

# Parent perspectives on home participation of high-functioning children with autism spectrum disorder compared with a matched group of children without autism spectrum disorder

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## Abstract

Few studies have focused on home participation of high-functioning children with autism spectrum disorder. We employed a mixed-methods design to explore and compare parent perspectives on (1) participation of children with and without autism spectrum disorder in activities at home, (2) the environmental features and resources that affect these children's home participation and (3) the strategies parents use to help their children participate at home. The Participation and Environment Measure for Children and Youth (PEM-CY) was used to gather online survey and qualitative data from parents of 99 high-functioning children with autism spectrum disorder and 241 children without autism spectrum disorder. Independent sample *t*-tests and  $\chi^2$  tests were used to explore differences between groups, and Cohen's *d* was calculated to examine effect sizes. Differences were obtained on all Participation and Environment Measure for Children and Youth dimensions but particularly when comparing parents' satisfaction and perceived environmental barriers to their children's participation. The qualitative analyses revealed that parents in both groups used similar strategies to facilitate their children's participation at home, although parents of children with autism spectrum disorder made use of more distinct modifications. Our results highlight the importance of environmental aspects and point to how practitioners can support families in their efforts to promote their child's participation at home.

## Keywords

autism, children, environment, home participation, parent-report, Participation and Environment Measure for Children and Youth, strategies

## Introduction

The importance of the home environment for children's positive development and well-being has been emphasised (Bronfenbrenner, 1986; Conger and Donnellan, 2007). Within the home, the child connects with other family members, and learns and develops through participation in leisure and pleasure activities as well as responsibilities (Anaby et al., 2013; Lawlor, 2003). Within Western societies, this includes playing with toys, pursuing hobbies, using the computer, watching television, managing personal care, doing homework for school and participating in household chores. Significant differences between children and youth with and without

disabilities have been described with parents of children with disabilities reporting lower levels of participation, more perceived environmental barriers and fewer supports to their children's participation in their homes

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(Amaral et al., 2014; Anaby et al., 2014; Dunn and Gardner, 2013; Law et al., 2013).

The extent to which children with autism spectrum disorder (ASD) participate in activities at home has not received much explicit attention in research. Our scattered knowledge about this topic comes mainly through information about participation in leisure activities, some of which occur within the home (Kramer et al., 2012; Little et al., 2014; Potvin et al., 2013) and from measures of adaptive behaviour (Bal et al., 2015; Duncan and Bishop, 2015) which focus on function and on activities required for personal and social self-sufficiency. Studies report that children and adolescents with ASD spend comparatively more time than other children engaged in discretionary solitary activities such as watching television and using the computer, and less time doing social activities within their homes (Orsmond and Kuo, 2011; Potvin et al., 2013; Shattuck et al., 2011). The literature on family routines provides additional information about the interactions of children with ASD and their families at home (Bagby et al., 2012; Boyd et al., 2014; Evans and Rodger, 2008; Larson, 2006; Marquenie et al., 2011; Schaaf et al., 2011) and highlight the importance of structure, predictability and the relevant adaptations that families make in order to facilitate family bonding and shared participation in activities at home.

Challenges in participation faced by children with ASD have been considered to be for the most part related to their underlying impairments, such as their lack of social and communication skills (American Psychiatric Association, 2013; Shattuck et al., 2011). Then again, environmental features may either support or restrict these children's possibilities of participating in activities at home. These features include sensory issues such as noise and lighting (Bagby et al., 2012), space and physical layout of the home, and the social and cognitive demands involved in various activities (e.g. regarding concentration, attention and interaction with others). The availability of relevant resources, services and supplies may also facilitate participation and well-being of the child and family at home (Hodgetts et al., 2015; McConnell et al., 2014).

This study is part of a larger research project focusing on the quality of life, participation and environment of children with disabilities living in Iceland (Egilson et al., 2016a, 2016b). This part of the study compared the views of parents of children with and without ASD about their child's participation in the variety of activities typically performed in the home and the extent to which features of the environment facilitate or restrict home participation. We also wanted to shed light on the strategies parents use to promote their child's participation in activities at home. The following questions were posed.

