EXPLORING THE SOCIAL PARTICIPATION OF CHILDREN AND ADOLESCENTS WITH SEVERE DEVELOPMENTAL DISABILITIES

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ABSTRACT

The goal of this study was to examine the social participation of children and adolescents with severe Developmental Disabilities (DD). Those with Intellectual Disabilities (ID) and Autism Spectrum Disorder (ASD) were reported to participate in significantly fewer activities and much less frequently than typically developing peers. Those with ID and ASD were reported to have fewer friends and poorer quality of friendships. In addition, those with ASD participated even less frequently in some activities and had fewer friends.

In terms of barriers to participation for those with DD, reasons relating to the child and not allowed or invited were frequently reported. In contrast, lack of availability and logistical reasons were not reported as a prominent barrier. A combination of child, family, and community factors significantly accounted for 30% of the variance in participation. Specifically, child's Adaptive Behaviour, Parental Socialization, and Type of School Program attended predicted activity participation.

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Our concept of "disability" and the rights of individuals with disabilities has evolved from referring solely to characteristics of the individual to include his or her social participation. According to the World Health Organization (2013), disability includes participation restrictions, which are described as problems in involvement in a life situation. Given this broad definition, participation could include any activity outside the home and, for children, outside the school environment, such as playing on a sports team or attending social outings with friends. Additionally, The United Nations Convention on the Rights of People with Disabilities (United Nations, 2006) includes the right to full and effective participation and inclusion in society. With the evolution of these principles, research is also progressing to provide us with a better understanding of the social participation of individuals with disabilities; yet there are still several gaps in this research.

It is well accepted that participation in social and physical activities promotes physical, emotional, and social wellbeing for children with and without disabilities (e.g., Geisthardt, Brotherson, & Cook, 2002; Murphy & Carbone, 2008). Participation in various recreational and physical activities outside of the school is associated with increased cultural awareness and psychological wellbeing, and it encourages community relationships for individuals with disabilities (Murphy & Carbone, 2008). There is also growing evidence for the importance of activity participation for individuals with Developmental Disabilities (DD) in particular, including psychological benefits (i.e., increasing levels of confidence and self-esteem), and the development and generalization of various skills (Caldwell & Gilbert, 1990; Datillo & Schlein, 1994; Patterson & Pegg, 2009). For example, participation in a competitive physical activity, such as Special Olympics, has been linked to positive self-concepts (i.e., competence, social acceptance, and general self-worth) in a heterogeneous sample of children and adults with DD (Weiss, Diamond, Demark, & Lovald, 2003). In another example, Buttimer and Tierney (2005) found that participation in leisure and recreational activities predicts quality of life and promotes inclusion in the community for youth with mild to moderate DD.

Moreover, lack of sufficient opportunities to participate in activities may prevent exploration of various areas of development that typically occur through such participation (i.e., social, intellectual, emotional, communicative, and physical) (King, Law, King, Rosenbaum, Kertoy, & Young, 2003). Lower levels of participation in physical activities for children with disabilities has also been linked to poor health and social isolation (Rimmer, Rowland, & Yamaki, 2007).

Despite the benefits of social participation, individuals with DD are often excluded from taking part in social activities (Bigby, 2012). The results from a number of studies suggest that those with DD are less likely to participate in activities outside of the home or school. In comparison to Typically Developing (TD) peers, children and adolescents with DD participate in similar levels of leisure and unstructured activities; however, they participate significantly less often in physical, recreational and social activities (e.g., Ehrmann, Aeschleman, & Svanum, 1995; King, Shields, Imms, Black, & Ardern, 2013; Solish, Perry, & Minnes, 2010). However, further examination of this latter result indicates that individuals with DD engaged in leisure activities that took place at home and were more solitary and passive (Buttimer & Tierney, 2005; Orsmond, Krauss, & Seltzer, 2004). In a more recent study, King et al. (2013) found that children and youth with mild to moderate DD participated in fewer active-physical and skill-based activities but in more recreational activities, in comparison to TD children. The researchers suggest that the differences between the groups could be due to limited physical, cognitive, and social skills of the child, and/or to a lack of encouraging environments.

In addition to limited participation in activities, individuals with DD are known to have a restricted social network, one that consists mostly of family members and paid employees, such as staff members and service workers (Amado, Stancliffe, McCarron, & McCallion, 2013). Buttimer and Tierney (2005) reported that adolescent students with a mild DD participated in leisure activities that were solitary and that participation occurred more often alone or with family members or school friends. They also found low participation in activities at local clubs and/or societies, and reported that the students made no reference to friends outside of school. Similarly, Krauss, Seltzer, and Goodman (1992) found that familial relationships predominated in the support network of a sample of over 400 adults with DD, and 42% of participants were reported to have no friends outside of their family. In another study (Amado et al., 2013), the researchers found that, on average, the social network of an individual with DD consisted of 3.1 people, with one of those being a paid service provider. They also found that this group was more likely to be accompanied in social and leisure activities by a staff member.

It is important to note that the lack of participation and small social networks of individuals with DD do not reflect a lack of desire on their part to participate in activities with peers. There is growing evidence that those with DD do want to participate in more social activities and to have more friends (e.g., Cummins & Lau, 2003; Froese, Richardson, Romer, & Swank, 1999). For example, after interviewing 52 adolescents and adults with mild to moderate DD, Froese and colleagues (1999) found that 81% of participants wanted to have more friends, 65% wanted the opportunity to develop a ‘best friend’ relationship, and overall, they felt the need to meet more people.

Most of this research on activity participation has focused primarily on adults and higher functioning children with disabilities, often those with physical or medical disabilities (e.g., King et al., 2003; Law et al., 2006). In contrast, the present research focuses on the social participation of children and adolescents who are "low functioning" with severe or complex needs (behavioural challenges, mental health, physical health needs, etc.), whom I will refer to as children and adolescents “with severe Developmental Disabilities (DD)”. The term DD will be used as an umbrella term encompassing Intellectual Disability (ID) and other associated disabilities, including Autism Spectrum Disorder (ASD). ID will be used to describe individuals with limitations in intellectual and adaptive functioning that originates during the developmental period (APA, 2013). ID is often associated with other disabilities that can be cognitive and/or physical (e.g., Down syndrome, fragile X, fetal alcohol syndrome). ASD is a neurodevelopmental disorder characterized by impairments in social-communication and social interaction, and the presence of restricted, repetitive patterns of behaviours, interests, or activities (APA, 2013). Furthermore, many individuals with ASD also have a co-morbid diagnosis of an ID, including the children and youth with ASD in the present research.

Children and adolescents with severe DD are often excluded from this type of research because of their complexities and level of functioning. Therefore, the field would benefit from a comprehensive examination of activity participation for this group and the factors that contribute to this lack of participation as reported in the literature. This thesis includes two studies or objectives. The first objective was to examine, using parent survey data, the social participation (i.e., activity participation and friendships) of children and adolescents with severe DD, including a group with ID only and a group with co-morbid ASD, compared to a matched group of TD peers. The second Objective was to report on a more in depth examination of social participation in a subset of the sample, including the number and kinds of peers (DD or TD) the children and adolescents participate with, the barriers to participation, and factors that impact activity participation for this sample. Each study will be contextualized with a brief literature review, before describing the sample, methods of data collection and results. Each study has a Discussion section and the paper ends with an overall Conclusion section.

Objective 1. Examining the Social Participation of Children and Adolescents with ID and ASD in Relation to a TD Sample

Solish et al. (2010) examined three types of activity participation for TD children and those with ID and ASD. Their study set the stage for the present research; therefore, the methodology and results will be described in some detail. They describe *social* activities as those taking place informally with peers (e.g., going to the movies with friends), *recreational* activities as formally organized and structured activities, which may include team sports and lessons (e.g., playing on a soccer team or taking music lessons), and *leisure* activities as more passive activities (e.g., watching television). The authors reported on online survey data from parents about their children's participation in these three types of activities as well as children's friendships. The children, aged 5 to 17 years, included a TD group ($n = 90$), a group with ASD (with or without co-morbid ID; $n = 65$), and those with ID only ($n = 30$). Parents completed the Activities Questionnaire, which consisted of 11 items for social activities, 13 items for recreational activities, and 10 items for leisure activities. For each activity, parents were asked whether the child participated in the activity and they could choose up to three of eight options to indicate with whom their child participated: (1) alone, (2) parent, (3) other family member, (4) other adult, (5) paid worker, (6) volunteer, (7) peers without disabilities, and (8) peers with disabilities. Furthermore, there was a section to examine the quantity of friendships. For this section, parents reported the number of mutual peers that their child had.

Solish et al. (2010) found that the ID and ASD groups, in comparison to the TD group, participated in significantly fewer social and recreational activities. However, they found no significant differences between the children with ASD and ID for any of the activity groups. Furthermore, the TD children were reported to participate at a higher percentage in almost all social and recreational activities in relation to the other two groups. On the other hand, they found no differences for participation in leisure activities amongst the three groups of children.

A novel contribution of this study was to report on "with whom" the children participated in the activity. Results revealed that the ID and ASD group, in comparison to the TD group, participated in significantly fewer social and recreational activities with other peers and significantly *more* social activities with parents and other adults. For leisure activities, again they found no differences in terms of with whom children participated. The results seem to be a reflection of the lack of peer relationships amongst children with disabilities, since the TD sample were reported to have more friends and were more likely to have a best friend (Solish et al., 2010). Similarly, King and colleagues (2013) found that TD children participated in significantly more recreational, active-physical, and self-improvement activities alone, when compared to children with an ID. The findings could be the result of additional supports required by children with disabilities to participate in activities. However, it has also been noted that additional supports could inadvertently minimize the opportunity to promote social interaction and independence for certain type of activities (King et al., 2013).

Furthermore, the results from Solish et al. (2010) revealed that children with ASD participated in more leisure activities with adults than the other two groups (TD and ID only). The researchers suggest that the participation with adults in the ASD group could be due to the extra support needed to participate in activities; the need for adults to ensure the child's safety; and greater likelihood that children with ASD access services such as respite and in-home supports.

In terms of the number of friends, Solish and colleagues (2010) found that children with ID and ASD had significantly fewer friends than the TD group. They also found that children with ASD had fewer friends than those with ID only, which could mean that children with ASD are even less included amongst peers than those with ID only. However, these authors only explored quantity of friendships, and more research is needed with regards to quality of these friendships for all three groups of children.

It is clear that individuals with DD comprise a heterogeneous group, including those with ASD, ID, and other related disorders. However, most studies have combined all individuals into one group, without distinguishing between the types of DD. Although the study by Solish et al. (2010) included children with ASD and ID, the authors do not specify children's severity (in fact, they did not collect such data) and their group sizes were uneven (the ID only group was quite small). Further, the groups differed demographically, with the TD group having parents with higher levels of education. In addition, their ASD group was comprised of children with or without ID, which indicates great within-group variability. Also, when examining friendships, most studies (including Solish et al., 2010) report only on the quantity of friendships, and do not report on the quality of these relationships.

Therefore, the first objective of this study will be to report and compare the social participation as well as both quantity and quality of friendships in large, well matched groups of TD children and children with ID and ASD. Based on existing literature we hypothesized that, compared to their TD peers, those with ID and ASD will participate in significantly fewer activities. Furthermore, we hypothesized that those with ID and ASD will have significantly fewer friends and poorer quality of friendships, in comparison to their TD peers. In addition, based on the inherent difficulties individuals with ASD have in peer relationships, we predict that this group will be at the greatest disadvantage.

Method

The Great Outcomes for Kids Impacted by Severe Developmental Disabilities project (GO4KIDDS) was an Emerging Team grant funded by Canadian Institutes of Health Research (PI: Perry). GO4KIDDS includes a number of studies using different methodologies, including several different parent Surveys. The objective of the overall project was to provide a better understanding about the health, well-being, and social inclusion of school-aged children and youth with severe DD and the experiences of their families. Data collection for this study was approved by the Human Participants Review Committee at York University.

The data used for Objective 1 of the present study came from the GO4KIDDS Basic Survey (Perry & Weiss, 2008) completed by parents of children and adolescents with DD nationwide. Participants were recruited through approximately 500 agencies across the country, and through postings on websites and social media sites. Parents of TD children and adolescents completed a modified version of the survey called the GO4KIDDS TD Survey. Recruitment for the TD sample was done through an online survey platform, Qualtrics. In order to make valid comparisons among the groups, the parents who completed the TD survey were screened initially to ensure their child did not have any developmental diagnoses or disabilities. They were sampled in such a way as to be similar to the previously collected GO4KIDDS sample based on a set of demographic criteria (i.e., parent age, gender, education, and immigration status, and child age and gender).

First, the data were screened for the presence of outliers and missing data and distributions were examined. Next, the Basic Survey and the TD survey were combined into one dataset, which included a variable for diagnostic group (TD vs. ID vs. ASD).

Participants

A total of 418 parents of children and adolescents (3 to 19 years) completed the Basic Survey online or by paper and pencil. Based on caregiver report, 186 of the children and youth had ID and 232 had ASD. A subset of this survey was completed in French (11%) and the rest in English. In addition, 210 parents of TD children and adolescents (4 to 19 years) completed the TD Survey. Sample characteristics relating to the child, as reported by parents, are shown in Table 1 and those relating to the parent are shown in Table 2.

