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ORIGINAL ARTICLE

Community participation and environment of children with and without autism spectrum disorder: parent perspectives

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ABSTRACT

Aim: This study explored parent perspectives of participation patterns and environmental supports and barriers for high-functioning children with autism spectrum disorder (ASD) within their communities compared with a group of children without ASD.

Method: The Participation and Environment Measure for Children and Youth was used to gather online data from parents of 99 children with ASD and 241 children without ASD. Mann–Whitney *U* test and chi-square tests were used to explore differences between groups and Cohen's *d* was calculated to examine effect sizes.

Results: Significant differences between children with and without ASD were observed for all participation and environment summary scores. Children with ASD participated less frequently, were less involved, and their parents were less satisfied with their child's participation in community-based activities. Parents of children with ASD also identified fewer supports for their child's participation and more environmental barriers than other parents.

Conclusion: Children with ASD participated less in community-related activities than children without ASD as perceived by their parents. Barriers limiting community participation included features of the social and physical environment and limited resources.

Significance: Occupational therapists should focus on decreasing environmental challenges in their efforts to facilitate participation of children with ASD in the community.

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Introduction

Increasingly, participation in occupations[1] is considered as a basis for a child's development, health and well-being [1–4]. Children's rights to participate in their communities and the importance of their joining in a wide range of cultural, artistic and other recreational activities are highlighted in article 31 of the United Nations Convention on the Rights of the Child [5]. Article 23 of the Convention emphasizes disabled children's right to special care and support so that they can live full and independent lives. Similarly, article 7 of the United Nations Convention on the Rights of Persons with Disabilities [6] highlights that all necessary measures shall be taken to ensure disabled children's full enjoyment of all human rights on an equal basis with other children. These rights declarations have led to an emphasis on promoting policies and practices that enable disabled children to belong, thrive and take part in their communities [7,8]. In the research agenda, there is also an increased emphasis on participation of disabled children, including the diversity and frequency of their occupations as well as their active involvement [9–13].

Throughout this article, the term 'disabled children' is used to signify that the disability arises in the interplay between the individual child (with an impairment) and society. Thus, disability is not considered as a condition of the child, as is implied by the phrase 'with disabilities', but rather something experienced as a result of social discrimination and exclusion [8,14]. In the past, disabled children's lack of participation was considered to be directly linked to their individual impairments; increasingly, however, environmental factors are considered to influence their interactions with their social surroundings [2,7,8]. In fact, compared with other parents, parents of disabled children consider the environment to be less supportive and report

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that their children encounter more environmental hindrances than other children [15–17]. Among the factors that reportedly limit disabled children's opportunities to participate in their communities are peer and adult attitudes, inaccessible built environments, as well as services, systems and policies that do not accommodate their needs [9,18–20].

Autism spectrum disorder (ASD) is a group of neurodevelopmental conditions that have in common deficits in social communication and interaction across multiple contexts, restricted and repetitive patterns of behaviour or interests and sensory issues [21]. A growing number of high-functioning individuals with ASD are being identified [22,23]. Numerous studies have focused on the epidemiology and symptoms of this group of children but there seems to be a dearth of information about their participation within their communities. Existing studies reveal nevertheless that children with ASD participate in fewer recreational occupations than other children [24–27], particularly occupations involving social relations [24,27,28]. Children with ASD also participate in fewer physical [24,25] and formal [25,28] occupations than same-age peers and are more likely to conduct their occupations in solitude or among adults [24,25,28]. Some former studies have not utilized measures that focus explicitly on participation in occupations and on occasion, they focus more on the frequency of certain behaviours than on the children's involvement, preferences and enjoyment while they participate.

Studies focusing on the recreational participation of children with ASD have typically had small samples ($n = 25$–52) that were selected by convenience [24,28,29]. To date, only one study has focused on the community participation of disabled children compared with children in general [15]. Since children with ASD may have more specific issues regarding their community participation than the larger group of disabled children, it is important to compare their community participation with that of children without ASD.

This study is part of a larger research project focusing on the quality of life, participation and environment of disabled children living in Iceland. This part of the study examined the views of parents of children with and without ASD about their child's community participation and the effect of the environment on this participation. The following questions were posed:

1. How is community participation of children with and without ASD similar or different?
2. What environmental factors support or challenge community participation of children with ASD?