1. How does participation of children with ASD in activities at home compare with that of children without ASD?

2. What environmental factors support or restrict participation of children with ASD in activities at home compared with participation of children without ASD?
3. Which strategies do parents of children with and without ASD use to help their children participate successfully in activities at home?

## Methods

A mixed-methods approach was utilised, combining survey data and qualitative data from an open question in an embedded design (Creswell, 2014). Survey data were utilised to answer the first two research questions, and qualitative data were used to support and augment the larger quantitative design and primarily to answer the third question.

## Participants

Parents of 303 high-functioning children with ASD ( $IQ \geq 80$ ), aged 8–17 years, were invited to participate. Their children, 258 boys and 45 girls, were recruited from diagnostic records for the vast majority of children diagnosed with ASD in Iceland, held in the State Diagnostic and Counselling Centre (SDCC) registry. Subsequently, the children were paired to a control group ( $N=1.199$ ) from the national registry by gender, residence, year and month of birth. The response rate among parents of children with ASD was 32.7% ( $n=99$ ) and 20% ( $n=241$ ) for parents of children without ASD. Most respondents were mothers who had a college or university degree, 57.6% for children with ASD and 67.2% for children without ASD. Table 1 summarises the characteristics of the participating parents and their children.

## Measure

The home section of the Icelandic version of the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al., 2010) 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 effects of environmental features for each setting. The measure was explicitly designed to obtain information on issues that could help guide policy and service design and delivery decisions (Coster et al., 2012). In the PEM-CY, participation is operationalised with three measurement dimensions: (1) frequency, (2) extent of involvement and (3) desire for change. Information on the number and diversity of activities in which a child participates (ever/never) is also gathered. For each of the 10 types of activities in the home section, the parent is asked to identify how frequently the child participates (8-point scale ranging

**Table 1.** Characteristics of the participating children and their parents.

Variable	Children with ASD, n (%)	Children without ASD, n (%)
Child gender		
Male	86 (86.9)	208 (86.3)
Female	13 (13.1)	33 (13.7)
Child age (years)		
Children (8–11)	47 (47.5)	98 (40.7)
Adolescents (12–17)	52 (52.5)	143 (59.3)
Respondent relationship to child		
Mother	89 (89.9)	212 (88)
Father	7 (7.1)	28 (11.6)
Stepmother	2 (2)	1 (0.4)
Respondent age (years)		
28–39	33 (33.3)	54 (22.4)
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)
High school or less	42 (42.4)	78 (32.4)
Type of community		
Capital area	61 (61.6)	153 (63.5)
Suburban (>4000 residents)	24 (24.2)	52 (21.6)
Small town/rural	14 (14.2)	36 (14.9)
Type of classroom <sup>a</sup>		
Regular classroom	88 (88.9)	236 (97.9)
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 without ASD is 235–241.

<sup>a</sup>A significant difference between the two groups:  $\chi^2 = 19.258$ ,  $df = 3$ ,  $p < 0.01$ .

from daily=7 to never=0); how involved the child is while participating (5-point scale ranging from very involved=5 to minimally involved=1); and whether the parent would like to see the child's participation in this type of activity change (no or yes). If yes, the parent is asked to clarify the type of change desired in terms of frequency, level of involvement and/or participation in a broader variety of activities (five options). Participation items (activity types) are listed in Table 2.

Perceived support and barriers in the home environment are assessed by 12 items. The parent is asked whether certain environmental features help or make it harder for their child to participate in activities at home on a four-point scale (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). Environmental features are listed in Tables 3 and 4. The PEM-CY item scores can be calculated either as a raw

score (average), percentage of a given answer or as a percent of maximum possible (POMP). The latter is appropriate where there may be missing data because not all items are applicable (Coster et al., 2011). A POMP score of 0 represents the minimum possible score and 100 represents maximum possible score (Cohen et al., 1999). Reliability and validity of the measure have been found to be acceptable for application in population studies (Coster et al., 2011).