Table 1

Child Characteristics (N=628)

		TD (*n* =210)	ID (*n* = 186)	ASD (*n* = 232)
Age	*M (SD)*	10.65 (4.40)	11.58 (3.90)	11.02 (4.00)
Sex	% Boys	69.0	56.8	79.7

Table 2

Parent Characteristics (N=628)

		TD (*n* =210)	ID (*n* = 186)	ASD (*n* = 232)
Sex	% Mothers	100	88.5	90.0
Marital Status	% Married	81.4	77.3	72.1
Neighbourhood Income	*M(SD)*	$61, 350 (15, 821)	$63,031 (16, 973)	$61,613 (17, 159)

Measures

Child and Parent Demographic Measures. The surveys (see Appendix A) included brief questions regarding the child's age, diagnosis, and gender. In addition, there were brief questions regarding the parents' age, gender, relation to the child, and marital status, and the median income of the family's neighborhood was derived from the postal code.

Social participation. The surveys included a brief version of The Activities Questionnaire (Solish et al., 2010). Based on caregiver report, the questionnaire examines the frequency of participation of six types of activities rated on a 5-point Likert scale (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = very often). The items were: (1) Unstructured Play (e.g., friends coming over); (2) Social Outings (e.g., going to the mall, to the movies, out for meals); (3) Special Occasions (e.g., birthday parties); (4) Sports Team (e.g., hockey, soccer); (5) Lessons (e.g., swimming, gymnastics, skating, etc.); (6) Community Activities (e.g., Sunday school, cubs/brownies, etc.). In the current sample, the measure had high internal consistency ($\alpha = .80$). There was a seventh item included in the GO4KIDDS version relating to activities for those with special needs which is not included in the present study as it was not asked of the TD sample.

Caregivers were also asked to select the child's number of friends (none, one, two, etc. up to six or more) for different types of friends (school friends, other friends, and relatives). Friends were defined as "both children wanting to be friends and/or enjoying time/activities with other". For the analyses in this study, two types of friendships are reported: school friends and other friends. In addition, caregivers were asked to rate the quality of the friendships in comparison to other peers the same age on a 5-point scale (very poor to excellent). No psychometrics are available for these questions.

Results

Comparing Activity Participation across Diagnostic Groups (ID vs. ASD vs. TD)

First, the three groups were compared on potentially confounding variables (those shown in Table 1 and 2) using one-way ANOVAs and chi-squares. There were no differences among the groups in terms of child age, marital status, parent gender, or neighbourhood income. As a result, there was no need for any covariates in the subsequent analyses. However, there were a disproportionate number of boys in the ASD group, as expected given the gender profile of the diagnosis.

As shown in Table 3, one-way ANOVAs were used to examine whether there were any differences in the frequency of social participation, as reported by caregivers, among the three groups. The ANOVAs for all six activities were significant. In addition, post hoc analyses revealed that the TD group participated more often in each type of activity than the other two groups. For four out of the six activities, the ID and ASD groups did not differ from each other; however, for two of the activities (Special Occasions and Lessons), the ASD group participated significantly less often than the ID group. Furthermore, one-way ANOVAs were used to compare the total number of activities for the three groups. The TD group participated in significantly more activities than the ID and ASD groups ($F = 8.06, p < .001$). On average the TD group participated in five of the six activities, the ID group participated in 3.5 of six activities, and the ASD group participated in three of the six activities.

Table 3

Mean Frequency[*] of Participation Across Groups for Each Activity

	TD *M (SD)*	ID *M (SD)*	ASD *M (SD)*	*F*	*p*	Post Hoc
Unstructured Play	3.50 (1.10)	2.01 (.97)	1.88 (.96)	168.85	<.001	TD > ID = ASD
Social Outings	3.61 (1.03)	3.14 (1.13)	3.06 (1.11)	16.44	<.001	TD > ID = ASD
Special Occasions	3.42 (.98)	2.04 (.92)	1.80 (.96)	179.70	<.001	TD > ID > ASD
Sports	2.87 (1.42)	1.53 (1.03)	1.52 (.99)	93.73	<.001	TD > ID = ASD
Lessons	2.90 (1.33)	2.58 (1.40)	2.39 (1.34)	8.06	<.001	TD > ID >ASD
Community Activity	2.47 (1.42)	1.89 (1.26)	1.80 (1.25)	16.06	<.001	TD > ID = ASD

[*] Note: 1= Never; 2=Rarely; 3= Sometimes; 4=Often; 5=Very Often

Comparing Number of Friends across Diagnostic Groups (TD vs. ID vs. ASD)

Figure 1 shows the frequency of the number of "school friends" for each group, as reported by caregivers. The majority of the TD group had 6 or more school friends, while almost half of the ASD group and 20% of the ID group had no school friends at all. Figure 2 shows the frequency of the number of "other friends" for each group. The majority of the TD group had several other friends besides school friends, while the majority of both ID and ASD group had no other friends.

Figure 1

Number of School Friends

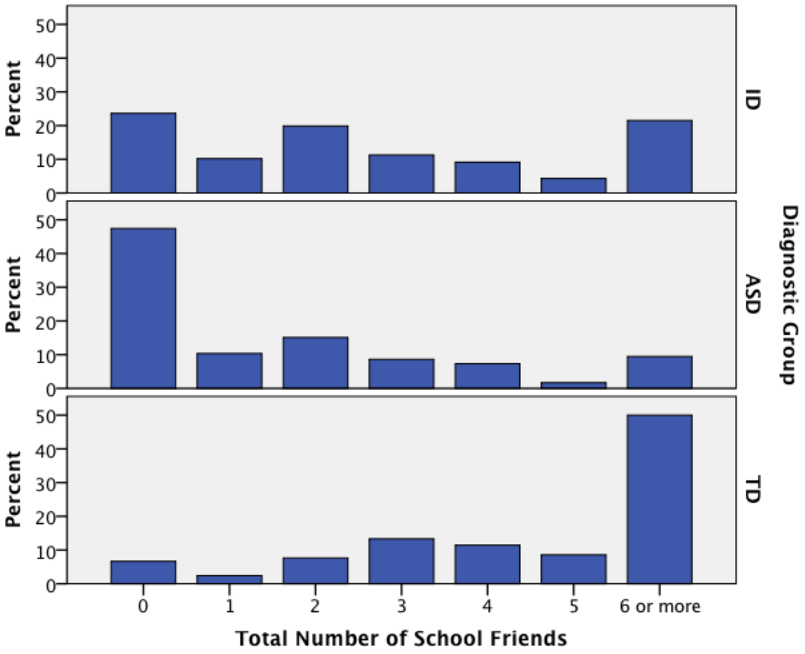
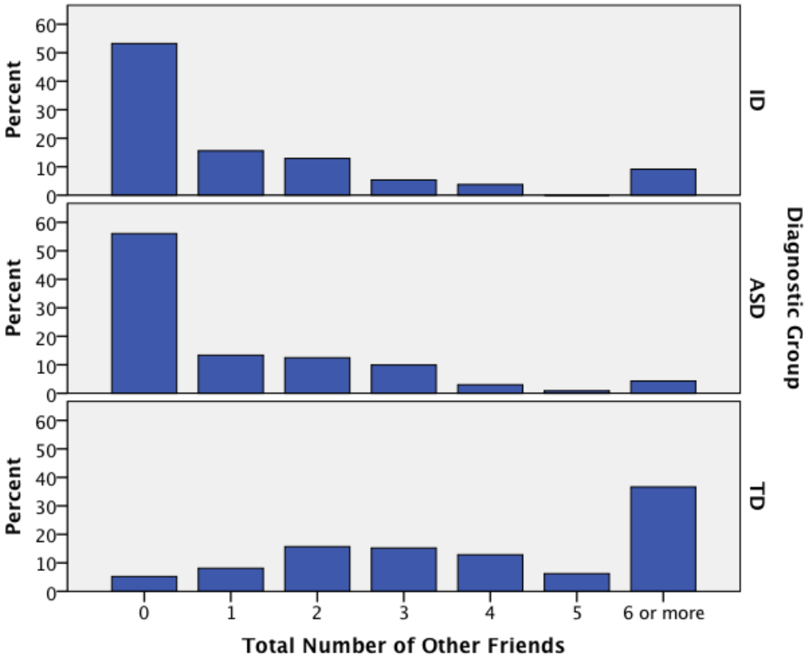


Figure 2

Number of Other Friends



Because so many individuals had no friends, the total number of friends was dichotomized into no friends or one or more friends, for both school and other types of friends. Ninety-five percent of the TD group had other friends, whereas 47% of those with ID and 44% of those with ASD had other friends. The pattern revealed was significant, Pearson Chi-Square (χ^2) = 145.67, $p < .001$ but there was no difference between the ID and ASD groups. Ninety-three percent of the TD group had school friends, whereas 76% of those with ID and 53% of those with ASD had school friends. The pattern revealed was significant, Pearson Chi-Square (χ^2) = 94.69, $p < .001$. In addition, further analysis revealed that a greater number of those in the ID group had one or more school friends than those in the ASD group ($\chi^2 = 25.04$, $p < .001$).

Comparing the Quality of Friendship for the Groups (TD vs. ID vs. ASD)

Figure 3 shows parent ratings of the quality of friendship for those children and adolescents who had one or more school and/or other friends. Those who had no friends were omitted from these analyses. The vast majority of the TD group had average to excellent quality of friendship, according to parents, while the majority of the ID and ASD group had very poor to average quality of friendship. The pattern was significant, Pearson Chi-Square (χ^2) = 216.73, $p < .001$.

For further statistical analysis, Table 4 shows the five categories of friendship quality collapsed into three categories (poor [1-2], average [3], and good [4-5]). Chi-squares revealed that the three groups differed significantly from one another ($\chi^2 = 291.85$, $p < .001$). Furthermore, the ID group and the ASD group differed marginally from one another in terms of quality of friendship, which was somewhat better in the ID group ($\chi^2 = 5.89$, $p = .052$).

Figure 3

Quality of Friendship

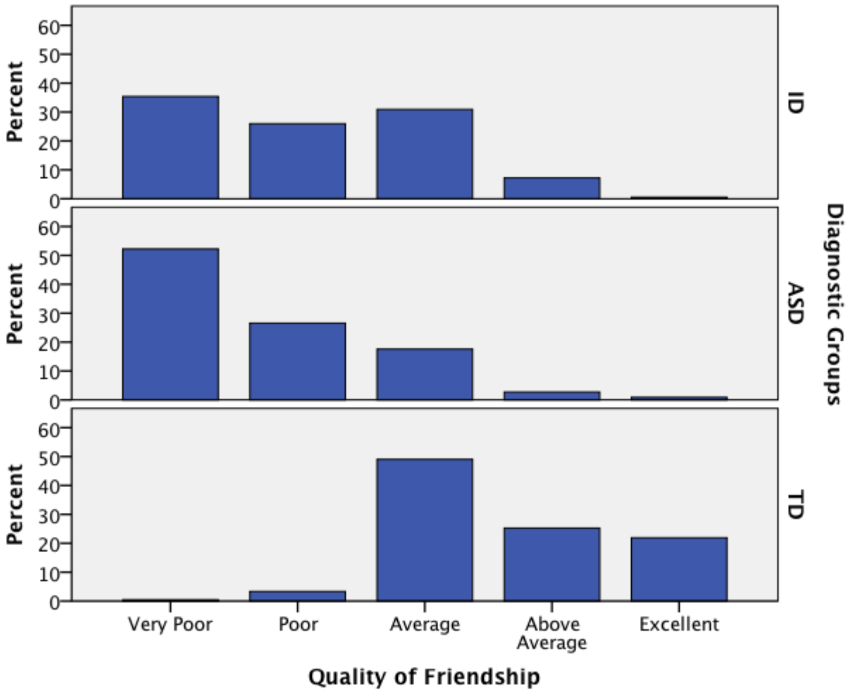


Table 4

Quality of Friendships (TD vs. ID vs. ASD)

	TD %	ID %	ASD %
Poor	3.8	61.3	78.8
Average	49.0	30.9	17.6
Good	47.1	7.7	3.6
Total (*N* = *613)*	181	222	210

Discussion

The purpose of the first objective of this study was to report on the social participation and friendship of three groups of children and adolescents. We compared the responses of caregivers with children with ID, ASD, and TD on a modified version of the Activities Questionnaire (Solish et al., 2010) found in GO4KIDDS Basic Survey. In addition, we examined the number, type, and quality of friends for each of the three groups.

Overall, those with ID and ASD in this study were reported to participate in fewer social activities than their TD peers. These findings, though unfortunate, were not surprising and were consistent with the existing literature that children with DD participate in fewer social activities (e.g., Badia et al., 2013; Solish et al., 2010). Children with DD have complex needs and limitations in various areas of adaptive functioning (e.g., poor motor, communication and social skills) and may exhibit maladaptive behaviours, which may lead to fewer opportunities to participate in various activities. In order to pursue these hypotheses, these child factors are examined as predictors of social participation in the second objective of this study.

The six social activities were individually compared for the three groups. Results showed that those with ID and ASD participated significantly less often in all six activities in comparison to their TD peers. Furthermore, those with ASD participated even less often than those with ID in special occasions with friends and in taking lessons. This particular finding is somewhat different from that of Solish et al. (2010). They found no difference between the children with ASD and ID in terms of social (i.e., special occasions with friends) and recreational (i.e., lessons) activities. However, it is difficult to compare the results since the categories were grouped differently in each study. For example, Solish et al. (2010) used a list of specific lessons, while we asked generally about any lessons the child might take. In addition, although the earlier study had a sample of children with ASD and ID, the authors do not specify children's severity. Our sample consisted of children and adolescents with severe DD and complex needs (e.g., physical disabilities or other medical conditions) and this group may be particularly disadvantaged in terms of social opportunities. In the second objective of the study, we examined this idea further by examining several specific child characteristics as well as other reasons for not participating for those with DD.