Material and methods

Participants

Parents of 303 high-functioning children with ASD (258 boys and 45 girls), aged 8–17 years were invited to participate. 'High-functioning' is defined as IQ $\geq$80, and was seen as an important criterion to increase a child's capacity to read and respond to a questionnaire, which was essential for parts of the larger study where children's views were elicited [30]. The children were recruited from the registry of the State Diagnostic and Counselling Centre (SDCC), which keeps diagnostic records of the vast majority of children diagnosed with ASD in Iceland. The children were then paired to children without ASD for control ($N = 1.199$) from the national registry by gender, residence, year and month of birth.

Measure

The Icelandic version of the Participation and Environment Measure (PEM-CY) [31] was used to gather data. The PEM-CY is based on parent-report and examines children's participation within the home, at school and in the community, and accompanying items about the environment for each setting [32,33]. For each of the 10 types of community activities (Table 3), the parent is asked to identify how frequently the child participates (never = 0 to daily = 7); how involved the child is while participating (5-point scale ranging from very involved to minimally involved); and whether the parent would like to see the child's participation in this type of activity change (yes or no). If yes, the parent identifies what kind of change is desired.

Perceived support and barriers in the environment are assessed by 16 items (see Tables 4 and 5). The parent is asked whether certain environmental characteristics help or hinder their child's participation in community activities (response options: not an issue, usually helps, sometimes helps/sometimes makes harder, usually makes harder); and about perceived adequacy of resources such as information, money or supplies (response options: not needed, usually yes, sometimes yes/sometimes no, usually no). The PEM-CY summary and item scores can be calculated either as a raw score (average), percentage of a given answer, or as a percentage of maximum possible (POMP), which is appropriate where there may be missing data because not all items are applicable [33]. A POMP score of 0 represents the minimum possible score and 100 represents maximum possible score [34].

Four summary scores related to community participation are created (see Table 2):

a. Participates ever: The score is the percentage of parents who say that their children attend or participate in activities in the community, with higher scores reflecting a greater number of activities;
b. Participation frequency: The score reflects average ratings across all 10 items and is reported as a POMP score, with higher scores indicating greater frequency;
c. Level of involvement: Higher scores reflect greater involvement;
d. Desire for change: The score is the percentage of items where parents desire change, with higher scores indicating lower parental satisfaction with their children's participation.

For the environment, three summary scores (POMP) are generated (Table 2):

a. Environment support: Higher scores indicate more supportive environment;
b. Environment resources: Higher scores indicate more available/adequate resources;
c. Total environmental supportiveness: Higher scores reflect greater supportiveness.

Procedure

Initially, the PEM-CY was translated into Icelandic according to author translation guidelines and pilot-tested with parents of eight children with and without ASD. Then an electronic version of the PEM-CY that allowed questions to be presented one at a time was developed and hosted by the University of Akureyri Research Centre (UARC). The SDCC also provided the UARC with information about the ASD group to enable them to draw a sample of children without ASD from the national registry.

Prospective participants received introductory letters by regular mail. The letters contained a link to the study website and a keyword that enabled participants to answer the measure electronically. In the letters parents were informed that by responding to the measure they thereby gave consent for their participation in the study. Two weeks later, parents received a reminder phone call that also gave them an opportunity to ask questions and seek more information about the study. Additional e-mail reminders were sent a week later to both groups.

Participation was anonymous, ensuring that no personal information was attached to the electronic questionnaire, and the setup ensured that the researchers did not receive any personalized data about respondents. A professional with long experience working with families of children with ASD at the SDCC was responsible for communication with the parents of children with ASD while professionals at the UARC contacted the control group.

Data were gathered from November 2013 to January 2014. The Icelandic National Bioethics Committee approved the study (VSN-13-081).

Data analysis

The data analysis compares the two groups of children on summary scores and each participation and environment item. Not all participants completed the entire survey; therefore, the number included in each analysis varied. For participation and environment items Mann–Whitney U test was used to test differences for continuous scales (95% significance level) (frequency, involvement, environment summary scores) and chi-squared tests were conducted for categorical responses (i.e. never participates, desire for change, environment supports or barriers item score).