In addition to survey items, parents were asked to answer the following question: 'What are some things that you or other family members do that help your child participate successfully in activities at home' and to describe up to three strategies they currently use. These data constitute the qualitative part of the study.

### Procedure

Initially, the PEM-CY was translated and adapted into Icelandic according to the authors' translation guidelines comprising forward/backward translation and an expert committee review. Thereafter, the questionnaire was pilot tested with parents of eight children with and without ASD. An electronic version of the PEM-CY that allowed questions to be presented one at a time was then developed and hosted by the University of Akureyri Research Centre (UARC). The SDCC provided the UARC with information about the ASD group to enable them to draw a sample of children for control from the national registry.

Prospective participants received introductory letters by regular mail. The letters contained a link to the study website and a password that enabled participants to answer the measure electronically. After 2 weeks, parents received a reminder phone call, which also gave them an opportunity to ask questions and seek more information about the study. Two additional reminders were sent by e-mail to parents in 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 personalised information about respondents. Data were gathered from November 2013 to January 2014. The Icelandic National Bioethics Committee (VSN-13-081) approved the study.

### Data analyses

The quantitative and qualitative datasets were analysed separately and then compared and contrasted to identify convergence and divergence between the two sources of information.

**Survey data.** The analyses compared the ASD and control groups on each participation and environment item. In keeping with the guidelines, a score was not calculated if two or more questions were left unanswered. A total of 14

**Table 2.** Differences in home participation activity types scores.

Participation items	Ever (%) <sup>a</sup>		Frequency, mean (SD) <sup>b</sup>		Involvement, mean (SD) <sup>b</sup>		Desire change (%) <sup>a</sup>		p-value
	Children with ASD	Children without ASD	Children with ASD	Children without ASD	Children with ASD	Children without ASD	Children with ASD	Children without ASD	
1. Computer and video games	100	100	6.74 (0.53)	6.73 (0.68)	4.53 (0.88)	4.21 (0.99)	71.7	63.5	0.146
2. Indoor play and games	88.9	88.4	4.42 (2.06)	4.12 (1.97)	3.36 (1.49)	3.48 (1.43)	73.7	57.7	0.005
3. Arts, crafts, music and hobbies	90.9	96.3	5.81 (1.53)	5.82 (1.52)	3.92 (1.29)	3.98 (1.1)	61.6	47.7	0.020
4. Watching television, videos and DVDs	100	99.2	6.7 (0.58)	6.66 (0.64)	4.46 (0.81)	4.23 (0.9)	66.7	57.3	0.108
5. Getting together with people	98	99.2	6.58 (0.81)	6.83 (0.6)	3.54 (1.14)	4.37 (0.9)	69.7	29.9	0.001
6. Socialising using technology	97	95	5.8 (1.51)	6.15 (1.42)	3.70 (1.24)	3.99 (1.23)	54.5	29.9	0.001
7. Household chores	93.9	96.3	5.06 (1.55)	5.51 (1.33)	2.78 (1.21)	3.24 (1.12)	90.9	80.1	0.015
8. Personal care management	99	98.3	6.74 (0.68)	6.93 (0.35)	3.76 (1.21)	4.49 (0.86)	66.7	25.3	0.001
9. School preparation	75.8	92.5	5.4 (1.92)	6.39 (0.98)	3.25 (1.33)	3.89 (1.11)	80.8	53.1	0.001
10. Homework	90.9	95.9	6.14 (1.08)	6.35 (0.72)	3.66 (1.23)	4.2 (1)	66.7	44	0.001

d = Cohen's *d* (effect sizes) are reported for differences related to ASD and are rounded to 2 decimal points. Based on Cohen's (1988) calculation, effect sizes 0.2 are considered small, 0.5 medium and  $\geq 0.8$  large.

<sup>a</sup>Based on  $\chi^2$  analyses.

<sup>b</sup>Based on *t*-test analyses.

