and there were additional obstacles brought on by COVID-19 to engage routinely in outdoor activities. Interestingly, among all the activities in the community, religious activities were the ones children most frequently participated in (followed by neighborhood outings), which is inconsistent with previous research among children with ASD, where unstructured physical activities were the most frequent ones (Mattinson et al., 2018; Simpson et al., 2018). This could be explained by the fact that most of the community outdoor activities were restricted during the pandemic, but religious gatherings may have been an exception.

In our study, children were more involved in computer/video games and watching TV compared to other activities at home, which is also consistent with previous studies (Egilson et al., 2018; Mattinson et al., 2018). Overall, we found that level of involvement (about somewhat involved) was similar across each activity in both home and community settings. This may indicate that the setting may not play a role in children's involvement level in activities actually done during the pandemic.

Moreover, on average 71% of the total activities in either home or community were desired to change by their parents, which implies that mothers were not very satisfied with their child's participation patterns either at home or in community. Indeed, mothers wanted to see change in 7/10 activities which is a relatively higher rate considering previous studies using same measurement scale (Kaya Kara et al., 2021; Marino et al., 2018; Simpson et al., 2018), and implies a participation pattern that is far from being 'optimal' or 'ideal' (even though children participated in activities fairly often). This finding is worth further investigating by combining, for instance, an individual interview with mothers to reflect on the PEM-CY results of their child. Specifically, we found that most mothers wished their children to change their personal

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care management at home. It is plausible that because of the pandemic many of the family routines have been disrupted including personal care, where for instance morning preparation and getting ready for school were not always carried out as usual and overall rhythm or structure of the day was interrupted (Cachón-Zagalaz et al., 2021; Vuković et al., 2021). For community setting, over 80% of the mothers wanted changes in their child's participation in neighborhood outings, community events, organized physical activities, and getting together with their peers in the community, indicating a strong need for those families to engage in outdoor organized programs and let their children have more opportunities to be part of community life. Besides, it is notable that since all these indicated activities are social in nature (and socializing with others was the most common issue in our sample), it would also be challenging for children with ASD to participate in a desired or 'optimal' way. It is plausible that the pandemic has imposed another layer of complexity involving limited opportunities for socializing– an area which is important for the development and thriving of this population (Rao et al., 2008; Williams White et al., 2007).

Overall, the present study found similar numbers of environmental items perceived as supports or barriers at the home and community settings. When looking at the environmental barriers and supports at home, we found that availability of time and money were the most common resources (reported by almost half of the families), which may suggest that parents had enough time to support their child's participation at home during the pandemic, as mothers were more present at home. In addition, attitudes/ actions of others who care for their child at home were the most common barriers perceived by the mothers, followed by availability of information (about activities, services, programs). Access to information, especially during times of crisis (but not only), is essential and can be facilitated by connecting families to parents' groups, local disability advocacy group as well as community organization to consult on activities that can be done in a safely manner. The importance of attitudes of others towards child participation and inclusion was also highlighted in several studies (Anaby et al., 2013; Krieger et al., 2018; Orsmond et al., 2004). Thus, effective intervention strategies to reducing these barriers are needed. For example, by providing education to individuals who work with these families and sharing relevant information with families especially during the lockdown.

When looking at the environmental barriers and supports in the **community**, access to personal transportation (car, bicycle) was mostly perceived as the environmental support to participation, allowing families to avoid public transportation and, consequently, reduce risk of virus transmission (Tirachini & Cats, 2020). The most common barriers for community participation in our study was lack of equipment or supplies such as sports equipment or assistive devices for those children during the pandemic. This is consistent with previous research showing that parents of children with ASD often have limited provision of resources (Egilson et al., 2017).

THE IMPACT OF CHILD, FAMILY AND ENVIRONMENT FACTORS

Our study's hypotheses were partially confirmed particularly when modeling outcomes at the **home** setting. Mother participation, an innovative factor in our study, had a unique contribution in explaining two out of the three participation outcomes, i.e., frequency involvement. The involvement model explained the highest level of the variance, i.e., 21%, and the effect of mother participation in this model was more pronounced. These findings also highlight the importance of the outcome of involvement when explaining participation patterns. In the **community**, results were somewhat unexpected. Income consistently explained both participation frequency and involvement and has explained the highest level of the variance in the frequency model, i.e., 44%. The section below discusses these findings in further details.