The TD group had substantially and significantly more friends than those with ID and ASD. In addition, those with ID had significantly more school friends than those with ASD. However, given that quality may be more important than quantity, unfortunately those with ID and especially ASD were reported to have very poor quality of friendships. These results are consistent with Solish et al. (2010), who reported that those with ID were more likely to have more friends and were more likely to have a best friend than those with ASD. This finding is not surprising given the nature of the ASD diagnosis. Social impairments are core deficits of the ASD, which make social interactions with peers more challenging and perhaps the meaning of friendship is different for persons with ASD. Furthermore, Solish et al. (2010) suggest that those with ASD have fewer opportunities to interact with peers and, even while participating in social activities, the presence of other adults is often required to support the child with ASD. This is especially likely in our sample of children and adolescents with severe levels of disability.

Children and youth with severe DD are often excluded from research due to their complex and challenging needs. The first objective of this study fills the gap in the literature about the social participation of these children and youth. Despite having similar desires as their

TD peers to participate in social activities (Cowart, Saylor, Dingle, & Mainor, 2004), the results from this study suggest that children and adolescents with DD participate much less in such activities. Shortage of opportunities to partake in activities could impact various areas of development, including social, intellectual, emotional, communicative and physical growth (King et al., 2003). In particular, such lack of opportunities is linked to the development of friendships (Geisthardt et al., 2002). Peer relationships provide sources of support and are linked to social growth and quality of life (Geisthard et al., 2002). Despite the benefits of participation in social activities and peer relationships, the results from this study suggest that those with DD are at a disadvantage. This is a particular area of concern for those with ASD, since they participated less frequently in activities and had fewer friends. The findings from this study indicate the importance of finding ways to encourage and provide opportunities for children and youth with DD to become more involved in social activities and build meaningful friendships.

This study had a number of strengths. The overall sample size for this study was large (*N* = 628), with roughly equal numbers of children and adolescents in each diagnostic group (TD = 210; ID = 186; ASD =232). In addition, the DD and TD sample were well matched on a number of variables (i.e., parent age, child age, province, immigration status, etc.), which allowed for comparisons to be made among the groups without fear of common confounding factors operating. The sample was quite diverse and inclusive. The survey was provided both online and by paper-and-pencil, and in English and French. This allowed for easy distribution across provinces in Canada and completion for those without access to a computer or Internet.

Although the study has a number of strengths, it is not without limitations. The data were based on caregiver report and precise information about various variables was not available. As with any online survey, the caregivers who completed the survey may not represent all of those with a child with DD. For example, parents who were less stressed, had more time, or felt that they are strong advocates for their child with DD, could have been more likely to complete this type of survey. Although the modified version of the Activities Questionnaire (Solish et al., 2010) had good psychometric properties, there is a lack consensus in the literature in terms of defining and measuring social participation. At best, frequency of participation in activities is a crude measure of a complex social process. Additionally, some of the variables used in the survey (e.g., quality of friendships) were not standardized measures and their psychometric properties are unknown. In addition, this study does not allow for examination of broader factors such as family factors and larger community factors that may influence children's social participation. Nor does it provide any explicit information about barriers to social participation to help us understand why children and adolescents with severe DD do not participate in social activities. Some of these limitations are addressed by Objective 2.

Objective 2. Exploring Factors that Impact Social Participation of Children and Adolescents with severe DD

There is ample evidence for the importance of activity participation. However, there is also the suggestion that children and adolescents with DD are at a disadvantage when it comes to participation. As mentioned earlier, it is well known that children with DD participate in significantly fewer activities outside of the home and school (e.g., Buttimer & Tierney, 2005; King et al., 2013; Solish et al., 2010), but reasons for this are less well understood. Therefore, it is important to consider the barriers and factors that may impact social participation, or lack of participation. To date, there remains a gap in the literature regarding the complex factors that may be involved in impacting the participation in various activities for this population.

Today, the term "disability" no longer solely focuses on the characteristics or impairments of individuals (i.e., diagnosis and skill level) but rather, emphasizes the social and environmental factors that contribute to the individuals' participation in society (Verdonschot, Witte, Reichrath, Buntinx, & Curfs, 2009). The Convention on the Rights of Persons with Disabilities (United Nations, 2006) draws attention to the social and environmental barriers that inhibit successful social participation for individuals with disabilities. Similarly, according to the Health and Activity Limitation Survey (Statistics Canada, 1995), the most commonly reported barriers for active participation for those with disabilities, were lack of physical ability, high costs, and proximity to facilities or programs. Thus, both individual factors (e.g., child's ability to participate in a given activity) and environmental factors (e.g., costs) likely influence people's participation in the community. Therefore, it is important for contextualizing the present study of those with DD to examine the literature in terms of child factors and environmental factors impacting participation more specifically.

Child Factors Impacting Social Participation

Age and Gender. Researchers have found differences in predictors of social activity as a function of age and gender (see King et al., 2009). A number of studies have found that participation decreases for individuals with physical disabilities as age increases (Maher, Williams, Olds, & Lane, 2007; Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010; Law et al., 2006). In terms of gender, girls with disabilities are found to participate in activities more frequently than boys with disabilities (Klaas et al., 2010; Law et al., 2006; Maher et al., 2007). However, the impact of gender depends on the type of activities, with girls more likely to participate in social and spontaneous activities and boys more likely to participate in physical activities (Bult Verschuren, Jongmans, Lindeman, & Ketelaar, 2011). It is important for the impact of age and gender to be simultaneously considered in the context of other important child and adolescent factors, such as functioning level, behavioural problems, and diagnosis.

Adaptive skills. The findings in the literature suggest that child characteristics can impact participation for various activities. In a comprehensive review of the literature (Bult et al., 2011), participation of individuals with disabilities was highly linked to gross motor function, manual ability, cognitive ability, communicative skills, age and gender. Similarly, LaVesser and Berg (2011) found that participation for preschoolers with ASD was related to child's behaviour and skills (i.e., toilet training, compliance, social skills, following directions, sensory difficulties, etc.). In another study of children with cerebral palsy, there was significant association between mobility, self-care, and domestic life skills with activity participation (Voorman & Dallmeijer, 2006). Similarly, greater social skills have been linked to participation in various activities for children with or without disabilities (Cowart et al., 2004). Based on these findings, there is a clear link between level of adaptive skills and activity participation.

Maladaptive behaviour. A diagnosis of DD is often accompanied by challenging behaviours (e.g., aggression) and comorbid psychopathologies (i.e., anxiety and depression) (Matson & Shoemaker, 2009). Individuals with DD who demonstrate problem behaviours are at greater risk of social exclusion (Bigby, 2012). The presence of these behaviours can reduce the number of friendships formed (Solish, Minnes, & Kupferschmidt, 2003) and the amount of time spent with peers (Geisthardt et al., 2002). Encouraging social inclusion for people with challenging behaviours may be beneficial in reducing levels of these behaviours (Bigby, 2012). However, the relationship between the level of maladaptive behaviours and social participation of those with severe DD is an area that has not been examined in the literature. Children and adolescents with more severe DD are likely to have both lower adaptive skill levels and higher rates of problem behaviour and thus may be especially disadvantaged in terms of social inclusion and participation.

Autism Spectrum Disorder. Impairments in social interaction (i.e., failure to develop peer relationships and lack of social or emotional reciprocity) are considered core diagnostic criteria for ASD (APA, 2013), and these deficits may be present with or without a co-morbid diagnosis of ID. Due to the described symptoms, those with the disorder are frequently referred to as "aloof" or "withdrawn", whereas those with other types of DDs (e.g., Down syndrome) are viewed as more friendly or sociable. As a result, it is sensible to assume that the presence of an ASD diagnosis could contribute to children's lack of participation in various activities. For example, LaVesser and Berg (2011) found that parents of preschoolers with ASD reported reasons relating to the child’s characteristics, as the main contributors to their children's lack of social participation. The authors report that this is an indication that the child has opportunities to participate but chooses not to. Therefore, the diagnosis of ASD is an important factor that could exacerbate social exclusion or lack of participation (refer to Objective 1); however, this topic has received surprisingly little empirical attention.

Family Factors Impacting Social Participation

Family demographic factors are known to influence children’s social participation. Based on a review of several studies, Bult et al. (2011) reported that non-Caucasian ethnicity of parents, lower parental education, lower parental physical functioning and higher levels of parental stress were linked to lower levels of participation for children with disabilities. Law et al. (2006) also reported that children with disabilities participated in fewer activities if families reported lower income, single-parent status, and lower parental education level. Additionally, it has been reported that caregivers of children with DD, in comparison to those with TD children, have lower SES (e.g., Emerson & Hatton, 2007; Leonard et al., 2005) and this may affect children's participation. For example, one study found that caregivers’ education and social class were related to participation in activities for children with Down syndrome (Sloper, Turner, Knussen, & Cunningham, 1990). Similarly, Mactavish, Stuart, and Tabourne (2010) found that patterns of family recreation varied depending on parents' income and employment status.

Family involvement and social support can also impact community participation and independence of children (King et al., 2003). For example, a family’s participation in leisure activities is linked to the level of child’s participation (King et al., 2006; King et al., 2009). Similarly, greater maternal participation in social and recreational activities has been reported to be a predictor of greater participation in social and recreational activities among adolescents and adults with ASD (Orsmond et al. 2004). However, more research is needed to examine the link between parental social participation and participation in social and recreational activities for children and adolescents with severe DD.

Parental mental health difficulties are linked to negative parenting styles, such as being emotionally unavailable or being less responsive to the child's needs (Goodman, Brogan, Lynch, & Fielding, 1993; Lovejoy, Graczyk, O'Hare, & Neuman, 2000). Furthermore, there is ample evidence in the literature linking parental mental health problems to negative child outcomes (Ruth, Wolfe, & Lyubchik, 2000; Rutter, 1966; Smith, 2003). For example, children of depressed mothers are known to have greater difficulties in social, behavioural, and academic domains (Ruth et al., 2000). Nolen-Hoeksema, Wolfson, Mumme, and Guskin (1995) found that children of depressed mothers were more likely to exhibit helpless behaviours during a puzzle task, and were less likely to problem-solve frustrating situations. With regards to social participation, there may be a link between parental mental health problems and deficits in children's social skills, as demonstrated by less active and exploratory play, and greater negative affect towards peers (Ruth et al., 2000).

Although a few studies have examined family variables related to social participation, more research is clearly needed in this area, especially for those with severe DD. Several factors common in clinical samples, especially in Canada, have not been studied in relation to the social participation of children and adolescents with severe DD. These include marital status, immigration status, number of siblings with DD, and parental mental health problems.

Community Factors Impacting Social Participation

Community factors that influence children's participation are related to services and supports available to families. For example, lack of transportation can hinder participation in leisure activities (King et al., 2003). In addition, Modell, Rider, and Menchetti (1997) found that children with moderate to severe DD who attended school in an integrated class, participated in significantly more recreational activities than those in special education classes. It seems reasonable to assume that there are more social opportunities with a class of TD peers versus a small number of DD peers, although this is more of an assumption than an empirical statement. Therefore, there may be a link between the type of educational placement and the social participation of children; however, this area needs further exploration, especially for the sample of children and adolescents with severe DD, who may be more likely to be placed in special education classes.

Barriers to participation in activities are often associated with difficulties obtaining access to facilities and programs (Buttimer & Tierney, 2005). Results from a study examining rural versus urban differences for children with special healthcare needs, showed that children living in rural areas were less likely to visit a pediatrician, and more likely to have unmet healthcare needs due to difficulties with transportation or unavailability of those services (Skinner & Slifkin, 2007). Similarly, it might be expected that children living in more rural and remote locations would have less access to community recreation programs, although again there is little actual evidence on this point.

Therefore, more research is needed to explore other important community factors (i.e., the size of the community and median income of the area) that may impact access to activities available for children and adolescents with severe DD.

Theoretical Models

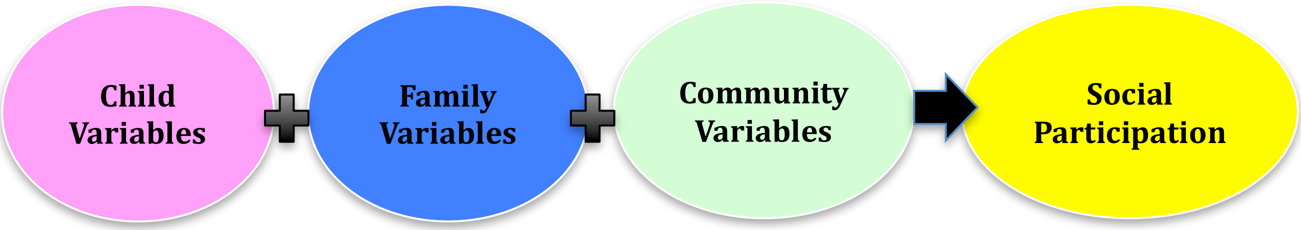
With so many potential factors involved in influencing social activity participation, it would be desirable to have a theoretical model to guide research. Across the literature, only one model, The Model of Factors Affecting the Participation of Children with Disabilities (King et al., 2003), examines the factors impacting the social participation of individuals with disabilities. This model adopts an ecological perspective (Bronfenbrenner, 1979) and addresses the relationship amongst the community environment, the family, and the child. It relates each factor at each level to the child's participation. It provides a strengths-based perspective, which focuses on the strengths of individuals and acknowledges the importance of supportive relationships and environments in creating positive outcomes for the child with a disability. The authors highlight five mediating factors of social participation: (1) absence of financial and time impact; (2) supportive home environment; (3) child's perception of his or her competence; (4) child's physical, cognitive, and communicative functioning; and (5) child's emotional, behavioural, and social functioning. This model is quite comprehensive and has much to recommend it.