**Table 3.** Differences in home environment: supports and barriers.

Environment items	Usually helps/not an issue		Sometimes helps, sometimes makes harder		Usually makes harder		p-value <sup>a</sup>
	Children with ASD	Children without ASD	Children with ASD	Children without ASD	Children with ASD	Children without ASD	
1. Physical layout	90.8 (89)	92.2 (213)	6.1 (6)	7.4 (17)	3.1 (3)	0.4 (1)	0.130
2. Sensory qualities	71.4 (70)	90 (207)	25.5 (25)	9.6 (22)	3.1 (3)	0.4 (1)	0.001
3. Physical demands of activities	65.6 (63)	90.9 (209)	25 (24)	7.8 (18)	9.4 (9)	1.3 (3)	0.001
4. Cognitive demands of activities	61.9 (60)	84.1 (191)	27.8 (27)	14.5 (33)	10.3 (10)	1.3 (3)	0.001
5. Social demands of activities	51 (50)	89.2 (206)	36.7 (36)	10 (23)	12.2 (12)	0.9 (2)	0.001
6. Child's relationships with family members	58.2 (57)	88.3 (204)	39.8 (39)	10.4 (24)	2 (2)	1.3 (3)	0.001
7. Attitudes of others	84.1 (69)	94.9 (205)	13.4 (11)	4.2 (9)	2.4 (2)	0.9 (2)	0.009

Values are in % (n).

<sup>a</sup>Based on  $\chi^2$  analysis.

**Table 4.** Differences in home environment: availability/adequacy of resources.

Environment items	Usually yes/not needed		Sometimes yes, sometimes no		Usually no		p-value <sup>a</sup>
	Children with ASD	Children without ASD	Children with ASD	Children without ASD	Children with ASD	Children without ASD	
1. Services in the home	74.5 (73)	94.4 (219)	19.4 (19)	4.3 (10)	6.1 (6)	1.3 (3)	0.001
2. Supplies in the home	76.5 (75)	93 (214)	23.5 (23)	6.5 (15)	0 (0)	0.4 (1)	0.001
3. Information	59.8 (58)	89.1 (205)	35.1 (34)	9.6 (22)	5.2 (5)	1.3 (3)	0.001
4. Time	45.9 (45)	71.2 (166)	46.9 (46)	27 (63)	7.1 (7)	1.7 (4)	0.001
5. Money	53.6 (52)	77.7 (181)	33 (32)	18.9 (44)	13.4 (13)	3.4 (8)	0.001

Values are in % (n).

<sup>a</sup>Based on  $\chi^2$  analysis.

questionnaires were excluded based on that criteria. Data were first screened via visual inspection and normality statistics to ensure that they met assumptions of normality. *t*-tests were used for continuous scales (i.e. participation frequency and involvement) and the level of significance was set at 0.01 to reduce the chance of Type I error. Chi-squared analyses were conducted for categorical responses (i.e. item scores for ever participates, desire for change and environment supports or barriers). Effect sizes were calculated and classified by Cohen's *d*, with 0.2 considered a small effect, 0.5 a moderate effect and  $\geq 0.8$  a large effect (Cohen, 1988). Not all participants completed the entire survey; as a result, the number included in each analysis varied. Pearson's *r* was calculated to examine whether there was an association between extent of parents' desire for change and perceived supportiveness of the environment.

**Qualitative data.** Altogether, 246 responses were received from parents of children with ASD and 431 from parents of children without ASD to the open question about the strategies parents used to promote participation at home. These answers were grouped and organised by characteristics in ATLAS.ti in line with the NCT-model of qualitative data analysis (Friese, 2014; Seidel, 1998). Initially, 48 codes were constructed by naming and defining actions and processes described by parents and trying to make sense of these in terms of similarities and differences. The initial codes were sorted, compared and contrasted and then collapsed into a scheme of 30 codes that were further scrutinised and compared during second-stage coding, presenting patterns for exploration and reflection. The main patterns of strategies used by parents were subsequently organised under seven categories. Initially, two team members independently coded the qualitative responses with 95% agreement. They then discussed, compared and merged similar codes. Full agreement was reached in identification of the final categories.