Effect sizes were calculated and evaluated by Cohen's d, with 0.2 considered as a small effect, 0.5 as moderate effect and $\geq$0.8 as large effect [35]. Spearman's rho was calculated to examine the association between parents' desire for change in their child's participation and the effect of the environment on the child's participation.

Results

Participants

Altogether, 99 caregivers of children with ASD and 241 caregivers of children without ASD completed valid questionnaires. Most respondents were mothers who had college or university degree, 57.6% for ASD group and 67.5% for children without ASD. The mean age of parents of children with ASD was 42.62 (SD = 6.85) and without ASD 43.7 (SD = 5.81). Mean age of children with ASD was 12.46 (SD = 3.14) and without ASD was 12.48 (SD = 2.67). Demographic differences between the groups (child gender and age, residence, and age and educational level of parents) were either not statistically significant ($p \geq 0.01$) or effect sizes were small ($d < 0.2$). Table 1 summarizes the sample characteristics.

PEM-CY summary scores

Significant differences between children with and without ASD were observed for all participation and

environment summary scores (see Table 2). Children with ASD participated less frequently and their levels of involvement were lower. More parents of children with ASD reported that they would like to see their child's participation change in community-based activities.

Parents of children with ASD also reported lower environmental supportiveness and resources for their child's community participation than other parents. Effect sizes comparing the magnitude of differences were large (0.81–1.18), except for number of activities performed in the community (0.7) with moderate effect.

Community participation item scores

Table 3 describes and compares participation at the item level for children with and without ASD. Across all participation dimensions, significant differences were found between the two groups on three types of activities: community events, organized physical activities, and getting together with other children in the community.

Less than 20% of parents in both groups reported that their children participated in religious or spiritual gatherings, and organizations, groups and clubs. This activity type showed no differences between groups across all participation dimensions.

The percentage of children with ASD who never participated was significantly higher than that of the children without ASD for five community activity types: community events, organized physical activities, getting together with other children in the community, working for pay, and overnight visits or trips.

The mean frequency of participation was significantly lower for children with ASD than for the children without ASD across seven activity types: neighbourhood outings, community events, organized physical activities, unstructured physical activities, classes and lessons, getting together with other children in the community, and overnight visits or trips. Effect sizes ranged from small to large with the largest effects for community events (0.92) and getting together with other children in the community (0.88).

The level of involvement of children with ASD was also significantly lower than among the children without ASD across seven activity types: neighbourhood outings, community events, organized physical activities, unstructured physical activities, getting together with other children in the community, working for pay and overnight visits or trips. Effect sizes ranged from small to large with the largest effect for unstructured physical activities (0.82).

Except for religious or spiritual gatherings significant differences between the two groups were obtained in parent's desire for change in all types of activities.

Across all community participation items, no effect was found specific to child's age, gender, residence or parent education.

Table 1. Participant characteristics.

Variable	Children with ASD, *n* (%)	Children without ASD, *n* (%)	*p*
Child gender			
Male	86 (86.9)	208 (86.3)	0.891
Female	13 (13.1)	33 (13.7)	
Child age (years)			
8–11	47 (47.5)	98 (40.7)	0.249
12–17	52 (52.5)	143 (59.3)	
Respondent relationship to child			
Mother	89 (89.9)	212 (88)	0.174
Father	7 (7.1)	28 (11.6)	
Stepmother	2 (2)	1 (0.4)	
Respondent age (years)			
28–39	33 (33.3)	54 (22.4)	0.156
40–49	51 (51.5)	151 (62.7)	
50–65	11 (11.1)	30 (12.4)	
Respondent education			
College or university degree	57 (57.6)	162 (67.2)	0.082
High school or less	42 (42.4)	78 (32.4)	
Type of community			
Capital area	61 (61.6)	153 (63.5)	0.953
Suburban (>4000 residents)	24 (24.2)	52 (21.6)	
Small town/rural	14 (14.2)	36 (14.9)	
Type of classroom			
Regular classroom	88 (88.9)	236 (97.9)	0.001
Special education class	11 (11.1)	5 (2)	

Not all participants provided information about all characteristics. Range for children with ASD is 96–99 and 235–241 for children without ASD. *p* is based on chi-square analysis.