However, there are some limitations to this model. The authors themselves acknowledge that it may not be applicable to children and families of various cultures. As a result, it is important to address the complexity of a multicultural population, such as our sample of Canadian parents. Therefore, the present study also explores family variables regarding country of birth and years living in Canada. Another limitation of King's model is the third mediating factor: child's self-perception of competence. This is especially hard to measure in our sample of children and adolescents with severe DD, since this group, by definition, have cognitive impairments, may be nonverbal, and have other complex issues. Therefore, this model developed for children with physical disabilities cannot be directly applied to our sample of interest.

There remains a gap in the literature about the factors that contribute to adequate participation of children and adolescents with severe DD. Therefore, the objective of this second part of the thesis was to investigate the different factors that impact social participation of this sample, including child variables, family variables and other community variables (See Figure 4).

Figure 4

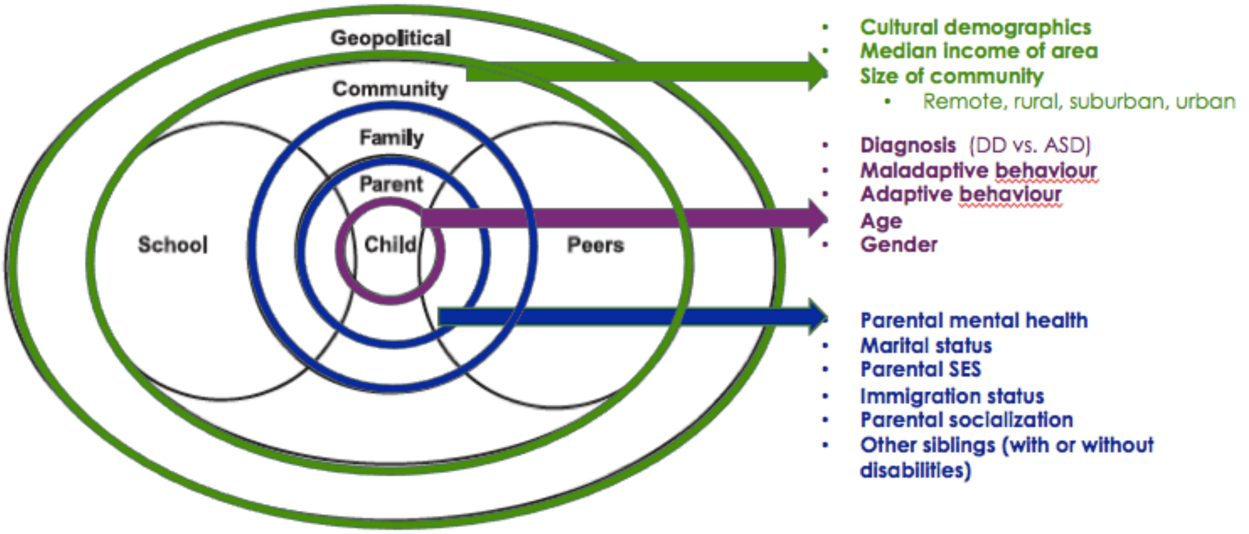
Factors Impacting Social Participation



Guided by the findings in the literature, it is important to examine the different factors that impact social participation with an ecological perspective, in which the individual interacts with various environmental systems, often portrayed as concentric circles. Therefore, the proposed study will be based on Bronfenbrenner's Ecological Model (Bronfenbrenner, 1979), which places the individual at the center of four systems: microsystem, mesosystem, exosystem, and macrosystem. Modified for this study, at the center of the model is the child with DD and the variables that relate to the child (i.e., level of adaptive and maladaptive behaviour, gender, and age, diagnosis of ASD). Then, we have family variables (i.e., parental mental health, marital status, number of siblings with DD, immigration status, SES, and parental socialization). The next layer involves the community in which individuals live (i.e., the size of the community, median income of neighbourhood, type of school placement and satisfaction with it) (See Figure 5).

Figure 5

Proposed Model of Factors Affecting the Participation of Children and Adolescents with Severe DD



Summary of Objective 2

The second objective of the study will be broken down into two parts. For the first part, I will report on the participation of children and adolescents with severe DD for seven types of activities. This will include a detailed account of the number of activities participated in, the frequency of participation, type of peers (DD or TD), and the reasons for *not* participating in each activity. The second part focuses on the predictors of activity participation at each level of the proposed model (child, family, and community factors). Based on the findings in the literature, we hypothesized that children's participation in activities will be impacted at each level of the proposed model. In terms of child factors, we hypothesized that an ASD diagnosis, older age, greater maladaptive behaviours, and lower adaptive skills, would predict lower participation in activities. In terms of family factors, we hypothesized that families reporting single-parent status, lower SES, recent immigration, infrequent parental socialization, parental mental health problems, and having other children with DD, would predict lower participation in activities. In terms of community factors, we hypothesized that living in remote and rural areas, attending self-contained special education classes, and parent dissatisfaction with the school placement, would predict lower participation in activities.

Method

The data used for this part of the study came from the GO4KIDDS Extended Survey, which was completed by a subset of about half the parents who had completed the Basic Survey used in Objective 1 (See Appendix B for detailed list of variables). This survey provides a more in-depth look at the social participation of children and adolescents with DD, including reasons why they did not participate in activities.

Participants

A total of 197 parents of children and adolescents with DD completed the Extended Survey online or by paper and pencil. Those who completed the Extended Survey received an honorarium of $50 for their time. The children reported on ranged from 3 to 19 years old and 58% have a diagnosis of ASD. See Table 9 for child and family characterstics.

Measures

Child Variables. The survey included questions about the age, gender, and diagnosis of the child. Child maladaptive and adaptive behaviour is based on the Scales of Independent Behavior-Revised Short Form (SIB-R Short Form; Bruiniks et al., 1996). The SIB-R Short Form consists of 40 items selected from 14 subscales of the SIB-R Full Scale. Each item was rated from 1 = *Never/Rarely* to 4 = *Does Very Well*. In the present study, we used only the first 35 items of the scale (with the permission of the publisher). In our sample, this scale of the measure had excellent internal consistency (α = .95). The Problem Behavior scale consists of eight behaviours (e.g., harmful to self, disruptive behaviour), which are rated based on frequency and severity. This scale had good internal consistency (α = .89) in our sample. In this study, the General Maladaptive Index (GMI) score is used, which combines all of the problem behaviours. The GMI scores can range from the most severe (-70) to the average range (-10 to +10).

Family Variables. The survey included questions regarding the caregiver and the family, which made it possible to operationalize family risk. First, caregivers were asked about their marital status; if separated, divorced, single or widowed, they obtained a risk score of 1. Second, they were asked about their immigration status; if they had been living in Canada for less than 10 years, they obtained a risk score of 1. Third, they reported on the number of other siblings in the family with disabilities; if they had another child(ren) with DD, they obtained a risk score of 1. Fourth, parental mental health, based on the Kessler 6- Item Psychological Distress Scale (K6; Kessler et al. 2003), was used to screen for serious mental illness; if they were in the clinical range on the Kessler 6, they obtained a risk score of 1. Finally, the scores on all the risk items were added to create a family risk variable, with scores ranging from 0 to 4, with higher scores indicating greater risk. Because of the skewed distribution of these scores, for statistical analysis, scores were then dichotomized. Those with scores greater than 2 were classified as being "at risk".

In addition the survey includes six questions regarding parental socialization (e.g., how often do you go out for dinner), rated on a 5-point scale ranging from a score of -2 (much less than other people) to +2 (much more than other people). These scores were averaged across the six questions for an overall parental socialization score. This scale had good internal consistency ($\alpha = .81$) in our sample.

Family's socioeconomic status was based on the Barratt Simplified Measure of Social Status (Barratt, 2012), which takes into account the respondents' education and occupation. Scores can be calculated for one- or two-parent households, and range from 8 to 66. Inter-rater reliability for this sample was reported as excellent, $r = .93$ (Shine, Perry, & Weiss, 2013).

Community Variables. One question was included in the survey regarding the size of the community the family lives in (i.e., remote, rural, suburban or urban). The median income of the neighborhood was determined based on the family's postal code (forward sortation index). In addition, the survey included one question regarding the type of school program that the child attends (i.e., self-contained special education classroom vs. integrated in regular class) and one question regarding parents' level of satisfaction with the child's education on a 5-point scale.

Social participation. The data on social participation were collected using a modified version of the Activities Questionnaire (Solish et al., 2010), inquiring about seven types of activities (similar to Objective 1 with the seventh item about special needs programs included).

There was a more specific set of response options than was used in Objective 1 on the 5-point scale ranging from: 1=*less than once a month* to 5=*every day*. In addition, if the parents had indicated that their child partakes in an activity, they were asked: how often, with whom, and who supports the child to do the activity. If their child did not participate in the activity, they were asked to indicate why not and given several options.

Prior to analysis, the data were screened and checked for the presence of outliers and missing data. Distributions were examined for all variables and internal consistencies computed.

Results

Frequency of Participation

Based on caregiver report, Table 5 shows the number of children and adolescents participating in each activity and, for those who do participate, the frequency with which they participate in each activity. For example, 65 (33%) of the children were reported to participate in Unstructured Play, and of those 65 children, participation took place less than once a month for 23%, once a month for 28%, once a week for 28%, twice a week for 17%, and every day for 5%. Of the seven activities, going to Social Outings (e.g., going to the mall) was the most frequently reported activity, with 77% of the children participating. Playing on a Sports team was the least frequent activity, with only 16% of the children participating. Of those who participated in each of the activities, very few participated in any of the activities daily and the majority of participating children were involved in the activities once per week or less.

Figure 6 presents the same data as Table 5 in a different way, showing the absolute percentage of children and adolescents participating at each level of frequency, alongside the percentage not participating. Using the same example as above, we saw that 33% participated in Unstructured Play, which means 67% of the children do not. As a fraction of the entire sample, participating in Unstructured Play took places less than once a month for 8%, once a month for 9%, once a week for 9%, twice a week for 6%, and every day for 2%. For all activities, the blue bar in Figure 6 representing lack of participation is the highest. A large majority of children were not reported to participate in Sports, followed by Community Activities, Unstructured Play, and Special Occasions. When examining the frequency of participation in this manner as a fraction of the entire sample rather than of the subset who were reported to participate, we can see that less than 10% participated in each of the activities more than once a week. Participation in Lessons and Community Activities tended to take place once per week when they did occur. Although more children participate in Social Outings than the other six activities, this participation reportedly took place less than once per week in most cases, with only approximately 20% reporting that it took place more often.

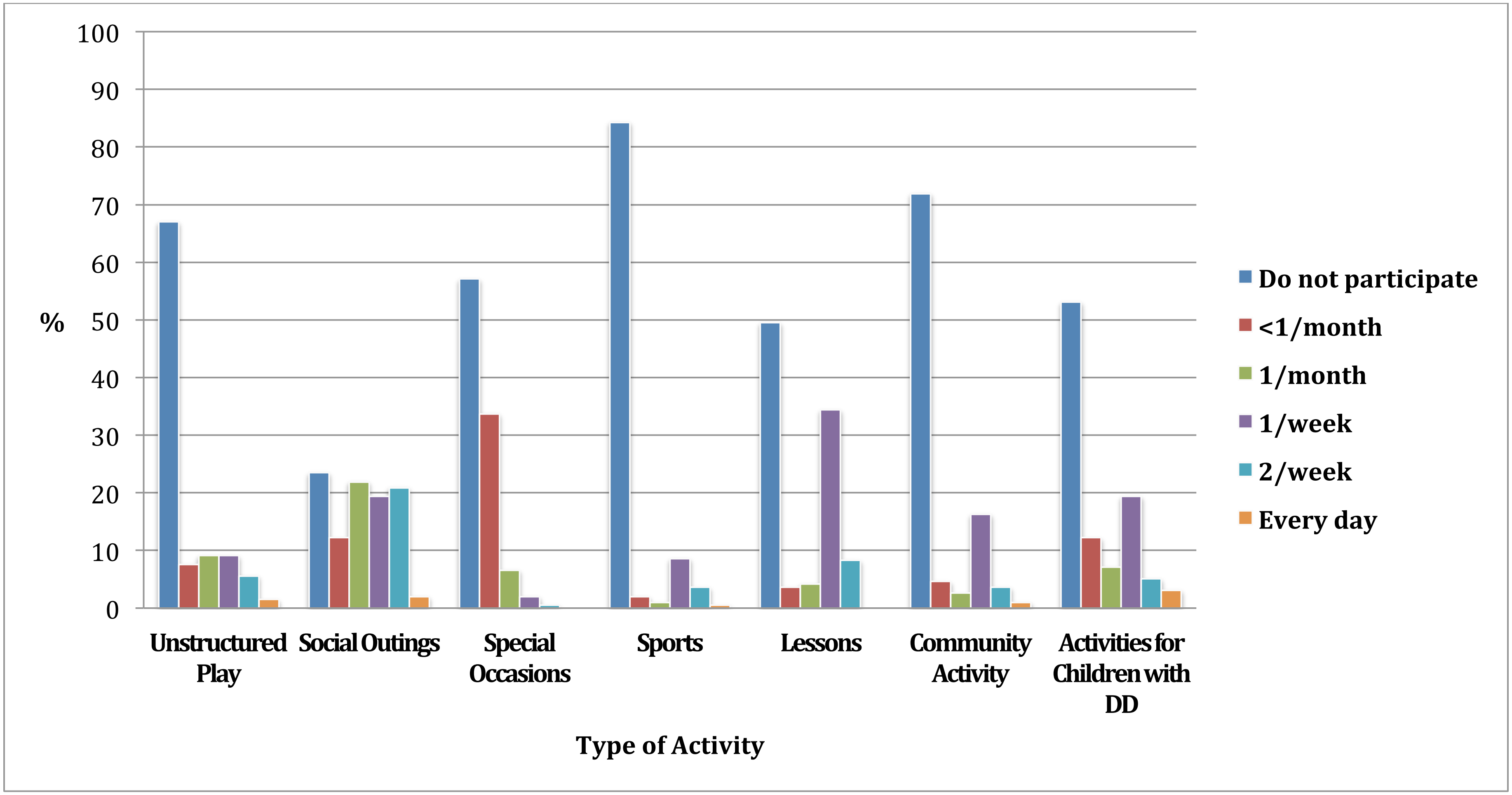
Table 5

How many participate and if yes, how often do they participate in each activity?

