

Participation of Children and Youth with Autism Spectrum Disorder: A Scoping Review

Sorayya Askari · Dana Anaby · Melanie Bergthorson · Annette Majnemer · Mayada Elsabbagh · Lonnie Zwaigenbaum

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Abstract

Introduction Participation in leisure activities is beneficial for children's health and development, including those living with Autism Spectrum Disorder (ASD). Available syntheses of knowledge about participation have focused primarily on children with physical disabilities; however, little attention is directed to children with ASD. The purpose of this study was therefore to synthesize research evidence regarding the patterns and determinants of leisure participation in this population.

Methods A scoping review of peer-reviewed studies published between 2000 and 2013 was performed. Two reviewers independently selected studies based on a systematic procedure. Inclusion criteria for studies were participants with

ASD, aged 5–17 years, and description of participation in leisure activities outside of school. Data were organized and synthesized based on domains of the International Classification of Functioning, Disability and Health (ICF): Body Functions, Activity Limitations, and Environmental factors.

Results Sixteen articles (out of 920) met the inclusion criteria and majority of those were descriptive in nature (69 %), whereas information about the factors that affect participation was reported in only 31 %. Overall, children with ASD participate in fewer leisure activities, mostly in the home setting, either with adults or on their own. Factors identified as associated with participation involved family support and social attitudes (environmental factors), sensitivity and behavioral challenges (body functions), and communication and interpersonal relationships problems (activity limitations).

Discussion Knowledge derived from this review provides preliminary understanding of and justifies greater attention towards the concept of participation in this population. Further research directions are suggested to address the identified gaps in the literature.

S. Askari (✉)

School of Physical and Occupational Therapy, McGill University,
Montreal, QC, Canada
e-mail: sorayya.askari@mail.mcgill.ca

D. Anaby

School of Physical and Occupational Therapy, McGill University,
3630 Promenade Sir-William-Osler, Hosmer House, Rm. 302,
Montreal, QC H3G 1Y5, Canada

M. Bergthorson

MAB-Mackay Rehabilitation Centre, 3500 Boulevard Décarie,
Montréal, QC H4A 3J3, Canada

A. Majnemer

School of Physical and Occupational Therapy, McGill University,
3654 Promenade Sir-William-Osler, Davis House, Room D-26,
Montreal, QC H3G 1Y5, Canada

M. Elsabbagh

Montreal Children's Hospital, McGill University, 4018 Ste-Catherine
West, Office: 145 Lab: 131, Montreal, QC H3Z 1P2, Canada

L. Zwaigenbaum

Glenrose Rehabilitation Hospital, University of Alberta, Edmonton,
AB T5G 0B7, Canada

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Introduction

In the last decade, “participation”, defined as involving oneself in a life situation (WHO 2001), has become a well-recognized concept, one of the important outcomes of rehabilitation interventions (Coster and Khetani 2008), and is considered a critical indicator of quality of life (WHO 2001). The World Health Organization, by developing the International Classification of Functioning, Disability, and

Health (ICF), has placed importance on the environment in supporting or hindering participation (WHO 2005). A person's ability to participate is seen as the outcome of interactions between aspects related to their health condition as well as contextual factors, which include environmental and personal factors (i.e., age, sex, and motivation) (WHO 2001). It has been well documented in the literature that participation in activities, particularly those that are leisure-based in nature, in their many environments (home, school, and community) is vital for children's well-being (King et al. 2003). Leisure participation for children and youth can be defined as involvement in formal and informal everyday voluntary activities of childhood performed in all types of environments, for example, joining a youth group or playing team sports (King et al. 2003). By participating in such activities, children develop skills and capabilities; form meaningful relationships; achieve mental and physical health; express their creativity and enjoyment; develop self-identity, self-esteem, and emotional well-being; and achieve purpose and meaning in their lives (King et al. 2003; Coster and Khetani 2008; Solish 2010; Law et al. 2006).

There is increasing evidence that participation of children and youth with disabilities in leisure activities is limited in comparison to their typically developing peers (Law et al. 2011; King et al. 2010; Engel-Yeger et al. 2009; Imms et al. 2008). Children with an Autism Spectrum Disorder (ASD) are no exception. The prevalence of children and youth categorized with ASD appears to be on the rise, affecting 1 of every 68 children in USA (CDC 2014). Results of a systematic review (Elsabbagh et al. 2012) revealed that the median of prevalence of pervasive developmental disorders (PDD) in North America (USA and Canada) is 65.5/10,000.