Table 2. Community participation and environment summary scores for children with and without ASD.

Community summary scores	Mean (SD) Children with ASD	Children without ASD	*U* (*p*)	*d*
Participates ever, %	58.5 (16.6)	69.2 (13.8)	−3.992 (0.001)	0.70
Participation frequency, %	46.5 (15.1)	57.9 (11.5)	−6.425 (0.001)	0.85
Level of involvement	3.5 (1)	4.2 (0.7)	−5.661 (0.001)	0.81
Desire for change, %	57.3 (31)	27.6 (26.8)	−7.645 (0.001)	1.02
Environment supports, %	73.3 (20.7)	92.7 (13.2)	−8.64 (0.001)	1.12
Environment resources, %	77.3 (20.1)	93 (12)	−7.757 (0.001)	0.95
Percent total environmental supportiveness %	75.2 (17.5)	92.7 (11.5)	−9.189 (0.001)	1.18

d = Cohen's *d* (effect size) are reported for differences related to ASD and are rounded to 2 decimal points. Based on Cohen's (1988) criteria effect sizes 0.2 are considered small effect; 0.5 as medium effect and ≥0.8 as large effect.

Table 3. Community participation items for children with and without ASD.

Items	Participates ever, % (*n*)[a]			Freauency, mean ± SD[b]			Involvement, mean ± SD[b]			Desire for chance, % (*n*)[a]		
	With ASD	Without ASD	*p*	With ASD	Without ASD	*p* (*d*)	With ASD	Without ASD	*p* (*d*)	With ASD	Without ASD	*p*
1. Neighbourhood outings	99 (95)	99.1 (220)	0.905	4.12 (1.62)	4.55 (1.42)	0.035 (0.28)	3.62 (1.2)	4.12 (0.93)	0.001 (0.47)	55.6 (55)	26.1 (63)	0.001
2. Community events	82.5 (80)	94.1 (209)	0.001	2.16 (1.07)	3.25 (1.28)	0.001 (0.92)	3.34 (1.36)	4.11 (0.95)	0.001 (0.66)	64.6 (64)	29.5 (71)	0.001
3. Organized physical activities	67.7 (65)	87.8 (195)	0.001	5.22 (1.61)	5.98 (0.97)	0.001 (0.58)	3.65 (1.33)	4.56 (0.85)	0.001 (0.82)	71.7 (71)	22.1 (53)	0.001
4. Unstructured physical activities	89.7 (87)	95.5 (210)	0.052	4.83 (1.71)	5.39 (1.56)	0.004 (0.34)	3.56 (1.12)	4.29 (0.94)	0.001 (0.71)	73.7 (73)	36.1 (87)	0.001
5. Classes and lessons	42.7 (41)	47.7 (104)	0.413	3.93 (1.89)	4.87 (1.66)	0.002 (0.53)	3.83 (1.22)	4.12 (1.14)	0.134 (0.25)	67.7 (67)	32.4 (78)	0.001
6. Organizations, groups, clubs	13.5 (13)	14.7 (32)	0.791	3.92 (1.71)	4.03 (2.07)	0.554 (0.06)	3.62 (1.66)	3.97 (1.45)	0.477 (0.23)	53.5 (53)	32 (77)	0.001
7. Religious or spiritual gatherings and activities	11.5 (11)	17.6 (39)	0.169	3.18 (1.99)	3.59 (1.62)	0.499 (0.22)	3.45 (1.57)	3.71 (1.25)	0.708 (0.18)	29.3 (29)	19.5 (47)	0.049
8. Getting together with other children in the community	88.7 (86)	99.1 (217)	0.001	4.5 (1.84)	5.86 (1.18)	0.001 (0.88)	3.52 (1.28)	4.35 (0.87)	0.001 (0.76)	72.7 (72)	32.8 (79)	0.001
9. Working for pay	24 (23)	46.6 (103)	0.001	3.57 (1.93)	3.42 (1.72)	0.749 (0.08)	3.25 (1.39)	3.91 (1.1)	0.027 (0.53)	36.4 (36)	20.3 (49)	0.002
10. Overnight visits or trips	64.6 (62)	88.1 (193)	0.001	1.92 (0.93)	2.36 (1.07)	0.004 (0.44)	3.69 (1.24)	4.17 (1.02)	0.006 (0.42)	47.5 (47)	24.9 (60)	0.001

d = Cohen's *d* (effect size) are reported for differences related to ASD and are rounded to 2 decimal points. Based on Cohen's (1988) criteria effect sizes 0.2 are considered small effect; 0.5 as medium effect and ≥0.8 as large effect.
[a]Based on chi-square analyses.
[b]Based on Mann–Whitney *U* test analyses.