		% of those who said yes				
Type of Activity (*N*=197)	Yes *n* (%)	< 1/month	1/month	1/week	2/week	Every day
Unstructured Play	65 (33.0)	23.1	27.7	27.7	16.9	4.6
Social Outings	151 (76.7)	16.0	28.7	25.3	27.3	2.7
Special Occasions	85 (43.1)	78.6	15.5	4.8	1.2	0
Sports	31 (15.7)	12.9	6.5	54.8	22.6	3.2
Lessons	102 (51.8)	7.2	8.2	68.0	16.5	0
Community Activity	56 (28.4)	16.4	9.1	58.2	12.7	3.6
Activities for children with DD	93 (47.2)	26.1	15.2	41.3	10.9	6.5

Figure 6

Frequency of Participation



For those who are participating, with whom do they participate in activities?

Table 6 shows the number of children and adolescents participating in each activity, and if they participate, what type of peers are participating in the activities with them (i.e., peers with DD, a mixed group of TD and DD peers, or all TD peers). For example, of those 65 children (33%) who participated in Unstructured Play, 59% participated with TD peers only, 28% with a Mixed group of peers, and 14% with only DD peers. Interestingly, 65% of those who participated in Sports Teams did so with DD peers. Looking at participation with TD peers primarily, Table 6 shows that over 40% of the children participated in Unstructured Play, Social Outings, Special Occasions, Lessons, and Community Activities with TD peers.

Figure 7 presents the same data as Table 6 in a different way, again showing the absolute percentage of children and adolescents participating with each type of peers, alongside the percentage not participating. Once again, it is important to note that the majority of children did not partake in the activities, as shown by the first bar of each set on the graph. In several cases, participation, when it did occur, was most often with TD peers. This was the case for Unstructured Play, Social Outings, Special Occasions, Lessons, and Community Activities. However the absolute percentage of children this reflects was 20% or less for all except Social Outings.

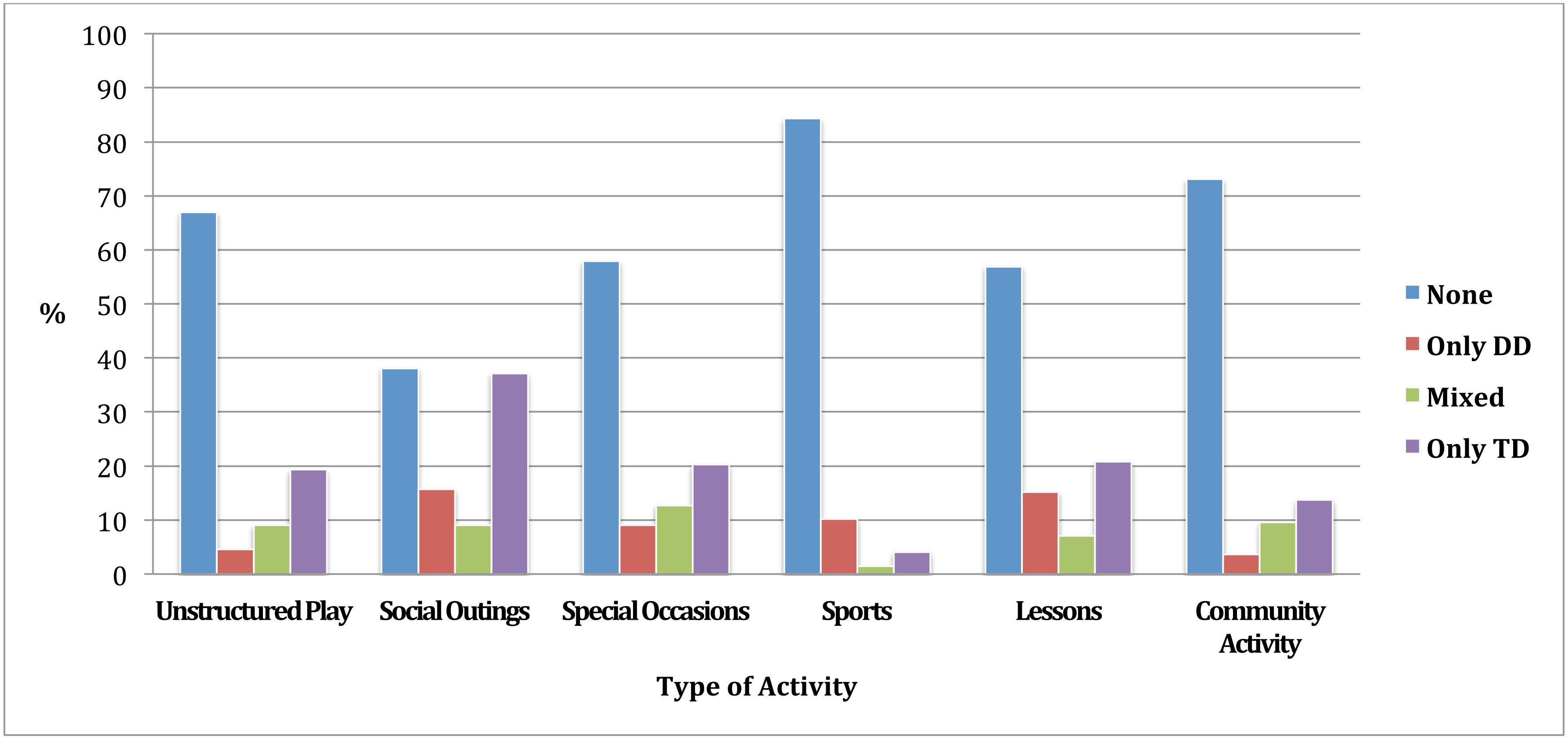
Table 6

If they participate, with whom do they participate?

		% of those who said yes		
Type of Activity (*N*=197)	Yes *n* (%)	Only DD	Mixed	Only TD
Unstructured Play	65 (33.0)	13.8	27.7	58.5
Social Outings	151 (76.6)	20.5	11.9	48.3
Special Occasions	85 (43.1)	21.2	29.4	47.1
Sports	31 (15.7)	64.5	9.7	25.8
Lessons	102 (51.8)	29.4	13.7	40.2
Community Activity	56 (28.4)	12.5	33.9	48.2

Figure 7

Type of peers for each activity



Reasons for not participating in each activity

Table 7 shows the number not participating and the percentage of respondents who indicated each reason for not participating in each activity. It is important to note that the reasons are not mutually exclusive; therefore, caregivers could have selected more than one reason for each of the activities. In the sample as a whole, all the reasons were selected for all of the activities. The child not being able to partake in the activity was one of the main reasons for not participating in Unstructured Play, Social Outings, Sports, and Community Activities. The child not being interested in the activity was one of the main reasons for not participating in Unstructured Play, Sports, and Community Activities. No support (or not adequate support) available to accompany the child was one of the main reasons for Lessons and Community Activities. The child not being allowed or invited to participate was one of the main reasons for not participating in Unstructured Play and Special Occasions. Logistical reasons (cost, distance, etc.) were one of the main reasons for not participating in activities for children with DD. Interestingly, unavailability was not selected as the main reason for not participating in any of the seven activities.

Because activity participation rates varied across activities and different (non-mutually exclusive) reasons were endorsed for different activities, it is difficult to grasp the relative importance of the reasons for not participating in a more general way. Therefore, the proportion of endorsements for each reason across activities was calculated in two steps: for each individual, the frequency of each reason was divided by the total number of activities the child did not participate in, and these values were averaged for all the individuals in the sample. As shown in Table 8, the range and the mean proportion was approximately the same for each reason endorsed across the activities, with means ranging from .50 to .64. Therefore, all of these reasons were relatively equally important in why children were not participating in these activities. Half to two thirds of the time each of these reasons was at least partially related to why these children did not participate.

Table 7

How many do not participate and why not for each activity

		Why not (%)					
Type of Activity	No n (%)	Not Able	Not Interested	Not Available	No support	Not Allowed	Logistics
Unstructured Play	135 (68.6)	40.0	43.0	24.4	37.8	51.9	16.3
Social Outings	47 (23.9)	48.9	29.8	23.4	38.3	36.2	14.9
Special Occasions	115 (58.4)	30.4	22.6	31.3	26.1	68.7	10.4
Sports	168 (85.3)	54.8	44.6	22.6	35.1	10.1	25.6
Lessons	97 (49.2)	37.1	25.8	19.6	44.3	3.1	35.1
Community Activity	144 (73.1)	39.6	42.4	22.2	40.3	11.1	18.8
Activities for Children with DD	106 (53.8)	24.5	27.4	31.1	24.5	6.6	38.7

* Note: Reasons are not mutually exclusive

Table 8

The proportion of time each reason endorsed for not participating across activities

	M (SD)	Min	Max
Not Able	.64 (.28)	.20	1.00
Not Interested	.59 (.31)	.17	1.00
Not Available	.50 (.26)	.17	1.00
No Support	.63 (.29)	.17	1.00
Not Allowed	.52 (.24)	.17	1.00
Logistics	.56 (.28)	.17	1.00

Summary of Results

This section will include a summary of results for each activity, including how many children and adolescents participated; if so, how often and with whom; and, if not, reasons why not.

Thirty-three percent of children participated in Unstructured Play with peers (e.g., at friends' houses, friends coming over), and of those, participation took place less than once a month for 23%, once a month for 28%, once a week for 28%, twice a week for 17%, and every day for 5%. For those who participated, 14% participated with peers with DD, 28% with a mixed group of DD and TD peers, and 59% with TD peers. The majority of children (67%) do not participate in Unstructured Play and the most frequently reported non-mutually exclusive reasons for not participating were that the child was *not able to* (40%), *not interested* (43%), and *not allowed or invited* (52%).

Seventy-seven percent of children participated in Social Outings (e.g., going to the mall, to the movies, out for meals), and of those, participation took place less than once a month for 16%, once a month for 29%, once a week for 25%, twice a week for 27%, and every day for 3%. For those who participated, 21% participated with peers with DD, 12% with a mixed group of DD and TD peers, and 48% with TD peers. Twenty-four percent of the children did not participate in the activity and the most frequently reported reason for not participating was that the child was *not able to* (49%).

Forty-three percent of children participated in Special Occasions with friends (e.g., birthday parties), and of those, participation took place less than once a month for 79%, once a month for 16%, once a week for 5%, twice a week for 1%, and none of the children participated in the activity every day. For those who participated, 21% participated with peers with DD, 29% with a mixed group of DD and TD peers, and 47% with TD peers. Fifty-eight percent of the children did not participate in the activity and by far the most frequently reported reason for not participating was that the child was *not allowed or invited* (69%).

Only sixteen percent of children played on a Sports team (e.g., hockey, soccer, etc.), and of those, participation took place less than once a month for 13%, once a month for 7%, once a week for 55%, twice week for 23%, and every day for 3%. For those who participated, 65% participated with peers with DD, 10% with a mixed group of DD and TD peers, and 26% with TD peers. The majority of children (85%) did not participate in the activity and the most frequently reported reasons for not participating were that the child was *not able* (55%) and/or *not interested* (45%).

Fifty-two percent of children took Lessons (e.g., swimming, gymnastics, skating, etc.), and of those, participation took place less than once a month for 7%, once a month for 8%, once a week for 68%, twice a week for 17%, and none of the children participated in the activity every day. For those who participated, 29% participated with peers with DD, 14% with a mixed group of DD and TD peers, and 40% with TD peers. Forty-nine percent of children did not participate in the activity and the most frequently reported reason for not participating was that *no support* (44%) was available.

Twenty-eight percent of children took part in Community Activities (e.g., Sunday School, Cubs/Brownies, etc.) and of those, participation took place less than once a month for 16%, once a month for 9%, once a week for 58%, twice a week for 13%, and every day for 4%. For those who participated, 13% participated with peers with DD, 34% with a mixed group of DD and TD peers, and 48% with TD peers. The majority of children (73%) did not participate in the activity and the most frequently reported reasons for not participating were that the child was *not able* (40%) and/or *not interested* (42%).

Forty-seven percent of children participated in Activities for Children with DD (e.g. Special Olympics, special camp programs), and of those, participation took place less than once a month for 26%, once a month for 15%, once a week for 41%, twice a week for 11%, and every day for 7%. Just over half the children (54%) did not participate in the activity and the most frequently reported reason for not participating was *logistical issues* (39%).

Predictors of Activity Participation

Table 9 shows the descriptive statistics on all the variables used for the multivariate regression analyses to examine predictors of participation. The number of activities that the children and adolescents participated in averaged around 2.5 out of 6 activities. Our sample had a mean age of 11 years and 58% also had a diagnosis of ASD. There was a wide range of adaptive and maladaptive behaviour. In addition, over half the sample was at risk of having family hardships, as measured by the constructed family risk variable. The Barratt score is an ordinal measure and used to estimate SES. Based on this measure, our sample had an average score of 39, which is intermediate (possible range 8-66). The mean score for parental socialization indicates that on average the caregivers reported their belief that they socialize somewhat less often than other people.