Despite the importance of participation, promoting participation in youth with ASD is not well integrated into clinical practice. Kadar and his colleagues illustrated this by comparing results of a survey administered to occupational therapists in 1999 to data reported a decade later (Kadar et al. 2012). Their results illustrated that sensory integration, an intervention that focuses on processing sensory information by targeting body functions (e.g., sounds, tactile, and proprioceptive sensation) (Schaaf et al. 2014), remains the most common therapeutic approach. When examining outcome measures, play and leisure assessments were ranked sixth among ten types of standardized outcome measures and were used only by 31.8 % of practitioners. Moreover, the focus of these assessments was on play skills and "quality" of play behaviors (in terms of initiation and ability to organize play interactions with objects and persons) and at times directed to specific types of play (e.g., imaginative) rather than level of participation in leisure activities. This indicates that the clinical focus is on body functions or impairment-based outcomes (e.g., adaptive behavior and sensory processing issues) with little attention directed towards participation in community-based

leisure activities (Kadar et al. 2012). To address this knowledge-to-practice gap, a shift towards a more activity-based approach within clinical practice might be necessary to increase participation in children and youth with ASD.

Current syntheses of the research evidence regarding the participation of at-risk children and youth focus primarily on children with physical disabilities (Bult et al. 2011), cerebral palsy (Shikako-Thomas et al. 2008; Imms et al. 2008) and on a broader range of disabilities (Anaby et al. 2013) with little attention to children with ASD. These studies found that participation in leisure activities for children and youth with physical disabilities is associated with different variables such as gross motor function, manual ability, cognitive ability, communicative skills, age, and gender as well as environmental factors like physical accessibility, supports, and attitudes. To our knowledge, no previous study provided an in-depth review of the existing evidence about participation that is specific to children and youth with ASD. This scoping review therefore aims to (1) map and synthesize current evidence related to participation patterns of children and youth with ASD and (2) identify research gaps in the existing literature to help plan future research on participation of children and youth with ASD.

Method

Scoping review (Arksey and O'Malley 2005), a method that aims to examine the extent, range, and nature of research activity in a particular field, was conducted. Scoping studies typically address broader topics, compared to systematic reviews, which often answer more focused questions from a narrower range of studies. A scoping review is an appropriate method to meet the objectives of this study, given that the area (participation) is complex and has not been reviewed comprehensively before in children with ASD.

Scoping review usually does not assess the quality of the existing literature, but may identify the gaps in the literature (Arksey and O'Malley 2005). The comprehensive nature of scoping reviews helps us to thoroughly and systematically map the existing literature regarding participation in children with ASD. This scoping review addressed the following question: *What is known about the participation in out-of-school activities of children and youth with ASD?*

The following methodological steps, as recommended by of Arksey and O'Malley's framework (Arksey and O'Malley 2005), guided this review:

1. **Systematic search**—Four electronic databases were used: Cumulative Index of Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE, and PsychINFO. All literature database searches were limited

to English language articles with English abstracts published between 2000—since the WHO (2001) postulated the concept of participation—and February 2014. Initial keywords were broad to capture the salient concepts of participation, ASD, and age range (Table 1).

2. **Study selection**—A screening spreadsheet with specific inclusion and exclusion criteria was developed in order to eliminate the irrelevant abstracts from this list, based on the focus areas identified within the research question. Peer-reviewed studies, regardless of their design, met the inclusion criteria if they focused on (1) children and youth with ASD, across the entire spectrum, and with an age range between 5 and 17 and (2) participation in activities outside of school. Studies were excluded if they focused on participation in work, self-care, and/or school activities. Two researchers independently reviewed articles and any disagreement was resolved by discussion in consultation with a third reviewer until a consensus for inclusion was reached.
3. **Charting**—According to the methodology of scoping reviews, the charting process is multi-staged, involving extraction of information from individual articles. Descriptive characteristics such as number of participants, age, diagnosis, type of study, outcome measure, type of participation, setting, and country of origin were extracted and organized, and key findings from the included articles create a detailed data extraction worksheet.
4. **Summation, collation, and synthesis**—The study findings were examined, compared, and discussed to determine the pattern of participation in out-of-school leisure-based activities among children with ASD. Possible determinants of participation were organized and synthesized based on the ICF domains (WHO 2001). These included (1) ASD-related impairments exhibited in body functions (e.g., mental functions and sensory functions); (2) activities limitations (e.g., communication, interpersonal relationships, and mobility); (3) personal or demographic factors (e.g., age, sex, and income); and (4) external or contextual factors (e.g., natural environment, products and technology, support and relationships, attitudes, and services, systems and policies).