## Results

### Home participation

Comparison of home participation item scores for the two groups of children can be seen in Table 2. No difference was obtained on the percentage of children who participated in specific activity types (ever participates) except for school preparation, where children with ASD scored lower. The mean frequency of participation in home activities among children with ASD was significantly lower than among children in the control group in three activity types: getting together with people ( $t(140.363)=-2.75$ ,  $p<0.007$ ), household chores ( $t(323)=-2.60$ ,  $p<0.01$ ) and school preparation ( $t(87.257)=-4.29$ ,  $p<0.001$ ). Effect sizes were small, except for school preparation with moderate effect size.

Parents of children with ASD reported significantly lower mean involvement in five types of activities: getting together with people ( $t(146.443)=-6.37, p<0.001$ ), household chores ( $t(312)=-3.1-22, p<0.001$ ), personal care management ( $t(135.380)=-5.36, p<0.001$ ), school preparation ( $t(286)=-4.04, p<0.001$ ) and homework ( $t(136.348)=-3.64, p<0.001$ ). Effect sizes for these activity types ranged from small to large with the largest effects for getting together with people. The mean involvement of participation was significantly higher among children with ASD in computer and video games than among peers ( $t(335)=2.787, p=0.006$ ), but with a small effect size.

Compared with parents of children without ASD, more parents of children with ASD desired change in their child's home participation. Significant group differences were found in six types of activities: indoor play and games, getting together with people, socialising using technology, personal care management, school preparation and homework. The largest differences (40%) were obtained for personal care management ( $\chi^2(1, n=335)=51.288; p=0.001$ ) and getting together with people ( $\chi^2(1, n=333)=45.845; p=0.001$ ). Across all activity types, only small and inconsistent differences were found specific to child's age, gender, residence or parents' education.

### Home environment

Parents of children with ASD considered fewer environmental features to facilitate and more features to restrict their children's participation at home than did other parents, who typically considered environmental features either as helpful or not an issue, and reported few hindrances. Parents of children with ASD were also more likely than other parents to consider environmental features as sometimes a help and sometimes a hindrance. Most hindrances were reported with regard to social, cognitive and physical demands of activities. Physical layout was the only item that showed no significant difference between groups (see Table 3).

Table 4 describes the availability and adequacy of environmental resources for both groups. Significant group differences were found for all items, as parents of children with ASD reported less often than other parents that environmental resources were available or adequate, and they reported a lack of these resources more often. Most differences were found regarding information ( $\chi^2(1, n=327)=37.313; p=0.001$ ), time ( $\chi^2(2, n=331)=21.349; p=0.001$ ) and money ( $\chi^2(2, n=330)=22.234; p=0.001$ ). Approximately 46%–60% of parents of children with ASD considered information, time and money to be adequate compared with 71%–89% of other parents. For all environmental items, the same factors were reported as barriers to the participation of children (8–11 years) and adolescents (12–17 years).

A significant negative correlation ( $r=-0.47, n=334, p<0.01$ ) was obtained between all parents' desire for change in their child's participation and how they perceived the supportiveness of the environment. Parents who perceived the environment to be less supportive of their children's participation reported a higher score of desire for change. The same pattern of relations, with only small variations in magnitude was found in both groups as was found for the sample as a whole.

### Strategies used to promote participation at home

The main patterns of strategies used by parents were organised under seven categories (listed in order of frequency): (1) *have positive interactions*, (2) *provide structure, guidelines and rules*, (3) *accommodate, adjust and prevent disputes*, (4) *educate and instruct*, (5) *make quality time* (6) *support interests and relationships with friends* and (7) *scold and reprimand* (see Table 5). All categories included strategies used by both parent groups, except for scold and reprimand, which seldom emerged and only among parents of children without ASD. Although both groups in fact utilised similar strategies, there was often a difference in descriptions of what they actually did, how or how often. Typically, parents of children with ASD were more specific in their descriptions and also made use of more distinct strategies, as is evident in some of the quotes in Table 5.

*Having positive interactions* was the largest category among both parent groups. This included being encouraging and supportive, which was the single most common strategy described. Other strategies within this category were keeping an overall positive outlook, involving the child in family activities, discussing matters in positive terms and complimenting the child for work well done.