Table 9

Descriptives for Child, Family, and Community Factors, and Activity Participation (N = 197)

Variables		Possible Range	Sample Range
Child Factors			
Diagnosis			
% ID	41.6		
% ASD	58.4		
Raw Adaptive Behaviour Score *M (SD)*	53.52 (20.93)	0 - 140	2 – 99
* General Maladaptive Index *M (SD)*	-15.31 (12.57)	– 70 to +10	-49 to +4
Age *M (SD)*	10.72 (3.55)		3.05 – 19.43
Family Factors			
% Families at Risk	58.9		
Barratt SES	38.75 (14.75)	8 – 66	8.00 – 66.00
Parental Socialization	-1.12 (.70)	-2 to +2	-2.00 to +1.57
Community Factors			
Median Income of Area	$65,380 (17,215)		$37,140 - $109,302
School Program			
% Regular Class	45.7		
% Special Education Class	50.3		
School Satisfaction	1.52	1– 5	1.00 – 4.00
Outcome			
Activity Participation *M (SD)*	2.45 (1.47)	0-7	0 – 6

* Note: SIB-R maladaptive index score; larger negative scores indicate more maladaptive behaviour

Table 10 shows the correlations examining the strength and direction of relationship among all of the variables. By Cohen's (1988) convention, a correlation coefficient between .10 and .29 is considered a weak association; between .30 and .49 is considered a moderate association; and.50 and greater is considered a strong association.

Activity Participation was weakly correlated with Diagnosis (*r* = -.16), Maladaptive Behaviour (*r* = .22), Family Risk (*r* = -.14), and School Program (*r* = -.26), and moderately correlated with Adaptive Behaviour (*r* = -.31) and Parental Socialization (*r* = -.41). Inter-correlations among predictors were also examined. Diagnosis was weakly correlated with Maladaptive Behaviour (*r* = -.26), Age (*r* = -.16), and Parental Socialization (*r* = -.15). Adaptive Behaviour was weakly correlated with Age (*r* = -.19), Barratt (*r* = -.14), and Parental Socialization (*r* = -.26). Maladaptive Behaviour was weakly correlated with Family Risk (*r* = -.27) and School Satisfaction (*r* = -.24), and moderately correlated with Parental Socialization (*r* = -.33). Age was moderately correlated with type of School Program (*r* = -.30). Family Risk was weakly correlated with School Satisfaction (*r* = -.19). Parental Socialization was weakly correlated with type of School Program (*r* = -.18) and School Satisfaction (*r* = -.24). SES, as measured by either the Barratt or the Median Income of the Area, was not significantly correlated with any of the other variables.

Table 10

Intercorrelations of Scores on Activity Participation with Child, Family and Community Variables

Measure	*1*	2	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*
1. Activity Participation	—	-.16*	.31**	.22**	-.11	-.14*	.10	.41**	.07	-.26**	.12
2. Diagnosis	-.16*	—	.09	-.26**	-.16*	.13	.04	-.15*	-.09	.05	-.06
3. Adaptive Behaviour	.31**	.09	—	-.11	.19**	-.01	.14*	.26**	-.11	-.11	.10
4. Maladaptive Behaviour	.22**	-.26**	-.11	—	-.08	-.27**	-.07	.34**	.07	-.06	.22**
5. Age	-.11	-.16*	.19**	-.08	—	-.03	.11	-.06	.07	.30**	-.01
6. Family Risk	-.14*	.13	-.01	-.27**	-.03	—	-.11	-.12	-.06	-.06	-.19**
7. Barratt	.10	.04	.04	-.07	.11	-.11	—	.01	.01	-.05	-.02
8. Parental Socialization	.41**	-.15*	.26**	.34**	-.06	-.12	.01	—	.06	-.18*	.24**
9. Median Income of Area	.07	-.09	-.11	.07	.07	-.06	.01	.06	—	.12	-.04
10. School Program	-.26**	.05	-.11	-.06	.30**	-.06	-.05	-.18*	.12	—	.01
11. School Satisfaction	.12	-.06	-.10	-.22**	-.01	-.19**	-.02	.24**	-.04	.01	—

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

Note: maladaptive behaviour was based on the SIB-R maladaptive index score; lower scores indicate more maladaptive behaviour

Proposed Model of Activity Participation

Hierarchical regression analysis was used to determine the predictors of Activity Participation. In Step 1, variables relating to the child (i.e., Diagnosis, Age, and Adaptive and Maladaptive Behavior) were entered. In Step 2, variables relating to the family (i.e., Family Risk, SES, and Parental Socialization) were entered. Finally, in Step 3, the variables relating to community (i.e., Median Income of Area, Type of School Program, and School Satisfaction) were entered.

Table 11 shows the results of the regression analysis. The results from Step 1 indicate that child factors significantly contributed to the regression model ($F_{(4, 197)} = 11.12$, $p < .01$) and accounted for 21% of the variation in Activity Participation. At Step 1, all of the child variables were significant. Introducing the family variables at Step 2 accounted for another 7% of the variance and this change was significant ($F_{(3, 197)} = 9.26$, $p < .01$). At this step, all child variables remained significant, except for Maladaptive Behaviour. Furthermore, of the family variables, Parental Socialization was significant. Finally, the addition of the community variables at Step 3 accounted for only another 2% of the variance and this change was not significant ($F_{(3, 197)} = 6.85$, $p = .16$). At this step, age and diagnosis were no longer significant but Adaptive Behaviour, Parental Socialization, and Type of School Program remained significant. In comparison to those in special education classrooms, those in regular classrooms participated in significantly more activities ($t_{(187)} = 3.1$, $p < .01$). Overall, the final model, which combined all of the child, family, and community variables, significantly accounted for 30% of the variance in Activity Participation ($F_{(10, 197)} = 8.92$, $p < .01$). The final model had significant coefficients for Adaptive Behaviour, Parental Socialization, and Type of School Program.

Table 11

Hierarchical Multiple Regression Analyses Predicting Activity Participation from Child, Family, and Community Variables

	Activity Participation		
	Model 1	Model 2	Model 3
Predictor	β	β	β
Step 1			
Diagnosis	-.17*	-.14*	-.12
Adaptive Behaviour	.38**	.28**	.27**
Maladaptive Behaviour	.20**	.10	.10
Age	-.19**	-.17*	-.13
Step 2			
Family Risk		-.06	-.07
Barratt		.09	.07
Parental Socialization		.26**	.24**
Step 3			
Median Income of Area			.09
Type of School Program			-.14*
School Satisfaction			.01
F	11.12**	8.92**	6.85**
ΔR^2		.07**	.02
Total R^2	.21**	.27**	.30**

* $p < .05$; ** $p < .01$

Discussion

The second objective of this study was to further report on the social participation of children and adolescents with severe DD. This included reporting on the number of activities participated in, the frequency of participation, the types of peers, and the reasons for not participating in the seven activities. In addition, we examined the child, family, and community predictors of activity participation in our sample.

A large majority of our sample was reported to not participate in three out of the seven activities, (i.e., Unstructured Play with Peers, Sports, and Community Activities). Nearly half of the sample did not participate in Special Occasions, Lessons, and Activities for Children with DD. These results are consistent with existing findings in the literature indicating that those with DD are less likely to participate in activities outside of the home or school. In contrast, we found that the majority of the children and youth participated in Social Outings. This finding was not unexpected, given that this category included activities such as going to the mall, going to the movies, or out for meals, likely with family members and not necessarily with peers. Although the category is called "Social" Outings, the activities may be more passive rather than social in nature, compared with other activities examined such as unstructured play with peers or attending special occasions. Overall, these finding are similar to a number of studies, including those discussed under Objective 1, indicating that children and youth with DD participated in fewer social, active or skill-based activities.

We also examined the frequency of participation for each of the activities. We found that nearly half of those who took part in Unstructured Play with peers or Social Outings, participated once a month or less. The majority of those who took part in Special Occasions, participated once a month or less. The majority of those who took part in Sports, Lessons, or Community Activities for Children with DD, participated once a week or more. The existing literature reports on whether or not children participate in the activities, but often not the frequency of such participation. Therefore, these results help us better understand the nature of participation for children and adolescents with DD. Although some individuals with severe DD participated in social and recreational activities (i.e., unstructured time with peers, social outings, and special occasions), participation did not occur frequently. However, of those who participated in Sports, Lessons, or Activities for Children with DD, participation occurred more frequently. This is not surprising since such organized activities typically occur on a regular schedule (e.g., every Saturday morning) and/or because parents often pay for these activities to occur regularly.

In addition, we asked caregivers to report on the type of peers participating in the activities with their child. For most of the activities that took place, nearly half of the those who participated did so with TD peers, which is encouraging. Aside from activities for Children with DD, only playing on a Sports team took place primarily with other peers with DD, suggesting that parents are accessing specialized support services offering this option. There is not much research concerning "with whom" children participate in these activities, especially the types of peers that participate. One study (Solish et al., 2010) explored this area, however, the researchers were concerned with activities done with parents versus peers. Although for this study, our "with whom" group did not consist of parents or other adults, we reported on a more detailed examination of the type of peers participating in the activities with the child with DD.

For those children and youth who did not participate, we examined the reasons for not participating in each activity. Although all of the reasons were selected for all of the activities, certain reasons were reported far more often. Reasons relating to the child, such as the child not being able to partake in the activity, or not being interested in the activity were frequently reported for Unstructured play with peers, Social Outings, Special Occasions, and playing on a Sports team. In addition, not being allowed or invited was quite frequently cited as a reason for not participating, which is rather concerning as it suggests a deliberate social exclusion of these children by others in their community. Logistical reasons (i.e., cost, distance, etc.) were not a prominent reason for most activities but were one of the main reasons for not participating in activities for children and adolescents with DD. No Support (or inadequate support) available to accompany the child was one of the main reasons for not participating in Lessons. Therefore, the results for this part of the study, suggest that child and environmental factors could hinder participation in various types of activities. According to Statistics Canada (1995) the most commonly reported barriers for participation for individuals with disabilities in Canada are lack of physical ability, high costs, and proximity to facilities or programs. However, the results from this study suggest that barriers are somewhat different for children and adolescents with severe DD. It is encouraging that availability and logistical reasons were not reported as frequently as the other reasons to be a barrier to participation for this population.

Finally, we examined the variables that predict participation for all of the seven activities combined. Guided by the findings in the literature, we examined the different factors that impact activity participation from an ecological perspective (similar to King et al., 2003). The proposed model places the child with DD at the center and the variables that relate to the child, such as level of adaptive and maladaptive behaviour, gender, age, and the presence of an ASD diagnosis. The next layer consists of family variables, such as parental mental health, marital status, number of siblings with DD, immigration status, SES, and parental socialization. The final layer contains community variables, such as the size of the community, type of school program and satisfaction with school program.

Based on hierarchical regression analyses, we determined the predictors of social participation at each level of the proposed model (child, family, and community factors). At the first level of the model, child factors accounted for 22% of variance in Activity Participation. At the second level of the model, family variables accounted for another 7% of the variance. At the third and final level of the model, community variables accounted for another 2% of the variance. Overall, the final model, which combined all of the child, family and community variables, accounted for 30% of the variance in social participation. This is consistent with our hypothesis that children's participation in activities will be impacted at each level of the proposed model. Therefore, the combination of child, family, and community variables significantly predicted the social participation of children and adolescents with severe DD.

In our final model, Adaptive Behaviour was the only child variable that significantly predicted activity participation in our sample. This finding is consistent with our hypothesis that higher levels of child's adaptive behaviour predict greater participation in various activities. In addition, there is abundant evidence in the literature that participation of individuals with disabilities is highly related to skill level (e.g., Bult et al., 2011; LaVesser & Berg, 2011; Lopes 2012; Voorman & Dallmeijer, 2006). Based on these findings, there is a clear link between children's level of adaptive skills and activity participation. Contrary to our hypothesis, other child factors such as maladaptive behaviour, gender, age, and the presence of an ASD diagnosis, were not predictive of social participation in the final model, although they were in the initial steps. This result is encouraging since it highlights that child characteristics alone are not predictive of social participation. Therefore, when family and community variables are considered simultaneously with child variables, child's functioning, age, gender and ASD diagnosis, are not as important in determining participation.

Of the family variables, Parental Socialization showed the highest zero-order correlation with child's activity participation (*r* = .41) and it significantly predicted social participation, after child variables were controlled. This finding is consistent with our hypothesis that the more parents participate in activities, the more likely their child with DD will participate in activities (or perhaps, vice versa). Only a few other studies have shown that family involvement or participation in social and recreational activities is linked to children's participation (King et al., 2003; Lopes, 2012). For example, greater maternal participation in social and recreational activities is a predictor of greater participation in social and recreational activities among adolescents and adults with ASD (Orsmond et al., 2004). Contrary to our hypothesis, greater SES did not predict greater social participation. This could be because our measure may not accurately represent the families' SES or could reflect a Canadian social context. Furthermore, we created the family risk variable, which included marital status, immigration status, having other child(ren) with disabilities, and parental mental health. Contrary to our hypothesis, the combination of these risk variables did not predict level of participation in activities. The risk variable was an attempt to combine a number of potential risk factors, each of which occurred in only a minority of this generally well-functioning sample and the combined score was very skewed and was, therefore, dichotomized. As a result, it may not have been sensitive enough to demonstrate the relations between individual variables and social participation.