Results

Overview of Results

A total of 920 articles (duplicates omitted) were initially identified as potentially relevant from our search of the electronic databases (see Fig. 1 for study selection process). In order to capture more recent information, an additional search between February 2013 and 2014 was conducted, using CINHALL database only, and revealed 300 articles of which none met the inclusion criteria. One member of the research team was responsible for reading the abstracts of all the articles identified in the search of electronic databases and applying the inclusion/exclusion criteria in the abstract screening spreadsheet. The article titles, abstracts, and full text of the 70 articles which were retrieved for charting were reviewed by two researchers. Sixteen of the identified articles met the inclusion criteria. The primary reasons for excluding articles were that they did not address participation in leisure activities in children with ASD ($n=38$, 70 % of the articles), did not fall within the age range ($n=6$, 11 %), addressed the activities at school ($n=7$, 13 %), and “non-original-study” articles, for example, commentary or program description or measure development ($n=3$, 6 %).

The selected studies were published between January 2000 and February 2014. Among the articles included, the majority of the studies were quantitative ($n=13$; 81.2 %) whereas two were qualitative studies (12.5 %) and only one mixed-methods study (6.2 %).

Most of the studies were conducted in the USA ($n=10$; 62.5 %) followed by Asia ($n=2$), India ($n=1$), Canada ($n=1$), UK ($n=1$), and Israel ($n=1$); across a range of age groups. It seems that most studies about leisure participation of children with ASD were produced in 2010 and 2011 (10 out of 16 articles) and were descriptive in nature focusing primarily on characterizing patterns of participation rather than testing the factors that affect these patterns. The majority of articles ($n=10$) focused on the quantitative aspect of participation (e.g., frequency and diversity), and three of them included the qualitative or subjective aspect of participation, in terms of enjoyment, as well. Additional aspects such as those related to performance or difficulties of participation and emotions in relation to participation were observed in the remaining studies ($n=6$). Table 2 summarizes the studies’ characteristics.

Table 1 Examples of search terms

Participation	ASD	Age range
“Participation”, “human activity”, “leisure”, “recreation”, “out-of-school activities”, “extra-curricular activities”, “activity”, “play”, “sports”, “arts and crafts”, “hobbies”, “community-based activities”, “community involvement”, “social participation”	“Autism”, “autistic disorder”, “ASD”, “PDD”, “PDD- NOS”, “Asperger syndrome”, “Kanner syndrome”	“Pediatrics”, “children”, “adolescence”, “youth”

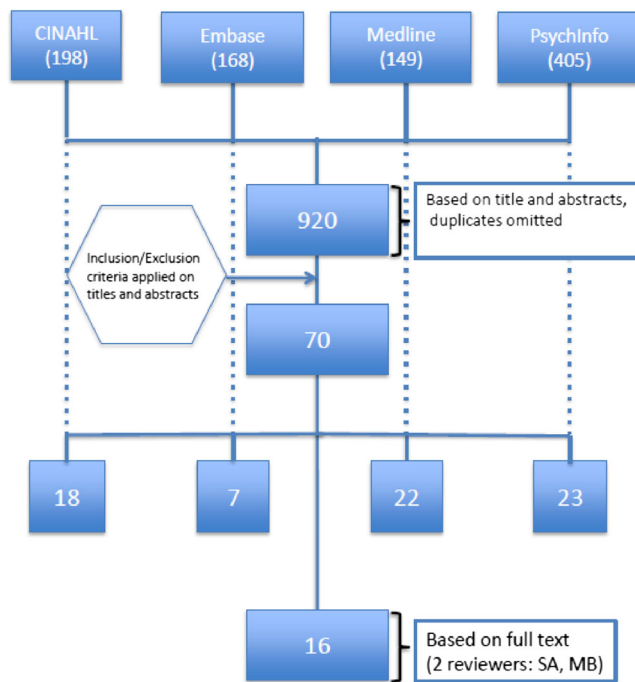


Fig. 1 Flowchart of study selection process

Types of Measures Used

In about half of the studies ($n=7$), the authors provided the questionnaires for their studies (i.e., used non-standardized measures). Standardized measures of participation included the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC) ($n=3$), accelerometer ($n=2$), the Preschool Activity Card Sort ($n=1$), and the Child Behaviour Checklist ($n=1$). Some of the researchers used qualitative methods to include interviews ($n=3$), activity logs ($n=2$), focus groups ($n=2$), and observations ($n=1$).

Evidence Related to Patterns of Participation in Out-of-School Activities

Patterns of participation in out-of-school activities were the focus of seven studies as their main objective and four other studies that examined both the patterns and determinants of participation in out-of-school leisure activities. Two main dimensions of participation were described including those related to the amount and frequency of participation (i.e., quantitative aspect) and those related to the subjective experience that is derived from engaging in activities (i.e., qualitative aspect).