*Provide structure, guidelines and rules* consisted of arrangements designed to structure and orchestrate daily tasks and routines. Parents in both groups described setting firm limits, for example, regarding computer use, and that their child had to help out with specific chores at home and also adhere to specific rules – as anyone else in the family. Use of visual supports and simple instructions were listed among parents of children with ASD, whereas only parents of children without ASD reported use of formal discipline.

Within the category of *accommodate, adjust and prevent disputes*, strategies like giving enough time and being there when needed were used frequently by both groups. Then again, parents of children with ASD much more often reported that they specifically chose, modified or adapted tasks and situations for their child. This entailed timing and thorough planning in advance so that their child had a better possibility of succeeding. These parents also made more use of reinforcements and reward systems than did other parents.

**Table 5.** Strategies used by parents.

Categories <sup>a</sup>	Quotes	
	Parents of children with ASD	Parents of children without ASD
Have positive interactions	We encourage her to participate and compliment her on tasks well done. We use and practice cooperation and helpfulness.	I try to be encouraging and positive. I encourage him to go with me to the stable.
Provide structure, guidelines and rules	We give him simple instructions. There are rules in the home that everyone has to follow.	We give him appropriate chores, i.e. taking out the trash.
Accommodate, adjust and prevent disputes	We use a visual timetable and a reward system. We try to prepare him well for any alternative situations and upcoming changes.	We try to adapt his chores in a fun way. Sometimes he gets a small reward for good and active participation, e.g. in housework.
Educate and instruct	We practice relations with family members through games and play. We direct and instruct him through his chores.	We offer help with homework and guide him through certain procedures.
Make quality time	We have family game nights.	He spends time with his father building things in the garage. Also we play cards, talk and have a nice time together.
Support interests and relationships with friends	Our home is open for friends who practice playing musical instruments with him, and to meet and talk.	The house is always open for her friends. We support his participation in sports and leisure activities.
Scold and reprimand		I often need to scold and reprimand him to get him to do his chores.

<sup>a</sup>Listed in order of frequency.

Educate and instruct. Both parent groups described teaching certain skills, coaching and using joint problem solving. They also followed up on matters and used general cues or reminders when necessary. Parents of children without ASD more often mentioned help with homework as one of their strategies, while parents of children with ASD more often described giving specific directions and instructions in relation to chores.

*Make quality time* consisted of strategies such as family outings, 'cosy evenings' watching a movie together, playing, singing and eating favourite foods. These strategies were used equally by both groups.

*Support interests and relationships with friends* involved promoting social participation with friends, sharing their children's interests and enabling them to join in social activities in and out of the home. Such strategies were listed by both groups although slightly more often by parents of children without ASD.

## Discussion

Across all three PEM-CY participation dimensions – frequency, involvement and desire for change – most differences between the two groups of parents' responses were found in two activity types: getting together with people and school preparation. Getting together with people involves interaction with family, peers and other houseguests and given the nature of ASD (American Psychiatric Association, 2013); these differences do not come as a surprise. In the open answers, parents in both groups described

how they promoted positive interactions, mainly by being supportive and by practising collaboration among family members through chores, routines and play. Parents of children with ASD were more selective in their choice of social activities within the home and also highlighted the importance of preparing their child in advance. In personal care management, differences were found in participation frequency and desire for change, and for household chores in frequency and involvement. These two activity types as well as school preparation entail initiating, planning and carrying out activities such as gathering materials, packing school bag, getting dressed, brushing hair or teeth, organising belongings and cleaning areas of the house. The difference between the two groups of children in these types of activities was also reflected in the open answers, where parents of children with ASD more often claimed that they helped their children organise their time, and that they themselves supervised or partly completed parts of activities of a practical nature.