The effects of mother participation

The frequency of mother's participation in each health-promoting activity was 'above 2-3 times a month' to 'once a week', while the most frequent activity mothers engaged in was 'inactive leisure activities alone' (e.g., reading, baking, computer use, listening to music). This may be explained by the employment status of the mothers included in our study where most of them had either a part-time or full-time job. Indeed, previous studies have identified lack of time as one of important barriers that contribute to physical inactivity of parents of children with ASD (Haegele et al., 2017; Kim et al., 2018). In addition, the t-test result

indicated that mothers of older children (aged 9-12) and those raising a child with one single health condition only (i.e., ASD) had significant higher levels of participation. This is not surprising because older children or children with fewer health conditions are often more independent and thus their mothers can have more time for themselves, to meet their own needs. It is also important to acknowledge the COVID-19-related psychological distress of female caregivers of autistic individuals (Friesen et al., 2021), which could change their coping strategies and behavior patterns in different activities.

The correlation results of our study suggested that mother participation has more impact on the participation of younger children and is more likely to be associated with child participation in home-based activities. This may be because younger children usually rely more on their parents for participation and readily follow and adopt their parents' habits (Milward et al., 2018; Sutherland et al., 2008). When entered into the regression model of the home setting, mother participation has a more pronounced effect on child's involvement and has a relatively lower effect on child's frequency. It is plausible that mothers who lead a healthy and balanced lifestyle are aware of the importance of the subjective experience derived from chosen activities. As such, they encourage their children to also engage in activities that are meaningful, enjoyable and align well with their interests. Such an approach can increase children's involvement in selected activities (rather than the amount or frequency of activities). This finding lends further support to the differences between these two participation dimensions: frequency and involvement, discussed extensively in the previous literature (Imms et al., 2016). Such findings highlight the importance of 'being in the moment' and fully focused, emotionally engaged and immersed in an activity- a critical element for children participation especially for those with ASD (Askari et al., 2015; Coster & Khetani, 2008).

Since mother participation is more amenable to change as opposed to other factors (i.e., child's age or at times severity of condition), it could be improved through appropriate intervention and, therefore, require further attention in clinical practice. Similarly, a recent study (Bjornstad et al., 2021) highlights the need to redirect our attention to interventions that promote the healthy behaviors of parent caregivers. The positive association between mother's own participation and their child's participation is congruent with previous studies

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that focused on preschool-aged children with various disabilities (mean age under 5 years old) (Williams et al., 2019) and those with ASD (Bar et al., 2016). Our findings further confirm this positive impact on child's participation as well as extending it to school-aged children with ASD. The reason why mother participation has no significant effect on children's participation in community-based activities in our study might be because community participation has always been more complex and harder to control in 'normal times' and in times of a pandemic, it become even more complex. However, this assumption merits further studies.

This is the first study to explore the impact of mother's own participation in the presence of other factors (known to influence participation) on the participation of school-aged children with ASD in both home and community settings. As such, it highlights several main key findings: First, mother participation could significantly explain child participation frequency and involvement at home, with a more pronounced impact on child's involvement level. Specifically, the more frequent mothers participate in leisure activities that promote their own health and wellbeing, the more involved their children are during participation in home-based activities. However, mothers' participation did not play a significant role in explaining the number of activities to which change was desired at home and could not explain any of the participation outcomes in the community. Second, based on correlations examined across groups, we found that at home, mother participation had a moderate to strong impact on child's participation for younger children ages 6 to 9; those with less functional issues; or in families with lower income. In the community, mother participation has more pronounced impacts on child's participation for children with ASD as a one single health condition. But if a child had more health conditions, mother participation had a greater impact for home-based activities. Third, mothers of older-aged children or of children who have one single condition of ASD, had a higher frequency level of their own participation.

Overall, the potential of mother participation in promoting children's participation clearly requires further investigation.