Several studies examined the quantitative domain of participation and provided information about the *diversity* of participation across different types of activities. Overall, relative to typically developing children, those with ASD participate in fewer activities (LaVesser and Berg 2011; Venkatesan 2005) and spend most of their time watching television (Shane

and Ducoff Albert 2008; Venkatesan 2005), playing video games; playing with cars, trains, and planes; and reading books, and have less involvement in dramatic play, play with dolls or action figures, and arts and crafts activities (Reynolds et al. 2011). Other studies, which focused on recreational and out-of-school participation, also found that relative to typically developing peers, children with ASD participate in fewer recreational activities (Hochhauser and Engel-Yeger 2010; Potvin et al. 2013; Hilton et al. 2008; Solish et al. 2010). Reduced participation levels were also evident in the home setting. High functioning children with ASD had fewer jobs and chores, which mostly were in the categories of kitchen and meal preparation. They had less involvement in chores such as animal care, babysitting, and general cleaning (Reynolds et al. 2011).

Participation in social activities was also examined. Shattuck et al. (2011) found adolescents with an ASD participate in fewer social activities; half of them experience none or very limited social activities with friends and only one third participate in social activities in the community with peers. Their findings are supported by the results of other studies among children with ASD (Solish et al. 2010) and those with HFASD (Hilton et al. 2008), but Potvin et al. (2013), who also examined high functioning children, found no difference in diversity of participation in social-type activities relative to typically developed children. There were inconsistent findings regarding participation in physical activities. Potvin et al. (2013) and Hilton et al. (2008) found that children with HFASD participate less in physical activities, but Rosser Sandt and Frey (2005) compared daily physical activity, physical education, recess activity, and after school moderate to vigorous physical activity levels between children with and without ASD and found no differences in any of the above physical activity types. Both groups were more active during recess compared to after school, and children with ASD were similarly active in recess and during physical education. Solish et al. (2010) found no significant differences among children with ASD, typically developed children and children with intellectual disabilities in the percentage of recreational or leisure activities in which the children participated with parents.

Information about the *intensity* or *frequency* of participation was also evident. A study found that children with HFASD have lower participation intensity, especially in social activities and in the informal domain (Hilton et al. 2008). Venkatesan (2005) also found that no matter the structure of the family (present or absent sibling, family size, etc.), children with ASD tend to watch more TV comparing to children with developmental disabilities. Two studies identified that children in the HFASD group reporting a greater intensity of participation in the recreational type of activities compared to typically developed children (Hilton et al. 2008; Potvin et al. 2013).

Table 2 Study characteristics

Reference ID	Authors	Sample and diagnosis	Age (year)	Type	Outcome measures	Type of participation	Main findings
29	Obrusnikova and Cavalier 2011	n=14 (ASD)	8–14	Quantitative	Accelerometer, Activity log, Photovoice	After-school activities	Children with ASD are at risk for health problems associated with inactivity. Discussion about various facilitators and barriers to their participation in moderately vigorous after-school physical activities.
30	Lam et al. 2010	n=594 (ASD=380, without ASD=214)	30–49 (parents)	Quantitative	Questionnaire (willingness, frequency, emotions, perceived importance, and difficulty in participation of community activities)	Community activities	Parents of children with ASD perceived more difficulty and experienced more emotional stress than parents with typically-developed (TD) children; however were just as willing to involve their children in community activities.
26	Poon 2011	n=20 (ASD)	Adolescents	Quantitative	Activities and participation rating scale (APRS)	All daily activities	Adolescents experienced severe difficulties with communication, domestic life, interpersonal relationships, and community skills. Mobility and self-care domains reported fewer difficulties.
21	Reynolds et al. 2011	n=52 (HFASD=26, Typically developed=26)	6–12	Quantitative; Pilot study	The child behavior checklist	All daily activities	Children with HFASD engaged more frequently in solitary activities and oftentimes were not expected to participate in family chores compared to TD. Sensory issues and difficulties with social interaction impacted the ability to successfully participate in many peer-based activities.
22	Hochhauser and Engel-Yeger 2010	n=50 (HFASD=25, Typically developed=25)	6–11	Quantitative	Children's Assessment of Participation and Enjoyment (CAPE)	Out-of-school activity participation	Atypical sensory processing in those with HFASD correlated with lower participation, specifically in social, physical and informal activities
25	Rosser Sandt and Frey 2005	n=28 (ASD=15, without ASD=13)	5–12	Quantitative	Accelerometer, Behavior of Eating and Activity for Children's Health: Evaluation System	Participation in recess, gym class and after school activities	No difference in activity levels between ASD and non-ASD groups. Majority of after school activities for ASD group = light physical

Table 2 (continued)