Community environment item scores

Table 4 describes and compares the extent of supports and barriers for children with and without ASD. Significant differences were obtained between parents' opinions of the effects of the environment on their child's participation on all items except physical layout. Apart from physical layout, approximately 33–70% of parents of children with ASD considered features of the environment either as supportive of their children's community participation or not an issue, compared with 79–92% of other parents. Additionally 6–27% of parents of children with ASD considered that environmental features made participation harder, compared with 1–4% of other parents. Across items, the most notable differences between the two groups were in social demands of activity, relations with peers, and cognitive demands of activity.

Significant group differences were also obtained between parents' opinions of the availability and adequacy of all environmental resources except for personal and public transportation (see Table 5). Apart from transportation, approximately 40–63% of parents of children with ASD considered that resources were available or adequate, compared with 79–94% of parents of children without ASD. The pattern was similar for lack of resources; approximately 5–20% of parents of children with ASD considered resources (other than transportation) to be lacking, compared with only 1–4% of other parents. About 20% of parents of children with ASD considered information not available/adequate compared with 2% of other parents; 17% of parents of children with ASD considered programs and services not available/adequate, compared with 1% of other parents; and 13% of parents of children with ASD considered money not available/adequate, compared with 4% of other parents.

For all environmental items, the same factors were reported as barriers to the participation of younger and older children. No effect was found specific to gender, residence or parent education. A significant ($p \leq 0.001$) negative correlation was found between the desire for change score and environmental supportiveness total score in both groups (children with ASD = −0.531; children without ASD = −0.484; the sample as a whole = −0.608).

Discussion

In this study, limited participation of high-functioning children with ASD in activities involving social relations was reflected in all three participation

Table 4. Supportiveness of the community environment: chi-squared comparisons of children with and without ASD.

	Usually helps/not an issue		Sometimes helps/sometimes makes harder		Usually makes harder		
Items	With ASD	Without ASD	With ASD	Without ASD	With ASD	Without ASD	*p*
1. Physical layout	91.6 (87)	92.1 (197)	7.4 (7)	6.4 (14)	1.1 (1)	1.4 (3)	0.937
2. Sensory qualities	63.2 (60)	92.1 (198)	30.5 (29)	7 (15)	6.3 (6)	0.9 (2)	0.001
3. Physical demands of activity	63.5 (60)	91.1 (195)	24.2 (23)	7.9 (17)	12.6 (12)	0.9 (2)	0.001
4. Cognitive demands of activity	51.1 (48)	89.1 (188)	40.4 (38)	9 (19)	8.5 (8)	1.9 (4)	0.001
5. Social demands of activity	33 (31)	85.5 (183)	40.4 (38)	10.7 (23)	26.6 (25)	3.7 (8)	0.001
6. Relationships with peers	38.9 (37)	83.3 (179)	42.1 (40)	15.8 (34)	18.9 (18)	0.9 (2)	0.001
7. Attitudes	53.7 (51)	87.3 (186)	37.9 (36)	11.7 (25)	8.4 (8)	0.9 (2)	0.001
8. Weather	59.4 (57)	79.2 (171)	27.1 (26)	19.4 (42)	13.5 (13)	1.4 (3)	0.001
9. Safety	70.2 (66)	85 (182)	23.4 (22)	13.1 (28)	6.4 (6)	1.9 (4)	0.006

Values are % (*n*). *p* based on Pearson chi-square analyses (significance level set at $p \leq 0.01$).

Table 5. Availability/adequacy of environmental resources: chi-squared comparisons of children with and without ASD.