The effects of income (before tax)

The annual income level of the family was proved to be a strong and significant contributing factor for explaining child participation in the community-based activities; however, its effects on frequency and involvement were in the opposite directions. Specifically, a higher level of income was associated with increased level of involvement but decreased level of frequency in the community participation. The negative association between income and community participation frequency is in contrast with previous studies which indicated higher income provides more opportunities and could lead to greater frequency of activities across different settings (Anaby et al., 2014; Krieger et al., 2018; Myers et al., 2015). There are several potential reasons why income in our study showed these unexpected results. Firstly, the Pearson correlation in our study indicated a significant and positive association between income level and the impact of the pandemic, which means that families with higher income levels reported more effects on their children's participation because of the pandemic. Secondly, it could also be because the fact that family in our study came from different locations (provinces) where restriction and public health regulation varied. As 26% of the participants were from the US, we further compared (using t-test) the difference in outcomes between the Canadian sub-sample and the sub-American sample. We found that the US sub-sample participated more frequently (mean difference 1.44, p<.01) and in greater diversity of activities (mean difference 2.6, p<.01) in the community setting, whereas Canadian sample had a higher frequency (mean difference 0.34, p<.05) and involvement level (mean difference 0.44, p<.01) at home. This significant difference may perhaps be due to the different policies between the countries during the data collection period. For example, the US may not have the same strict rules of lockdowns and a limited number of people for social gatherings as in Canada. Thirdly, this unexpected direction of the correlation may be also related to the distribution of income levels in our study since almost 60% of participants report their annual family income below \$39,999. Moreover, there were a great number of families (82.3%) who lived in a region with a population of more than 20,000 people while only three families in our study lived in the rural area. Lastly, evidence shows that higher-income families can still experience economic disadvantage through uncontrolled consumption or poor distribution of resources (Treanor, 2016), thus income in

isolation may not be an effective indicator of economic disadvantage (Arakelyan et al., 2019).

The reason for a positive impact of income on community involvement level may have been because a higher family income could help to connect with others and provide flexibility in the activities, as suggested by Krieger et al (2018), and higher income could also predict higher levels of cognitive stimulation in child growth, which further foster child intrinsic motivation, as suggested by Dearing et al (2009). Our t-test result also shows significant higher score of community involvement level (t=-3.33, p=0.001) in the group with higher income level (>\$40,000). This finding is consistent with a study focusing on adolescents with ASD which indicated that children from families in lower income were less likely to be involved in any extracurricular activities (Shattuck et al., 2011). The different magnitude and direction of the impact between frequency and involvement also further supports that they are two distinct dimensions of participation.

The effects of environment

Children with ASD were typically restricted by environmental barriers and the global pandemic could make the situation even worse (Patel, 2020). The findings in our study showed that the higher the number of environmental barriers at home, the greater the number of activities mothers wanted to change at home. This finding emphasizes the importance of the environment to child's participation at home and coincides with previous research (Marino et al., 2018). Recent study also indicated that a supportive housing environment has always been described as inadequate in terms of its capacity to meet the needs and its flexibility to suit the preferences of individuals with ASD (Weiss et al., 2021). Thus, reducing the barriers in the home setting is needed to improve children's participation at home. Interestingly, our findings indicated that environment features did not explain levels of frequency and involvement. This may be explained by the new reality that families faced during the pandemic where they had to stay at home regardless if the home environment is supportive or not. Further studies, qualitative in nature, can verify this assumption.

Our finding also highlights the importance of a supportive community environment on child's participation since it was found to be a significant factor in explaining community participation frequency although the impact was small. Especially during times of crisis, creating new social opportunities for participation that are informal or unstructured is necessary to provide valuable outcomes (Anaby et al., 2021). However, this positive prediction on child attendance or frequency was inconsistent with a recent study, which indicated community supportiveness could only predict child involvement but not attendance(Devenish et al., 2020). Nevertheless, during the pandemic environment barriers and supports may have played a smaller role than usual given the restrictions. Concurrently, Anaby et al (2021) were able to show that removing environmental barriers (using the PREP approach-*Pathways and Resources for Engagement and Participation*) during the pandemic is challenging yet variable. It required creative solution-based strategies from the therapists, the parents and other stakeholders involved. Indeed, environmental features are modifiable factors and should be further integrated in clinical practice supporting parents and their children in improving and sustaining level of participation especially in adverse times.