Reference ID	Authors	Sample and diagnosis	Age (Year)	Type	Outcome measures	Type of participation	Main findings
13	Potvin et al. 2013	$n=61$ (HFASD=30, peers=31)	7–13	Descriptive quantitative	CAPE/Preference for activities of children	Leisure	activities, time spent in front of TV/video games. Children with HFA differed from TD in terms of diversity, social aspects and location of recreation. There was no statistically significant difference in personal intensity, enjoyment or preference of recreation.
24	Shattuck et al. 2011	$n=900$ ASD compared with adolescents with learning disabilities, mental retardation, and speech/language impairments	adolescent-young adulthood	Quantitative	Social participation with friends, general social participation, and disability-related social participation	Social participation	Adolescents with ASD were significantly more likely to have fewer social peer interactions (receiving phone calls, invited to social activities) than other disability groups. Correlates of limited social participation = low family income and impairments in conversational ability, social communication and functional cognitive skills.
28	Obrusnikova and Miccinello 2012	$n=103$ (42 % Autism, 41 % Asperger's Syndrome, 18 % PDD-NOS)	5–21	Qualitative; quantitative mixed-methods	An online, open-ended questionnaire and focus-group interviews with emphasis on participation in after school physical activities	participation in physical after-school activities	Social, motor, attention, and behavioral difficulties, combined with limited interests may contribute to decreased participation in physical activity in children with ASD.
20	Shane and Ducoff Albert 2008	$n=89$ (ASD)	Childhood; <18 years	Descriptive; Survey Results	A survey (four sections including: background information and demographics; television; video; and computer use)	Leisure	On weekends, children tended to engage in media-related activities, excluding other play activities. There was a strong preference for watching cartoons.
23	Hilton et al. 2008	$n=105$ HFASD($n=52$), control ($n=53$)	6–12	Quantitative	CAPE	Out-of-school activity participation	Children with HFASD participate in a more limited range of activities than TD peers but were similar in their diversity of participation in formal activities.
18	La Vesser and Berg 2011	$n=144$ (ASD=103)	36–72 months	Quantitative	Preschool activity card sort	Participation in everyday activities	Children with an ASD participate in significantly fewer activities in all domains than do TD children.

Table 2 (continued)

Reference ID	Authors	Sample and diagnosis	Age (year)	Type	Outcome measures	Type of participation	Main findings
7	Solish et al. 2010	n=185 ASD=65, TD=90, Intellectual disability (ID)y=30	5–17	Quantitative	The on-line version of the Activities Questionnaire	Social/recreational/leisure activities; friendship	No significant differences between ASD and ID for participation in social and recreational activities. These groups also participated more with adults but ID had more friendships than ASD.
31	Thompson and Emira 2011	n=44 (ASD/Attention Deficit Disorder (ADD))	Parents/caregivers of children with ASD/ADD	Qualitative	Focus group interviews with parents/caregivers	Leisure	Three main themes; a sense of isolation and lack of engagement, staff training and attitudes, and the tension between whether to engage in mainstream or special provision.
19	Venkatesan 2005	n=140 (ASD=51, Developmental disabilities=89)	18–126 months	Descriptive	A semi structured “Interview Schedule” and a “Daily Activity Log Schedule”	Daily activities	This sample of children spends the majority of their daily schedule on “sleeping” (43.24 %), followed by time spent at “school” (14.41 %), on “feeding” activities (10.34 %) and “watching television” (9.61 %), respectively.
27	Howel and Pierson 2010	Four mothers with total of seven children with ASD	8–14 years	Qualitative	25 open-ended questions	Social (religious education activities)	None of the children with ASD interacted with church peers outside of the Sunday school context. All mothers felt the church had a responsibility to include children with ASD to the best of their abilities

Patterns of participation were also addressed by examining *where* participation occurs and *with whom*. Five studies suggested that children with ASD participate in activities performed primarily alone or with family members (Hochhauser and Engel-Yeger 2010; Potvin et al. 2013; Hilton et al. 2008; Solish et al. 2010; Venkatesan 2005). These findings align with the results of the Shattuck et al. study (2011) that found adolescents with an ASD were significantly more likely never to see or be called by friends or never be invited to activities. Solish et al. (2010) also found that half of children with ASD had no friends at all. It was reported that children with ASD participated in out-of-school activities mostly at home or locations close to home (Hochhauser and Engel-Yeger 2010; Potvin et al. 2013; Hilton et al. 2008). These results are in line with the findings of Poon (2011) which proposed that children with ASD have more difficulties in participation in community environments than at home.

Very few studies examined the subjective aspects of participation in terms of *levels of enjoyment and preferences*. Children with HFASD in one study, in comparison to their typically developed peers, showed significantly less enjoyment when participating in recreational, physical, or social activities or whether in formal or informal activities (Hochhauser and Engel-Yeger 2010). Conversely, Potvin et al. (2013) and Hilton et al. (2008) found no difference in enjoyment of activities for children with HFASD. Furthermore, no significant difference in preference of activities was reported in these studies comparing children with HFASD and their typically developed peers (Potvin et al. 2013; Hilton et al. 2008).