In terms of community factors, we rejected our hypothesis that there is a link between the size of community and parental satisfaction with school placement. However, we used crude measures for these variables; the size of the community was a simple dichotomized variable and may not have been sensitive enough, and parental satisfaction with the school program may not have been an accurate measure. However, the type of school program significantly predicted social participation. This finding is consistent with our hypothesis that attending integrated education classes will result in greater participation in activities. Rider and Menchetti (1997) also found that children with DD in a regular class took part in more recreational activities than those in special education classes. However, it is important to contextualize this finding by acknowledging that there may be a number of differences between children and youth in special education versus regular classes that may confound these comparisons. On the other hand, several important child characteristics were controlled by virtue of having been entered into the regression at an earlier step. Therefore, these results indicate a clear link between inclusive educational placements and greater social participation of children and youth.

The second objective of this study has addressed several theoretical and clinical gaps in the literature. Thus far, the only existing models examining predictors of activity participation have been developed for individuals with physical disabilities (King et al., 2003) or for younger children with various levels of DD (Lopes, 2012). Therefore, they cannot be directly applied to our sample of children and youth of all ages with severe DD. In addition, individuals with severe DD are often excluded from this type of research because of their complexities and level of functioning. This research has significant implications for how we conceptualize social participation in this population and the barriers to active participation in various activities. The proposed model provides a strengths-based perspective, which focuses on the strengths of individuals and families and acknowledges the importance of supportive relationships and environments in creating positive outcomes for children and adolescents with severe DD.

Given the benefits of social participation, strategies can be aimed at tackling some of the barriers or factors that may hinder a child with DD from taking part in such activities. The results indicated that children's adaptive behaviour was an important predictor of social participation. Therefore, it is important to encourage intervention and educational programs to help children build skills necessary to promote participation in various activities. Furthermore, the results showed that parental social participation was a significant predictor of children's participation in activities. Therefore, providing better support or more opportunities for caregivers to participate in various social activities could improve the social participation of their children. This is a relatively new finding in the literature and an area that needs to be further explored. Additionally, the results showed that those in regular educational programs were more likely to participate in activities, not surprisingly. This could mean that there are more opportunities within a class of TD peers, even for children and adolescents with severe DD, than a class of only DD peers.

This study had a number of strengths. We had large (*n* = 197) and diverse sample of parents of Canadian children and adolescents with DD. The sample was unique, with most individuals having multiple diagnoses and complex needs. Furthermore, based on standardized measures of children's skills and problem behaviours, we could confirm that our sample consisted of children and adolescents with severe needs. Similar to Objective 1, the survey was provided both online and by paper-and-pencil. This allowed for easy distribution across provinces in Canada and completion for those without access to a computer or Internet. Finally, we had rather extensive information about each participant regarding the variables of interest.

Although the study has a number of strengths, it is not without limitations. As with Objective 1, the data were based on caregiver report; therefore, participation was based on parental perception rather than an objective view of activity participation. Additionally, it was a volunteer sample, which may not represent all caregivers with a child with DD. Furthermore, there are a number of measurement issues in this study. Several of the measures were developed for the purpose of the GO4KIDDS survey and may not be reliable or valid indicators of various constructs (e.g., parental socialization). These measures were not standardized and their psychometric properties are unknown. Finally, as mentioned in Objective 1, the concept and definition of social participation is still unclear, and there is no agreement in the literature in terms of measuring this construct. Parent report of activity participation is, at best, a crude indicator of the complex construct of social participation or social inclusion.

Future studies should explore predictors of social participation using better measures. In particular, there is a need to develop psychometrically sound measures of social participation of children and adolescents with DD. In addition, given the findings from this study, there is a need for a valid measure of the social participation of parents, as well. It would be ideal to have systematic behavioural observations of participation, or receive additional information regarding participation from active members in the child's community (e.g., teachers, community leaders, coaches, peers). Finally, the survey did not include a number of other family and community variables that may predict social participation for this sample. Further research is needed to examine other parental and community factors that may impact participation, such as availability of various activities, accessibility to services (i.e., transportation) and facilities (King et al., 2003).

Conclusion

The results from this study confirm that children and adolescents with severe DD, including those with ASD and ID, participate in fewer social activities than their peers. Although some children and youth with DD participate in some social and recreational activities with TD peers, participation occurred much less frequently in comparison to their peers. Social participation is known to be an important part of children's development and lack of participation can have a negative impact on development (e.g., King et al., 2003). The results from this study, though perhaps not surprising, are alarming, since children with DD will likely not gain the benefits of social participation, given that they participated in fewer activities and much less often than their peers. Furthermore, since our conceptualization of "disability" includes participation restrictions (WHO, 2013), inherently disability is being reinforced for this group of individuals.

Children and adolescents with DD are also at a greater disadvantage when it comes to their social networks. They have fewer friends and poorer quality of friendships in comparison to their peers. This finding is concerning, since those with DD may feel isolated and lonely. This finding reflects the existing literature suggesting that those with DD have social networks that consist of mostly family members and paid staff. However, it is encouraging that when participation did take place, half of those with DD participated with TD peers. This is an indication that when participation occurs, children are integrated and included in social settings, showing this is possible and is happening in some settings.

This is a particular area of concern for those with ASD, since they participated even less frequently in some activities. This result is somewhat different from what was found in the literature, which could be due to the severity and complexity (e.g., presence of physical disabilities or other medical conditions) of our ASD sample. Furthermore, those with ASD have even fewer friends and poorer quality of friendships. The findings are quite disheartening, since they indicate that children and youth with ASD are not socially included in activities and friendships.

In terms of barriers to participation, reasons relating to the child (i.e., unable to participate or uninterested in the activity) were most frequently reported. This could indicate that while some children do not have the skills to participate, others do not want to participate. Therefore, some children may not perceive lack of participation negatively (particularly those with ASD). Additionally, not being allowed or invited was also quite frequently reported. Unfortunately, this finding suggests that peers, other parents, and programs in the community may deliberately exclude individuals with DD. In contrast, it is encouraging that parents did not report lack of availability of activities and logistical reasons (i.e., costs) as prominent reasons for not participation in social activities. Overall, parents appear to have access to programs and the resources needed to help their child take part in various activities. However, children's skill levels and lack of inclusion by peers were reported as the main barriers to participation for this population.

It is important to find ways to encourage and provide opportunities for this group of children to become more involved in social activities and build meaningful friendships. The literature suggests that child, family, and community variables may determine a child's engagement in social activities. Based on these broad factors, we found that child's adaptive behaviour, parental social participation, and child's educational setting were significant predictors of participation in activities for children and adolescents with severe DD. It is not surprising that children's adaptive behaviour was predictive of social participation, since it is likely that those with higher-level skills are more likely able to partake and engage in various social activities. Furthermore, greater parental social participation predicted greater social participation for the child. Although parental socialization can have a major impact on children's participation in activities, the directionality and mechanism of this relationship warrants further research. Furthermore, the conceptualization and measurement of both parental and child social participation requires further clarification. Finally, those in integrated educational programs were more likely to participate in activities. This finding is not surprising, since the literature suggests that those in regular classroom are more likely to be socially included. The movement of mainstreaming children with disabilities into regular programs is based on the assumption that proximity to TD peers is important for providing opportunities for inclusion.

Examining predictors and barriers of social participation has important implications in both community and clinical settings. With a better understanding of these factors, parents, service providers, and policymakers can implement more effective intervention strategies, policies and programs to enhance social participation for this population. For example, the findings highlight the importance of helping children and youth with DD to develop the necessary skills to be able to participate in social activities. Therefore, intervention and education programs can address these limitations in skill levels, which in turn can help encourage children's socialization. Furthermore, intervention programs are often aimed at providing the child with support; however, the results from this study indicate that it is also important to provide better support or more opportunities for caregivers to participate in various social activities.

More research is needed on the topic of social participation of children and adolescents with DD, preferably using mixed methods. While some research exists in this area, social inclusion is often times based on caregiver report. Therefore, it is necessary to clarify the conceptualization of social participation and find a reliable measure for social inclusion and or participation. Inclusion does not simply mean attending an event; thus observational data is needed to examine if children and youth with DD are actively participating with peers during these activities. This could include using a reliable observational measure of social participation in various settings to examine how often children socially engage with other peers, and the quality of interactions with peers. It would also be useful to interview individuals, other than parents, who interact often with the child in various settings (i.e., support staff, teachers, and peers). In-depth interviewing may provide us with a better understanding of the child’s level and quality of participation, as well as facilitating and hindering aspects of the situation. Furthermore, the results of this study suggest that child, family, and community variables all predict children’s participation in a number of activities. It would be beneficial to explore this topic by examining other related variables not included in this study, such as access to resources, level of parental social support, parental self-efficacy, and societal attitudes and knowledge towards individuals with disabilities. In addition, more sophisticated statistical analyses could be used to examine the relationship between these variables and the mediating or moderating effects on social participation.

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Appendix A: GO4KIDDS Basic Survey Portions

Preliminary Information

What is your postal code? __________

What is your month and year of birth (MM/YY)? ___________

1. What is your relationship to the child with severe DD?

    1. Biological Parent
    2. Adoptive Parent
    3. Step Parent
    4. Grandparent
    5. Other (Please specify ____)

2. What is your gender?

    1. Male
    2. Female

3. What is your marital status?

    1. Married or common-law
    2. Separated, divorced, single or widowed
    3. Other

1.A. About your child

If you have more than one child with disabilities, please choose the child with the **most severe** developmental disability and answer all the questions about that child only.

1.A1. Is the child:

1. A boy
2. A girl

1.A2. What is the child's month and year of birth (MM/YY)? ____________

1.A3. Which one of the following best describes your child's diagnosis? *(check all that apply)*

- ☐ Developmental Disability, Intellectual Disability, Global Developmental Delay, Developmental Handicap, or Mental Retardation
- ☐ Autism, Pervasive Developmental Disorder (PDD) or Autism Spectrum Disorder (ASD)
- ☐ Other syndrome or diagnosis (please specify ___________________________________)

Social and Recreational Activities

1.A31 *Does your child…..*	*Not available / No opportunity*	*Never*	*Rarely*	*Sometimes*	*Often*	*Very Often*
1. Spend unstructured time with peers (e.g., friends coming over)	*NA*	*1*	*2*	*3*	*4*	*5*
2. Go on social outings (e.g., going to the mall, to the movies, out for meals)	*NA*	*1*	*2*	*3*	*4*	*5*
3. Go to special occasions with friends (e.g., birthday parties)	*NA*	*1*	*2*	*3*	*4*	*5*
4. Play on sports teams (e.g., hockey, soccer, etc.)	*NA*	*1*	*2*	*3*	*4*	*5*
5. Take lessons (e.g., swimming, gymnastics, skating, etc.)	*NA*	*1*	*2*	*3*	*4*	*5*
6. Take part in community activities (e.g., Sunday School, Cubs/Brownies, etc.)	*NA*	*1*	*2*	*3*	*4*	*5*
7. Take part in social & recreational programs for children with disabilities (e.g., Special Olympics, special camp programs)	*NA*	*1*	*2*	*3*	*4*	*5*

1.A32. How many friends does your child have (friends are defined as both children wanting to be friends and/or enjoying time/activities with the other):

School friends	0	1	2	3	4	5	6 or more
Other friends	0	1	2	3	4	5	6 or more
Relatives (e.g. cousins)	0	1	2	3	4	5	6 or more

1.A33. Approximately how many of these friends have developmental disabilities?

1. None (0%)
2. A few (25%)
3. About half (50%)
4. Most (75%)
5. All (100%)

1.A34. Compared to other children the same age, how would you rate the <u>quality</u> of the friendships that your child has?

1. Very poor
2. Poor
3. Average
4. Above average
5. Excellent

Appendix B: GO4KIDDS Basic and Extended Survey Portions

Child Variables

A1. Is the child:

1. A boy
2. A girl

A2. What is the child’s month and year of birth (MM/YY)? ___________

A3. Which one of the following best describes your child’s diagnosis? *(check all that apply)*

☐ Developmental Disability, Intellectual Disability, Global Developmental Delay, Developmental Handicap, or Mental Retardation
☐ Autism, Pervasive Developmental Disorder (PDD) or Autism Spectrum Disorder (ASD)
☐ Other syndrome or diagnosis (please specify ______________________________)

D. Please tell us about your child’s behaviour, mental health, and psychological well-being in more detail than Survey 1.

D1. Adaptive Behaviour – Mark how well the individual does (or could do) each task completely without any help or supervision. If you have not seen the individual do the task (or if he or she never has the chance to do the task), mark how well you think he or she could do the task now (without any help). Mark the highest rating (3: Does very well) for tasks that are now too easy for the individual.