	Usually yes		Sometimes yes, sometimes no		Usually no		
Items	With ASD	Without ASD	With ASD	Without ASD	With ASD	Without ASD	*p*
1. Personal transportation	91.8 (89)	96.8 (211)	6.2 (6)	2.3 (5)	2.1 (2)	0.9 (2)	0.151
2. Public transportation	85.3 (81)	89.9 (195)	8.4 (8)	8.3 (18)	6.3 (6)	1.8 (4)	0.117
3. Program and services	61.5 (59)	94 (204)	21.9 (21)	4.6 (10)	16.7 (16)	1.4 (3)	0.001
4. Information	39.8 (37)	88.6 (187)	39.8 (37)	9.5 (20)	20.4 (19)	1.9 (4)	0.001
5. Equipment and supplies	63.3 (57)	87.6 (184)	27.8 (25)	9 (19)	8.9 (8)	3.3 (7)	0.001
6. Time	51.6 (49)	79.4 (170)	43.2 (41)	18.7 (40)	5.3 (5)	1.9 (4)	0.001
7. Money	55.3 (52)	79.2 (168)	31.9 (30)	17 (36)	12.8 (12)	3.8 (8)	0.001

Values are % (*n*). *p* based on Pearson chi-square analyses (significance level set at $p \leq 0.01$).

dimensions as measured by the PEM-CY: frequency, involvement and parent satisfaction. These results echo those of other studies that have found more limited participation of high-functioning children with ASD in recreational activities that entail some kind of social components, compared with same-age peers [25,28]. Lack of close social or friendship relations may affect these children's opportunities of getting together with other children and participating in various events within their communities [24,25,28,36,37]. Then again the findings may also reflect different preferences of children with ASD and children in general, such as placing more importance on activities performed in solitude or together with parents, or that they prioritize the quantity of time they spend with another individual rather than close relations [30,37]. Since this study reflects the views of parents, it should also be noted that the views of children with ASD and their parents on the children's quality of or contentment with social relations may differ [38]. In a previous study involving the same population of children [30], it was found that even though the children with ASD reported difficulties in social relations as well as often being alone, they did not necessarily consider themselves lonely. Their parents, on the other hand, were very concerned about their child's social well-being. Parents' less positive appraisal of their child's social functioning may reflect that they more readily accept the social construction of normality [39] as to what is adequate or preferable in terms of social relations. Ideally the perspectives of both children and their parents should be sought in order to acknowledge the complexities of the children's social participation and to outline ways to foster their social relationships.

In this study children with ASD also participated less frequently in organized and unstructured physical activities, they were less involved, and their parents more often desired change in such activities than did parents of other children. These findings also correspond with the previous study [30], where both the children with ASD but particularly their parents reported concerns for the children's physical well-being. Interestingly, participation in religious or spiritual gatherings and activities showed no differences between the two groups of children across all PEM-CY scales.

Overall, more group differences were found in the environment section than in the participation section. The significant differences in many item-level comparisons and the large effect size in the overall environmental supportiveness summary score reflect great disparities between the two groups of children.

The environmental factors that parents of children with ASD most often considered as either not supporting or directly hindering their child's participation included the social, cognitive and physical demands of activities, as well as relations with peers. Many occupations involve both social and physical features and

some activities that may appear primarily physical in nature, such as team sports, also involve social demands [40]. The complex interrelation between social and physical aspects is highlighted in a recent study [41] that found the primary barrier for physical activity engagement of high-functioning children with ASD to be lack of a peer partner, while supportive or physically active friends was the most important facilitating factor. Often physical activities include organization and praxis, and also occur in crowds, which may be challenging for children with ASD [25,42]. In order to support community participation of children with ASD the features of relevant activities may need to be modified, especially those that include social and physical aspects. This involves educating those who associate with children with ASD, such as their parents, friends and teachers.

Although parents of children with ASD have described how diverse sensory experiences may complicate their children's partaking [43–45], only a few parents in this study considered sensory quality as a barrier to their children's participation in the community. Then again, almost none of the other parents considered sensory quality as a barrier. Although few parents of children with ASD reported attitudes of others as a barrier to their child's participation, they were much less likely to report attitudes as supports.

The lack of information, suitable programs and services, equipment and supplies reported in this study is consistent with previous research showing that parents of children with ASD often are critical of the provision of services and information they receive, especially as their child gets older [46–48]. The fact that more parents of children with ASD considered money as usually inadequate compared with other parents, may reflect more financial hardship among families of children with ASD, which is in keeping with a recent review study pointing to high costs of supporting children and youth with ASD [49]. Financial resources clearly affect families' opportunities to enable their children to participate in costly recreational activities such as organized sports.