Determinants of Participation in Out-of-School Activities

Identified determinants were organized based on the domains of the ICF: body functions, activity limitations, and contextual characteristics (WHO 2001).

Body Functions Several body functions including sensory, mental, and behavioral functions were found to be associated with participation. Two papers provide evidence for the negative influence of *sensory sensitivity*—a common dysfunction that involves the inability to process and regulate sensory input (Tomchek and Dunn 2007)—on participation. One study found that children with HFASD had atypical sensory processing abilities that were correlated with lower participation, specifically in social, physical, and informal activities (Hochhauser and Engel-Yeger 2010). Their findings were in line with the results of another study which identified that children with HFASD who had more sensory processing dysfunctions demonstrated lower levels of activity, social, and school competence (Reynolds et al. 2011). *Mental function* was another factor among adolescents with ASD that had an impact on participation whereby lower functional

cognitive skills were significantly associated with higher likelihood of friends never calling, never being invited to activities, and no extracurricular activities comparing to peers with learning disabilities, intellectual disability, and speech/ language impairments (Shattuck et al. 2011). Finally, *behavioral issues* (e.g., stereotyped and repetitive behaviors) exhibited by some children with ASD served as a barrier for participation (Howel and Pierson 2010). For example, parents felt hesitant about placing their children in uncontrolled situations due to their behaviors and their children therefore no longer attended church. Instead, they received respite care during services due to their disruptive behaviors during Sunday school (Howel and Pierson 2010). Finally, the effect of *motor function* was also evident. Difficulties with motor skills were perceived by the parents as barriers to their child's participation in physical activities after school. Parents reported that their child "cannot keep up with other children because of their lack of coordination, balance, and poor gross motor skills." These challenges were reported to lead to bullying and consequently to "frustration, anger, and sadness" (Obrusnikova and Miccinello 2012, p. 71). In a study which assessed perceived barriers to and facilitators of after-school participation in physical activities, children with ASD cited that they lacked the skills, coordination, or balance to participate in physical activities they thought they would enjoy such as biking, skateboarding, or skating (Obrusnikova and Cavalier 2011).

Activity Limitations Severity of communication and social interaction difficulties, which are the key implications of ASD, were associated with lower levels of participation. Lower *social and communication ability* was significantly associated with higher likelihood of never seeing friends, friends never calling, and never being invited to activities. Conversational limitations were also associated with higher odds of friends never calling, never being invited to activities, and having no involvement in extracurricular activities (Shattuck et al. 2011). *Interpersonal relationships* were another influential factor. A study found that half of children with ASD had no friends at all (Solish et al. 2010), and they were more likely never to see friends, never to get called by friends, and never to be invited to activities (Shattuck et al. 2011). Parents reported that their children had no friends at church and no play dates or phone conversations occurred outside of the Sunday school environment (Howel and Pierson 2010). Parents also noted that their children had difficulty taking turns, initiating social interaction with peers, expressing their thoughts, or comprehending rules or regulations (Obrusnikova and Miccinello 2012).

Personal Factors Families' financial constraints within the family can also be a barrier to participation. A study found that adolescents with ASD from families in lower income groupings had significantly higher odds of never being invited

to activities, never seeing friends, or being involved in any extracurricular activities (Shattuck et al. 2011). Another personal factor that was reported to have an effect on participation of children with ASD was age. One study reported that diversity of participation in out-of-school activities reduced as children grew older (Hilton et al. 2008). However, this finding was not consistent across articles. Shattuck et al. (2011), in their study on social participation of adolescents with ASD, found that age, sex, race, ethnicity, and school-related factors were not significantly related to social participation outcomes. A number of studies also suggested that gender had no significant effect on participation of children with and without ASD (Reynolds et al. 2011; Rosser Sandt and Frey 2005).

Environmental Factors Natural environment including climate and animals/pets was deemed an important determinant. While good outdoor conditions (e.g., good weather and no insects) were perceived as facilitators of physical activities, bad outdoor conditions (e.g., inclement weather, allergies, or presence of insects) were reported as barriers to physical activities (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011). Aspects of the built environment, in terms of availability of parks and playgrounds in the community, were reported as facilitators for participating in physical activities (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011).

Lack of equipment, or unsafe equipment such as a broken racket, baseball bat, trampoline, or other playground equipment, or *products and technology*, was reported as barriers for participation in physical activities (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011). Facilitators to participation included the availability and quality of resources in or outside of house. Two studies found that the presence of direct exercise equipment such as a bike or scooter; supportive exercise equipment such as sneakers or a fan; a playground or a swimming pool at the house; and a good surface for walking or running could facilitate physical activity participation for children with ASD (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011).