	Never or rarely	*Does, but not well*	*Does fairly well*	*Does very well*
1. Makes sounds or gestures to get attention.	*0*	*1*	*2*	*3*
2. Reaches for a person whom he or she wants.	*0*	*1*	*2*	*3*
3. Picks up small objects with hand.	*0*	*1*	*2*	*3*
4. Swallows soft foods.	*0*	*1*	*2*	*3*
5. Transfers small objects from one hand to the other hand.	*0*	*1*	*2*	*3*
6. Stands for at least 5 seconds by holding on to furniture or other objects.	*0*	*1*	*2*	*3*
7. Pulls self into a standing position.	*0*	*1*	*2*	*3*
8. Imitates actions when asked, such as waving or clapping hands.	*0*	*1*	*2*	*3*
9. Puts small objects into containers and takes them out again.	*0*	*1*	*2*	*3*
10. Stands alone and walks for at least 6 feet.	*0*	*1*	*2*	*3*
11. Removes socks.	*0*	*1*	*2*	*3*
12. Shakes head or otherwise indicates “yes” or “no” in response to a simple question such as, “Do you want some milk?”	*0*	*1*	*2*	*3*
13. Points to familiar pictures in a book on request.	*0*	*1*	*2*	*3*

14. Says at least 10 words that can be understood by someone who knows him or her.	*0*	*1*	*2*	*3*
15. Eats solid foods with a spoon with little spilling.	*0*	*1*	*2*	*3*
16. Ask simple questions (for example, “What’s that?”).	*0*	*1*	*2*	*3*
17. Walks up and down stairs by alternating feet from step to step (may hold handrail).	*0*	*1*	*2*	*3*
18. Uses the toilet at regular times when placed on the toilet or a toilet chair or when taken to the bathroom.	*0*	*1*	*2*	*3*
19. Says last name when asked.	*0*	*1*	*2*	*3*
20. Uses the toilet, including removing and replacing clothing, with no more than one accident per month.	*0*	*1*	*2*	*3*
21. Uses complex sentences containing “because” (for example, “I’m not going outside today because it’s raining”).	*0*	*1*	*2*	*3*
22. Takes appropriate-size portions from serving dishes.	*0*	*1*	*2*	*3*
23. Prints first name, copying from an example.	*0*	*1*	*2*	*3*
24. Changes clothing that is dirty from normal wear.	*0*	*1*	*2*	*3*
25. Ties shoelaces and keeps them tied.	*0*	*1*	*2*	*3*
26. Adjusts the water faucets for proper temperature in the bathtub or shower.	*0*	*1*	*2*	*3*
27. Goes at least 4 blocks (or ¼ mile) from home, school, or work alone or with friends of the same age.	*0*	*1*	*2*	*3*
28. Reads and understands materials such as books, comics, or magazines.	*0*	*1*	*2*	*3*
29. Washes and dries dishes and puts them away.	*0*	*1*	*2*	*3*
30. Finds a telephone number in the white pages.	*0*	*1*	*2*	*3*
31. Gives directions to help someone else find his or her way to a place at least ½ mile away.	*0*	*1*	*2*	*3*
32. Accepts criticism of a job without showing anger.	*0*	*1*	*2*	*3*
33. Reads one or more articles in a regular newspaper at least weekly.	*0*	*1*	*2*	*3*
34. Loads and operates a washing machine using an appropriate setting and amount of detergent.	*0*	*1*	*2*	*3*
35. Reaches unfamiliar locations in a city or town with the use of a map.	*0*	*1*	*2*	*3*

D2. Problem Behaviour – Some behaviours are common at certain ages and are not of concern. Sometimes they cause a problem. If an individual does not exhibit problem behaviours in a category, check "No" and score the item "Never" (0) for frequency and "Not serious" (0) for severity. If you check "Yes," check its *frequency* and *severity*.

1. **Hurtful to self** – *Does (name) injure his/her own body*—for example, by hitting self, banging head, scratching, cutting or puncturing, biting, rubbing skin, pulling out hair, picking on skin, biting nails, or pinching self?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(circle one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(circle one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

2. **Hurtful to Others –** *Does (name) cause physical pain to other people or to animals*—for example, by hitting, kicking, biting, pinching, scratching, pulling hair, or striking with an object?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

3. **Destructive to Property –** *Does (name) deliberately break, deface, or destroy things—*for example, by hitting, tearing or cutting, throwing, burning, or marking or scratching things?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

4. **Disruptive Behaviour** – *Does (name) interfere with the activities of others—*for example, by clinging, pestering or teasing, arguing or complaining, picking fights, laughing or crying without reason, interrupting, or yelling or screaming?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

5. **Unusual or Repetitive Habits –** *Does (name) have any unusual behaviours that he/she may do over and over—*for example, pacing, rocking, twirling fingers, sucking hands or objects, twitching (nervous tics), talking to self, grinding teeth, eating dirt or other objects, eating too much or too little, staring at an object or into space, or making odd faces or noises?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

6. **Socially Offensive Behaviour** – *Does (name) behave in ways that are offensive to others—*for example, talking too loudly, swearing or using vulgar language, lying, standing too close or touching others too much, threatening, talking nonsense, spitting at others, picking nose, belching, expelling gas, touching genitals, or urinating in inappropriate places?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

7. **Withdrawal or Inattentive Behaviour–** *Does (name) have difficulty being around others or paying attention*—for example, keeping away from other people, expressing unusual fears, showing little interest in activities, appearing sad or worried, showing little concentration on a task, sleeping too much, or talking negatively about self?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

8. **Uncooperative Behaviour**– *Does (name) have any behaviour that is uncooperative*—for example, refusing to obey, do chores, or follow rules; acting defiantly or pouting; refusing to attend school or go to work; arriving late at school or work; refusing to take turns or share; cheating; stealing; or breaking laws?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

Family Variables

G. Please tell us about you as a parent and your family

G7. How many other children (not including the child you are reporting about), if any, have a disability?______

G9. Please answer these questions about **yourself**, the person completing the survey:

What gender are you?

1. Male
2. Female

What is your relationship to the child?

1. Biological parent
2. Adoptive parent
3. Step parent
4. Grandparent
5. Other (Please specify__________________)

Country of birth: ___________________________

If born outside of Canada, how many years have you lived in Canada? ___________________________

What is the highest level of education completed?

1. Less than 7th grade
2. Junior high / Middle school (9th grade)
3. Partial high school (10th or 11th grade)
4. High school graduate
5. Partial college (at least one year)
6. College / University graduate
7. Graduate degree

What is your occupation? Please be specific (e.g., legal secretary, bank executive, truck driver)

____

Do you currently work outside the home?

1. Not currently
2. Part-time
3. Full-time

G10. Please answer these questions about your **partner** or **other caregiver**:

What gender is he/she?

1. Male
2. Female

What is his/her relationship to the child?

1. Biological parent
2. Adoptive parent
3. Step parent
4. Grandparent
5. Other (Please specify__________________)

What is the highest level of education completed?

1. Less than 7th grade
2. Junior high / Middle school (9th grade)
3. Partial high school (10th or 11th grade)
4. High school graduate
5. Partial college (at least one year)

6. College / University graduate
7. Graduate degree

What is his/her occupation? Please be specific (e.g., legal secretary, bank executive, truck driver)

____

Does he/she currently work outside the home?

1. Not currently
2. Part-time
3. Full-time

1.C3. Feelings - During the **past 4 weeks** how much of the time did you feel…

	None of the time	*A little of the time*	*Some of the time*	*Most of the time*	*All of the time*
1. So sad nothing could cheer you up	*0*	*1*	*2*	*3*	*4*
2. Nervous	*0*	*1*	*2*	*3*	*4*
3. Restless or fidgety	*0*	*1*	*2*	*3*	*4*
4. Hopeless	*0*	*1*	*2*	*3*	*4*
5. That everything was an effort	*0*	*1*	*2*	*3*	*4*
6. Worthless	*0*	*1*	*2*	*3*	*4*

1.C6. Socializing - Compared to other families, how often do you do the following activities:

	Much Less Than Other People	*Somewhat Less Than Other People*	*About As Much As Other People*	*Somewhat More Than Other People*	*Much More Than Other People*
1. Socialize with friends in your home	*1*	*2*	*3*	*4*	*5*
2. Socialize with friends in their homes	*1*	*2*	*3*	*4*	*5*
3. Go out on family outings (e.g., to parks, Science Centre, etc.)	*1*	*2*	*3*	*4*	*5*
4. Go out to restaurants as a family	*1*	*2*	*3*	*4*	*5*
5. Attend Church or other religious services	*1*	*2*	*3*	*4*	*5*
6. Go on vacations with children	*1*	*2*	*3*	*4*	*5*
7. Go on vacations without children	*1*	*2*	*3*	*4*	*5*

Community Variables

1.B3. If your child does attend school, what kind of school program is it?

1. Regular class with no special help
2. Regular class with some special help
3. Regular class with full time 1:1 aide or teaching assistant
4. Smaller special education class
5. Other (Please specify: ______________________)

1.B4. Overall, how satisfied are you with the quality of your child's education?

1. Very dissatisfied
2. Somewhat dissatisfied
3. Mixed
4. Somewhat satisfied
5. Very satisfied

G3. What is the best way to describe the size of your community

1. Remote area Canada
2. Rural Area of Canada
3. Suburban Area of Canada
4. Urban Area of Canada

What is your postal code? _________

Activity Participation

F. Please tell us about your child's participation in social and recreational activities.

F1. Social and Recreational Activities – Listed below are some social and recreational activities we asked you about in the Basic Survey. Please indicate for each one, whether he/she participates in it and how often. If it is an activity your child does participate in, please indicate with whom he/she does it. If your child does not do it, please indicate the reasons why not.

1. Does your child spend unstructured time with peers (e.g., at friends' houses, friends coming over)

Yes *(if yes, answer below)*

How often? *(circle one)*	With whom? *(choose all that apply)*
1 Less than once a month	Peers without disabilities
2 Once a month	Peers with disabilities
3 Once a week	
4 Twice a week	Who helps/supports your child with participation in this activity?
5 Everyday	
	Parent(s)
	Other family member
	Other adult (paid or unpaid)
	Other (please specify)____________________

No *(if no, answer below)*

Why not? *(choose all that apply)*

Child not able to
Child not interested
Activity not available
No support (or not adequate support) available to accompany child
Child is not allowed or invited
Logistical reasons (distance, cost, etc.)
Other (please specify):________________________________

2. Does your child go on social outings (e.g., going to the mall, to the movies, out for meals)?

Yes *(if yes, answer below)*

How often? *(circle one)*	With whom? *(choose all that apply)*
1 Less than once a month	Peers without disabilities
2 Once a month	Peers with disabilities
3 Once a week	
4 Twice a week	
5 Everyday	Who helps/supports your child with participation in this activity?
	Parent(s)
	Other family member
	Other adult (paid or unpaid)
	Other (please specify)____________________

No *(if no, answer below)*

Why not? *(choose all that apply)*

Child not able to
Child not interested
Activity not available
No support (or not adequate support) available to accompany child
Child is not allowed or invited
Logistical reasons (distance, cost, etc.)
Other (please specify):________________________________

3. Does your child go to special occasions with friends (e.g., birthday parties)?

Yes *(if yes, answer below)*

How often? *(circle one)*	With whom? *(choose all that apply)*
1 Less than once a month	Peers without disabilities
2 Once a month	Peers with disabilities
3 Once a week	
4 Twice a week	
5 Everyday	Who helps/supports your child with participation in this activity?
	Parent(s)
	Other family member
	Other adult (paid or unpaid)
	Other (please specify)____________________

No *(if no, answer below)*

Why not? *(choose all that apply)*

Child not able to
Child not interested
Activity not available
No support (or not adequate support) available to accompany child
Child is not allowed or invited
Logistical reasons (distance, cost, etc.)
Other (please specify):________________________________

4. Does your child play on sports teams (e.g., hockey, soccer, etc.)?

Yes *(if yes, answer below)*

How often? *(circle one)*	With whom? *(choose all that apply)*
1 Less than once a month	Peers without disabilities
2 Once a month	Peers with disabilities
3 Once a week	
4 Twice a week	
5 Everyday	Who helps/supports your child with participation in this activity?
	Parent(s)
	Other family member
	Other adult (paid or unpaid)
	Other (please specify)____________________

No *(if no, answer below)*

Why not? *(choose all that apply)*

Child not able to
Child not interested
Activity not available
No support (or not adequate support) available to accompany child
Child is not allowed or invited
Logistical reasons (distance, cost, etc.)
Other (please specify):________________________________

5. Does your child take lessons (e.g., swimming, gymnastics, skating, etc.)?

Yes *(if yes, answer below)*

How often? *(circle one)*	With whom? *(choose all that apply)*
1 Less than once a month	Peers without disabilities
2 Once a month	Peers with disabilities
3 Once a week	
4 Twice a week	
5 Everyday	Who helps/supports your child with participation in this activity?
	Parent(s)
	Other family member
	Other adult (paid or unpaid)
	Other (please specify)____________________

No *(if no, answer below)*

Why not? *(choose all that apply)*

Child not able to
Child not interested
Activity not available
No support (or not adequate support) available to accompany child
Child is not allowed or invited
Logistical reasons (distance, cost, etc.)
Other (please specify):________________________________

6. Does your child take part in community activities (e.g., Sunday School, Cubs/Brownies, etc.)?

Yes *(if yes, answer below)*

How often? *(circle one)*	With whom? *(choose all that apply)*
1 Less than once a month	Peers without disabilities
2 Once a month	Peers with disabilities
3 Once a week	
4 Twice a week	
5 Everyday	Who helps/supports your child with participation in this activity?
	Parent(s)
	Other family member
	Other adult (paid or unpaid)
	Other (please specify)____________________

No *(if no, answer below)*

Why not? *(choose all that apply)*

Child not able to
Child not interested
Activity not available
No support (or not adequate support) available to accompany child
Child is not allowed or invited
Logistical reasons (distance, cost, etc.)
Other (please specify):________________________________

7. Does your child take part in social & recreational programs for children with disabilities (e.g., Special Olympics, special camp programs)?

Yes *(if yes, answer below)*

How often? *(circle one)*
1 Less than once a month Parent(s)
2 Once a month
3 Once a week
4 Twice a week
5 Everyday

Who helps/supports your child with participation in this activity?

Other family member
Other adult (paid or unpaid)
Other (please specify) ___________________

No *(if no, answer below)*

Why not? *(choose all that apply)*

Child not able to
Child not interested
Activity not available
No support (or not adequate support) available to accompany child
Child is not allowed or invited
Logistical reasons (distance, cost, etc.)
Other (please specify):________________________________