The effects of child factors

Our study found that child's age and the number of functional issues were two significant child factors in explaining the level of participation at home (with a stronger impact of child age). However, these factors had no significant contribution for explaining any participation outcomes of community-based activities. Specifically, the older the child, the higher the involvement level and the lower number of activities mothers wanted to see change. This may be because older children become less dependent on their parents to schedule activities and are more aware of their preferences and choices. Our t-test results also reported significant group differences in the home involvement level (t=-3.12, p=0.002) between different age groups, with the older age group having a higher score.

With respect to the number of functional issues, surprisingly, this factor had no significant correlation with any participation outcomes, and its negative coefficient in the home model (β =-0.2) indicated that participation of child with more functional issues was perceived by their parents as more satisfying (lower number of activities change was desired). This could be explained by the fact that the checklist used (a list of functional issues) might

not have been sensitive enough to capture the severity of a child with ASD. Other more rigorous assessments pertaining specifically for children with ASD, such as the Autism Classification System of Functioning: Social communication (ACSF:SC) (Di Rezze et al., 2016) are recommended in future studies. Further investigation is needed to explore this unexpected direction.

The number of health conditions of the child was another child factor we assessed but was not put into the regression model due to its small variance (ordinal 3-levels variable). However, we found that it actually influenced the association between other factors and participation outcomes, based on the correlation result test across groups. For example, a child with more functional issues would less frequently participate and attend less number of activities at home if they only have ASD as their health condition. The statistical influence of this child factor could be further tested in a future study by using a more rigorous measurement scale.

MODELS EXPLAINING THE PARTICIPATION OUTCOMES

Multiple linear regressions where explanatory variables were entered in blocks allowed for previously identified factors impacting participation to be explored. However, few significant contributing factors were observed within each mode, and none of the factors could explain variance in desire for change in community activities (secondary hypothesis). Moreover, the impact of some factors which we anticipated to be positive (based on the previous literature) appeared to be negative in our study (e.g., income, functional issues).

The frequency model explained a higher variance in the community setting ($R^2=44.1\%$) and explained lower percentage of the variance in the home setting ($R^2=7.6\%$). Although the model was significant, this amount of the variance of home frequency was also lower compared with previous studies (Ambrose et al., 2021; Williams et al., 2019). In the home frequency model, mother participation was the only factor that significantly contributed to explaining its variance in the presence of others. This may remind us that factors included in our study only provided a limited view of the home participation frequency; there are more explanatory variables associated with the pandemic that could further contribute to predicting

child participation patterns, such as parents being anxious and concerned about their child's health (Esentürk, 2020).

As aforementioned, involvement is an important concept to understand child's preference in activities they would like to be actively engaged in. It is a unique dimension of participation compared with frequency especially for children with ASD (Coster & Khetani, 2008; Coster et al., 2013). Therefore, involvement level, as a distinct dimension, was modeled in our study in order to estimate the "quality" of participation, providing a deeper view of the child's participation pattern. The amount of variance accounted for in the final model of community involvement was low (12.5%) compared previous study (Ambrose et al., 2021; Marino et al., 2018), where income was the unique and significant predictor in the model over the others.

Parents' desire to change was rarely investigated in the previous studies regarding children with ASD. However, our study found that combinations of the explanatory variables did not explain a significant degree of its variance in community and the amount was very small ($R^2=2\%$, p>.0.5). On the other hand, in the home model, greater variance of 'desire for change' was explained ($R^2=17.4\%$, p<.0.5). This participation outcome requires further investigation since it emphasizes parents' perspective about the specific activities they actually want to see change in and, therefore, can assist in goal setting and guide a tailored treatment plan for each family. New potential variables, especially those related to the pandemic, e.g., policies and public health guidelines, need to be investigated in order to better explain parents' desired change for their child's participation in the community.