Much of the available evidence regarding the effect of the environment on participation is focused on children with physical impairments [18] and to our knowledge the specific environmental challenges that high-functioning children with ASD may face in their community participation have not been explored until now. There are, however, many similarities between the results of this study and those of Bedell and colleagues [15], e.g. the environmental barriers most frequently reported focused on the features and demands of the activity itself. The fact that some of the same areas identified as barriers for some parents of children with ASD were identified as supports or as not needed/not an issue for others reflects the importance of acknowledging individual variations, focusing on each child within his or her context.

The negative correlation between parent satisfaction (as reflected in their desire for change) and the environmental supportiveness total score in both groups illustrates the role of contextual features on children's possibilities to participate and underscores the importance of considering an activity and a setting as a joint entity [32,50,51]. In order to foster such place-based participation, key factors and processes that account for children's experiences of attendance (being in a place) and involvement in everyday life need to be specified [52]. It has been pointed out that attendance in a setting is strongly influenced by the availability, affordability and accessibility of appropriate supports, each of which can be best advocated for at policy and service levels. A child's involvement, however, is related to how accommodating and acceptable the setting is both to the child and to others with whom he or she participates in occupations [11,13]. This study provides an important understanding of the environmental characteristics that may enhance or restrict the attendance and involvement of children with ASD in community settings [50]. Further investigation into this area may outline more specific ways to promote their participation through acceptances, accommodations and services.

Although the importance of the environment for participation and well-being is increasingly stressed in the literature, this has not been reflected in research, much of which may in fact serve to reproduce and re-inscribe prevailing cultural ideologies about ASD. Hammell [53] encourages occupational therapists to question dominant assumptions, taken-for-granted ideas and practices reinforcing the ideology that impairments are the 'reason' for diminished social participation of disabled persons (p. 241). The lack of environmental supports for children with ASD in this study reflects how their diminished community participation may relate to the effects of different contexts, discriminatory practices, and even poverty. Thus, attention should be directed to the social, cultural, economic and political aspects that influence the community participation of children with ASD, as well as the way in which social processes and cultural images create and re-recreate their disability [8,53]. Also, when the community participation of these children falls short of universal human rights standards, it should be

understood as a human rights violation and not as resulting from their impairment or immaturity.

Strengths and limitations

This study had a higher number of participants than previous studies focusing on the community or recreational participation of high-functioning children with ASD [25]. An additional strength of the study is the fact that the control group was not a convenience sample but population-based and chosen according to the same criteria as parents of children with ASD on the basis of their child's gender, date of birth and residence.

The relatively low response rate is nevertheless a limitation to this study. In addition, the information about the children's participation and environment was gained only from parents, and the views of children with ASD and their parents often differ [30,54,55]. In particular, aspects of involvement – such as affect, motivation, and social connection – may best be evaluated through direct response from the child [13]. Mothers constituted a great majority of respondents in this study, with over-representation of parents with college degrees. This echoes the experiences of those who have found that families with higher education seem more willing to participate in studies [56]. Nevertheless, it should be noted that parent's education was not found to be associated with differences in ratings. No information was gathered about the financial resources of the participating families or about services received other than special education services. Lastly, it is not known whether parents of children with co-occurring impairments in addition to ASD may have different experiences, since no information was gathered about these issues.

Conclusion

This study shows more limited community participation of children with ASD compared to children without ASD as reported by parents. It also reflects a striking lack of environmental supports and resources which might enable children with ASD to attend and be more involved in their communities. These findings challenge occupational therapists to extend their focus from the impairment of the child to the impact of environmental arrangements in order to facilitate community participation of children with ASD.

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Disclosure statement

The authors report no conflicts of interest.

Note

1. The term "occupations" is used here in accordance with accepted terminology in the context of occupational therapy. However, the Participation and Environment Measure (PEM-CY) uses the term "participation in activities". Throughout this article, these two terms are used selectively in context, according to whether they reflect the occupational therapy perspective, or refer to the PEM-CY analysis.

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