

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

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# Introduction

Study part of a larger research project focusing on the life quality, participation and environment of disabled children living in Iceland.

We explored and compared parent perspectives on:

- 1) participation of children with and without ASD in activities at home
- 2) the environmental features and resources that affect these children's home participation
- 3) the strategies parents use to help their children participate at home

Results based on the answers of 99 parents of children with ASD and 241 children without ASD

# Participation and Environment Measure – Children and Youth (PEM-CY)

- Parent-report questionnaire for children and youth aged 5 to 17 years.
- 3 sections: **Home**, school, and community.
- Each section asks about participation and environment.
  - Participation questions:
    - How often?
    - How involved?
    - Desire for change.
  - Environment questions:
    - Environmental factors and activity demands.
    - Resources.

# Main results

- Children with ASD participated less frequently and were less involved than their peers at home.
- Their parents were less satisfied with their children's participation than were other parents.
- 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
- Both groups of parents used similar strategies to facilitate their children's participation at home
  - although parents of children with ASD made use of more distinct modifications.

# Differences in home environment: supports and barriers

Environmental items	Usually helps / not an issue		Sometimes helps, sometimes makes harder		Usually makes harder		p <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	<b>65.6</b> (63)	<b>90.9</b> (209)	25 (24)	7.8 (18)	<b>9.4</b> (9)	1.3 (3)	0.001
4. Cognitive demands of activities	<b>61.9</b> (60)	<b>84.1</b> (191)	27.8 (27)	14.5 (33)	<b>10.3</b> (10)	1.3 (3)	0.001
5. Social demands of activities	<b>51</b> (50)	<b>89.2</b> (206)	36.7 (36)	10 (23)	<b>12.2</b> (12)	0.9 (2)	0.001
6. Child's relationships with family members	<b>58.2</b> (57)	<b>88.3</b> (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 % (n).

<sup>a</sup> Based on chi-square analysis.

# Differences in home environment: availability/adequacy of resources

Environmental resources	Usually yes / not needed		Sometimes yes, sometimes no		Usually no		p <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	<b>59.8 (58)</b>	<b>89.1 (205)</b>	35.1 (34)	9.6 (22)	5.2 (5)	1.3 (3)	0.001
4. Time	<b>45.9 (45)</b>	<b>71.2 (166)</b>	46.9 (46)	27 (63)	<b>7.1 (7)</b>	<b>1.7 (4)</b>	0.001
5. Money	<b>53.6 (52)</b>	<b>77.7 (181)</b>	33 (32)	18.9 (44)	<b>13.4 (13)</b>	<b>3.4 (8)</b>	0.001

Values are % (n).

<sup>a</sup> Based on chi-square analysis.

# Conclusion and implications

- The lack of environmental supports for children with ASD reflects how their diminished participation may relate to environmental effects, discriminatory practices, and even poverty.
- In order to support participation of children with ASD, attention should be directed to social, cultural, economic and political aspects.
- Important to focus on and adapt the features of activities.
  - Especially those that include social and physical demands.
  - Identify and use environmental supports that can potentially modify existing barriers
- The focus should be on the daily lives and situation of each family raising their child with ASD.



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ORIGINAL ARTICLE

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

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Original Article



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