Child participation in household chores promotes socialisation into family roles, joint responsibilities and obligations and also supports future caring for self and others (Dunn and Gardner, 2013; Law, 2002). Recent research has demonstrated differences between children with disabilities other than ASD and typical peers in household chores (Amaral et al., 2014; Dunn and Gardner, 2013), and Reynolds et al. (2011) found that parents seem to require less work from their child with ASD within the home than other parents. Our findings, however, suggest that parents of children with ASD in fact use a variety of strategies to

include their child in household chores, such as prioritising chores the child can manage, timing, preparing and modifying chores to help the child succeed, and by ‘picking the battles’.

According to parents, the least differences were obtained between the two groups of children in activities that typically do not involve much interaction. Interestingly, we found no difference in participation frequency for the use of computers, televisions and videos, in contrast with studies that have found that children and adolescents with ASD spend more time on media use in their homes than on other leisure activities (Hochhauser and Engel-Yeger, 2010; Kuo et al., 2011; Orsmond and Kuo, 2011; Potvin et al., 2013). However, the children with ASD in our study were more involved in computer and video games than were their typically developing peers, which may reflect their preferences as well as their overall attention, concentration and engagement in such types of activities. In the open answers, parents of children with ASD reported how they set limits and restrictions for their child’s computer use, which is in agreement with the findings of a recent study exploring mediation strategies of parents of adolescents with ASD (Kuo et al., 2015).

Parents of children with ASD were more likely to want their child’s home participation to change but a large percentage of parents in both groups were in fact not content with their children’s participation, as reflected in the overall high scores for this dimension. In particular, all parents expressed desire for change in their child’s participation in household chores. In Iceland, both parents typically work long hours outside the home (Statistics Iceland, 2015), so sharing the housework among family members becomes very important. These parents’ prior attempts to engage their child in household chores – such as by setting priorities and structuring routines – had clearly not been effective enough.

As expected, less perceived environmental supportiveness was associated with a greater desire for change in participation and this pattern of relations held for both groups. The environmental features that parents of children with ASD most often considered as restricting their child’s participation in activities at home were the social and cognitive demands of activities. This ties in well with information gained from the participation part, as most differences between the two groups were obtained in activity types that involve initiative, planning and interaction with others. Communicating and interacting with others is a known challenge for children with ASD and a recent study (Hochhauser et al., 2015) found how this may relate to their lack of negotiation strategies – such as cooperation, communication and compromise skills – that may call for adaptations of social and cognitive demands of activities. Physical demands were commonly listed as a barrier to participation of children with ASD, which is in line with evidence showing how motor challenges may

affect participation in activities among children with ASD (Little et al., 2014).

Sensory processing issues are considered to be highly prevalent among children with ASD (Ausderau et al., 2014), and their parents have reported how experiences related to the amount and type of sound, touch and light affect their children’s possibilities for participation in and out of the home (Bagby et al., 2012). Therefore, it is of interest that compared to social, cognitive and physical demands, relatively few parents in our study considered sensory demands as restricting their children’s participation at home. Possibly, parents had already foreseen and adapted some types of sensory stimuli in their homes, as reflected in their common use of strategies that entail anticipating and preventing challenges. It should also be acknowledged that vestibular, proprioceptive and kinaesthetic processing affect performance in activities that may appear to primarily require motor planning and skills (Ayres, 2005), which parents may consequently regard as physical. Activities entailing complex sensory and physical demands can also bring about a combination of challenges, which may differentially impact different children’s navigations through activities and spaces at home. By moving the focus to the demands of activities rather than focusing on the child’s underlying impairments, we may better understand the embodiment of autism and childhood (Smith, 2016) and also become better able to modify and accommodate some of the challenges children with ASD face in activities within their homes. In fact, aspects of the environment are often more amenable to change compared with child functional issues (Anaby et al., 2014; World Health Organization (WHO), 2007).