Although participation is a human behavior that often results is relative lower R-square explained, we need to try our best to figure out the potential reason for the level of variance explained based on real-life circumstances. One way of doing this is paying attention to the potential moderation effect of a specific variable in the association between an explanatory variable and the outcomes. For example, mothers need to be more aware of the impact and importance of their own participation in health-related/leisure activities on their children's participation, especially when they have a younger age of child with ASD.
LIMITATIONS

This study has some limitations. This study was conducted during COVID-19 and employed a convenience sampling method involving children from different districts and, thus generalizability of the findings should be done with caution. First, the sample size of our study was estimated based on the literature before the pandemic, however, it did not allow us to further examine the interaction effects between factors or to apply a more advanced analysis to better explain our outcomes. Future studies with larger samples are thus needed. Second, given the fact that we were using an online survey to collect data and some of the participants were recruited through specific online network only, the diagnosis of ASD was reported by their parents rather than by a formal medical document. At the same time, recruitment was done via ASD-oriented organizations and, thus, we believe that the survey reached our targeted population. Third, annual income, self-reported via the survey questions, can be sensitive in nature and may not always be reported accurately by subjects. Fourth, participation patterns of fathers or other main caregivers were not considered in the current study. This was done to ensure feasibility and alleviate measurement burden. Further larger studies are needed to understand the effect of the participation of both parents/caregivers on child's participation. Finally, this study examined participation at the home and in the community settings excluding the school environment. This was done because we assumed that mother participation (one of our explanatory variables) may not have an effect on child's participation in school. It was also done to reduce measurement burden. Further studies however are needed to examine all participation domains and settings to gain a more comprehensive profile of child's participation.

CHAPTER V | CONCLUSION

SIGNIFICANCE

This study is one of the first studies to examine actual participation patterns and environment factors of school-aged children with ASD during the COVID-19 pandemic. Therefore, it enhances our understanding and provides unique insights on the participation patterns of this vulnerable population during adverse times.

Participation is an important outcome for children with ASD that can have a positive impact on their well-being and development. The findings of our study generated knowledge on the role of child, family, and environmental factors in explaining their participation patterns at home and in community activities. Specifically, our findings reveal that, for the first time, the impact of mother's own participation on the participation of school-aged children with ASD in the home setting and in the presence of other important factors. Indeed, findings highlight the unique positive contribution of mother's own participation on child participation. It emphasizes the role of mother's actual participation in leisure-oriented health-promoting activities in facilitating healthy habits or lifestyle of the entire family unit. It can also increase awareness of both clinicians and parents of the importance of promoting and maintaining health of mother caregivers.

Findings of this study enhanced our understanding of the impact of modifiable explanatory factors on the participation of school-aged children with ASD. Such knowledge can re-direct clinical attention towards the development of interventions targeting factors more amenable to change. This may include improving mother participation through intervention programs and/or adapting the environment to meet family needs. Such efforts can improve the participation level of this population, especially during challenging times, like the COVID-19 pandemic. Intervention programs, such as Pathways and Resources for Engagement and Participation (PREP), can be adjusted to facilitate participation of this vulnerable group during a pandemic.

Future research is needed to discover additional factors impacting the participation patterns of children with ASD, and consequently, to forge new pathways to improve their participation level during times of crisis and beyond.

CHAPTER VI | REFERENCES

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CHAPTER VI | APPENDICES

APPENDIX 1: ELABORATION OF THE COVID-19 EFFECTS

1) Restricted community activities: including "during the pandemic most of the in-person community activities were all online" "can't visit family members or have sleepovers" "the organized physical activities such as swimming lessons were all cancelled" "absence of holiday camps" "no cinema or other places of entertainment they can attend" "closures of adapted sport centers they need to go" "restrictions to go to the library, pool and indoor playground" "waitlist of out-school activities are even longer" "reduce the exposure to outside and not participating any activities" "restriction in exploring outside".

2) Social demands barriers: including "wasn't able to interact with peer" "lack of communication with others" "lose contact/connections with friends and classmates" "improper relational formation" "Relationship Bridge" "less independent".

3) **Cognitive demand barriers**: including "hard for a lively mood" "affect focus and attention ability" "afraid to everyone except family" "greater outbursts" "less active" "less interest in education" "doesn't like online activity and not ask for help when left behind".

4) Lack of supports: including "lack of support group" "lack of proper focus by others" "lack of electronic aided education" "lack of playing tools and time" "barriers in others attitudes".

5) **Financial issu**e: including "low source of income" "not able to get a tangible job and make money to cater for child's needs" "lost most of the income".