Five papers provided evidence for the influence of *social supports* on participation. The support of parents, siblings, peers, and pets served as facilitators for participation (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011). Parents of children with ASD liked to take their children to community activities, as frequently as parents with typically developed children (Lam et al. 2010). Lack of support was cited as a barrier for participation in some studies. Parents did not have time; they did not let children go outdoors (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011; Howel and Pierson 2010) or engage in activities without their supervision (Thompson and Emira 2011). The lack of a peer partner for leisure pursuits was found to limit participation in physical activities (Obrusnikova and

Miccinello 2012; Obrusnikova and Cavalier 2011). Parents reported the lack of empathy and understanding from staff and service providers as a barrier to accessing leisure facilities (Thompson and Emira 2011).

Negative *attitudes* within communities can be a significant barrier to participation among children with ASD. Parents reported that members of their church did not understand autism and sometimes did not support their children in attending church (Howel and Pierson 2010). Results of a qualitative study revealed that vulnerability and exposure to bullying were barriers for children with ASD to access organized leisure activities (Thompson and Emira 2011). The same study also found that staff awareness and understanding had a significant impact on parents' and caregivers' experiences of access to leisure. Another study found that parents of children with ASD perceived that taking part in leisure and recreation activities is not as important as other community activities like shopping, going to restaurants, transportation, and health and personal care (Lam et al. 2010).

Services and policies that support participation were evident. Greater participation of youth with ASD was associated with availability of activity programs in the community (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011). Some schools provided after-school physical activities that promoted the participation of children with ASD in these activities (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011). Limited services including availability of accessible transportation services (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011), lack of community programs (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011), and access to information (Thompson and Emira 2011) were perceived as barriers to the participation of children and youth with ASD. Parents reported that mainstream settings didn't provide them with enough information about local availability of leisure facilities (Thompson and Emira 2011). A qualitative study found that staff training needs to be improved to familiarize them with children's and families' needs (Thompson and Emira 2011). On occasion, the school workload did not permit the children with ASD to participate in after-school physical activities (Obrusnikova and Miccinello 2012; Obrusnikova and Cavalier 2011).

Discussion

Although this review employed systematic and broad strategies to review evidence, only 16 relevant articles were found, indicating that existing knowledge about participation of children with ASD is limited. Moreover, evidence is descriptive in nature and about 70 % of articles (11 out of 16) focused only on the pattern of participation of children with ASD, with only

a few studies focused on characterizing determinants of participation. Furthermore, few studies used objective standardized measures of participation, and when used, were predominantly performed in children with HFASD. Future studies can focus on developing and testing models that predict participation among children with ASD across the entire spectrum while using standardized, psychometrically sound measures.

Overall, our findings suggest that participation of children with ASD in out-of-school activities is restricted. These children primarily participate in activities located in their home, alone or with family and other adults. Similar patterns were found in previous research among children with physical disabilities (Law et al. 2011; Bult et al. 2011; King et al. 2010; Engel-Yeger et al. 2009; Imms et al. 2008; Shikako-Thomas et al. 2008). Such findings lend further support to Law et al.'s assertion (2004) that participation is not necessarily diagnosis-specific and other predictors, such as those related to the functional abilities and family and environment characteristics, are important to consider when explaining child's involvement in activities. Further studies are needed, however, to tease out the differences and similarities across health conditions.

Given the nature and clinical representation of ASD, which usually involve social and communication impairments (APA 2000), one might expect that participation restrictions would be evident, particularly in social activities. However, findings suggest that participation restrictions are also observed in different types of activities including physical, recreational, and informal activities. Thus, when assessing participation, for both research and clinical purposes, it is important to address a range of activity categories/domains in order to capture a participation profile that is comprehensive and informative. The Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al. 2012) is an example of an assessment that includes a diverse set of activities while considering the subjective aspect of participation—an important dimension that was addressed in only few of the reviewed studies.

As expected, our findings revealed that core deficits of ASD (i.e., communication impairments, social deficits, and abnormal restrictive, repetitive, and stereotyped behaviors) as well as other characteristics associated with the disorder (e.g., maladaptive behavior) had an impact, for the most part, on children's participation. In addition to these ASD-related impairments, problems in gross and fine motor ability were equal barriers to participation of children with ASD. Comorbidity of physical and motor problems among children with autism is an emerging focus in the literature (Matson et al. 2011) and thus requires further attention.

Overall, this review, in congruence with the previous findings in the area of participation (King et al. 2006), indicates that the participation of children and youth with ASD in out-of-school activities is a complex phenomenon that is

influenced by a range of factors. As seen from our data, influential factors were related to the child's functions and abilities, for example, sensory function and communication and interpersonal relationships abilities as well as to aspects of their family and their environment. An important environment-based facilitator often reported included social supports from family and friends. In contrast, identified barriers within the environment involved negative attitudes, lack of support from family, and service providers as well as limited availability of programs and services. These findings support the assumption that diagnosis and its clinical manifestations are not the only important factor influencing participation, rather, the environment is very influential (Law et al. 2004). Although it may be difficult to change the ASD-related impairments such as cognitive and social relationship challenges, it may be feasible to modify the environment to facilitate participation. Further attention can be directed towards the environment as a potential focus of interventions aimed at promoting participation.