The significant group differences found for availability and adequacy of environmental resources (see Table 4) echo the findings of recent studies reporting that families of children with ASD are often critical of the information and supports they receive (Hodgetts et al., 2015, 2016; Stefánsdóttir and Egilson, 2016). The lack of time reported by parents of children with ASD probably reflects that these children typically take longer to get going and complete activities and also require more support than other children (Boyd et al., 2014; Reynolds et al., 2011), which is also in line with parents’ open answers. The lack of money expressed by these parents is noteworthy and signifies that families with children with ASD may experience more economic hardship than other families do, consistent with recent evidence (Buescher et al., 2014). Taken together, the lack of resources and supports experienced by these families poses a serious concern. A large Canadian study (McConnell et al., 2014) found that families of children with disabilities – most of whom had ASD – who had low levels of social support and who also experienced financial hardship struggle more than those with more resources, even if the behavioural problems of their child with ASD are taken out of the equation. We agree



with the authors who stressed the importance of culturally relevant resources and that consideration be given to system-level challenges, for example, policies and processes that create inequity and exclude families of children with disabilities.

Interestingly, there were more similarities than differences in the strategies used by the two parent groups, such as emphasising positive interactions, providing structure, timely and important instructions, and fostering quality family times of different sorts. The specific differences between the groups should nevertheless be noted, especially the extent to which parents of children with ASD modified activities and settings to facilitate their child's participation at home. These parents' answers often reflected how they read their child's behaviour at different times and provided adjustments when needed. These parents also made more use of specific reinforcements and reward systems than did other parents, who mostly described general guidelines and rules that they applied in their homes. These results do not come as a surprise, as they reflect that all parents use a variety of strategies to help their children succeed, develop and participate at home. In addition to these general strategies, parents of children with ASD seem to prioritise and apply more specific methods – related to their perceptions of what the child is able to manage – and these may vary between children, families and situations. More attention needs to be directed to the cultural and individual degree of variation in how families organise, adapt and sustain their participation in activities and routines at home (Boyd et al., 2014; Gallimore and Lopez, 2002; Marquenie et al., 2011).

Comparing these results from the home section of the PEM-CY with those from the community and school sections of the instrument, parents of children with and without ASD considered the frequency of activities in which their child participated to be most in the home and least in the community. Then again, parents in both groups considered more need for change in participation in activities in the home than in the other two contexts (Egilson et al., 2016a; Jakobsdóttir et al., 2015). This seems to reflect the importance parents place on their child's participation at home (Bagby et al., 2012; Law et al., 2013). An investigation of the specific types of change parents desire may give an indication of how practitioners should prioritise in order to best support families in promoting their child's participation in activities at home. That information will be published elsewhere.

### *Strengths and limitations*

Our study has some limitations. In particular, the low response rate is a concern. As a group, the participants differed from the Icelandic Census data, as the majority was well educated and most respondents were mothers. Apart

from the question in the home environment section, no information was gathered about financial resources or about services received other than special education services. Also, we do not know whether parents of children with more ASD severity or with co-occurring impairments may have different experiences than other parents, since we did not gather information about these issues. The PEM-CY reflects a Western perspective, and we acknowledge that home participation may vary across cultures.

Our study also has several important strengths. The external validity of our findings was enhanced by our sampling strategy, such as the large comparison group that was randomly selected and paired to the children with ASD. The mixed design provided an important understanding of the parent reports and their use of strategies at home. Although we acknowledge that the perspectives of children and their parents may differ (Egilson et al., 2016b; Hemmingsson et al., 2016), parents are more likely to have insight into their children's participation in activities at home than in situations where they themselves are not present. In the quality of life part of our larger study involving the same population of children, no difference was found between the ratings of children with ASD and their parents on the dimension of autonomy and parent relations (Egilson et al., 2016b), which reflects the quality of the interaction between child and parent, whether the child feels loved and supported by the family, the child's level of autonomy and his or her financial resources. The fact that children and their parents seem to agree about these important issues may strengthen the overall validity of our study findings.

### **Conclusion**

This study outlined participation patterns of children with ASD in their homes, disclosed environmental features that influenced their participation, and provided information on strategies used by parents to help their child succeed. In line with our results, we suggest that attention should be directed more to features of the environment, especially to the availability of resources and to the specific demands distinct activities pose to the child with ASD. It is also important to identify and use environmental supports that can potentially modify existing barriers (Anaby et al., 2014). To design helpful interventions that can be sustained within each home, the focus should be on the daily lives and situation of each family raising their child with ASD.

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