Negative social attitudes are critical as an important environmental barrier to the participation of children with ASD in out-of-school activities. This finding aligns with the results of the scoping review by Anaby and colleagues (Anaby et al. 2013) describing participation in children with a range of disability types. They found that the attitudinal domain was among the most important environmental factors that negatively affected participation of children with disabilities.

Research Gaps and Future Directions

This scoping review reveals several gaps in the literature. First, most of the articles in this scoping review focused on describing patterns of participation (11 out of 16); there was no study which investigated a wide range of determinants of participation comprehensively. The articles that identified potential predictor variables of participation addressed only a special activity (such as participation in physical activities—three articles), a special setting (church), or a specific determinant (media). So, there is a need for studies that examine a range of child-specific, family, and environmental determinants of participation in after-school-activities of children with ASD across different activity types and settings. Notably, most studies that applied objective standardized measures of participation were used on the subset of children with HFASD. Therefore, objective evidence on the extent and range of participation across the entire spectrum of children with ASD is needed, as is the determinants on this more representative population. Second, most of quantitative studies were cross sectional in nature and there is additional need for longitudinal studies that will consequently allow for causal inferences. Moreover, identified studies often compared children with ASD to a diverse range of groups (typically developed children, children with learning disorders, intellectual

disability, speech/language impairments, Attention Deficit Disorder, and developmental disabilities) which could lead to inconsistent findings.

Third, all of the qualitative studies focused specifically on parental perspectives; there were no studies that address the perspectives of children with ASD. Fourth, most of the studies were conducted in the USA (10 out of 16), so there is a gap for evidence within different cultural contexts and geographical locations, factors that are known to influence participation (Clover et al. 2012). Finally, our findings suggest that negative attitudes and social supports are important environmental factors associated with level of participation. Further examination of these factors is needed. Indeed, such environmental factors are potentially modifiable, thus future studies that develop and test interventions to minimize or nurture environmental conditions would be of interest. Our findings suggest that clinicians and researchers should be comprehensive in their measurement of participation, elucidating both subjective and objective aspects of participation while accounting for environmental barriers and supports. For example, the PEM-CY is such measure as it captures both frequency and involvement aspects of participation and directly links environmental features to participation in three different settings: home, school, and community (Coster et al. 2012).

Potential Implications

This scoping review can increase clinicians' and researchers' awareness of the concept of participation as an important outcome of rehabilitation in this population of interest. With increasing knowledge about the specific modifiable environment-based factors that are significant to children's participation, clinicians can engage and support parents with useful strategies for removing barriers and providing information about community programs for different activities, in order to promote their children's social inclusion. Clinicians can evaluate their clients individually and consider all ASD-related challenges and environmental factors that can negatively affect participation in order to choose the best intervention strategies.

Strengths and Limitations

The systematic and broad search of all the relevant articles published in academic journals is the strength of this study. Grey literature was not included in the search and therefore some relevant information may be missing. This study did not complete a quality assessment of studies in the review. However, evaluation of quality of studies is not typically conducted in scoping reviews due to the large variety of study designs and research approaches (Rumrill et al. 2010). Finally, the review focused only on out-of-school participation. This is because the structure and policies in school-based and out of

school-based participation can be different. The environmental factors have a unique impact on out-of-school activities, notably for leisure, and play important roles in child development and well-being (Larson 2000). Nevertheless, investigation of determinants of participation of children with ASD is an emerging area of research, and hence further attention can be directed to other areas of participation such as school-based activities in order to generate a more comprehensive synthesis.

Conclusion

Knowledge about participation of children with ASD is incomplete and for the most part is descriptive in nature. There are different factors that can positively or negatively affect participation in children and youth with ASD. Future studies can focus on testing a comprehensive model of determinants of participation of children with ASD while including environmental factors using advanced statistical methods (e.g., Structural Equation Modeling) to better understand the underlying mechanisms of participation in this high-risk population, and utilize longitudinal and semi-experimental designs to better understand evolution and intervention effects. Both practitioners and decision-makers can focus their attention on specific determinants, such as attitudinal challenges and social supports, in order to promote social participation and inclusive communities. The literature highlights a number of important environmental determinants, as compared to child-related deficits, suggesting a potential shift in practice from "fixing" the child to more environmentally-based approaches focused on modifying the task and/or the environment, to promote greater participation.

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