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

Egilson, Jakobsdóttir & Ólafsdóttir, 2017
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.

Egilson, Jakobsdóttir & Ólafsdóttir, 2017
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

<table>
<thead>
<tr>
<th>Environmental items</th>
<th>Usually helps / not an issue</th>
<th>Sometimes helps, sometimes makes harder</th>
<th>Usually makes harder</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Children with ASD</td>
<td>Children without ASD</td>
<td>Children with ASD</td>
</tr>
<tr>
<td>1. Physical layout</td>
<td>90.8 (89)</td>
<td>92.2 (213)</td>
<td>6.1 (6)</td>
</tr>
<tr>
<td>2. Sensory qualities</td>
<td>71.4 (70)</td>
<td>90 (207)</td>
<td>25.5 (25)</td>
</tr>
<tr>
<td>3. Physical demands of activities</td>
<td><strong>65.6</strong> (63)</td>
<td><strong>90.9</strong> (209)</td>
<td>25 (24)</td>
</tr>
<tr>
<td>4. Cognitive demands of activities</td>
<td><strong>61.9</strong> (60)</td>
<td><strong>84.1</strong> (191)</td>
<td>27.8 (27)</td>
</tr>
<tr>
<td>5. Social demands of activities</td>
<td>51 (50)</td>
<td><strong>89.2</strong> (206)</td>
<td>36.7 (36)</td>
</tr>
<tr>
<td>6. Child’s relationships with family members</td>
<td><strong>58.2</strong> (57)</td>
<td><strong>88.3</strong> (204)</td>
<td>39.8 (39)</td>
</tr>
<tr>
<td>7. Attitudes of others</td>
<td>84.1 (69)</td>
<td>94.9 (205)</td>
<td>13.4 (11)</td>
</tr>
</tbody>
</table>

Values are % (n).

^a Based on chi-square analysis.
Differences in home environment: availability/adequacy of resources

<table>
<thead>
<tr>
<th>Environmental resources</th>
<th>Usually yes / not needed</th>
<th>Sometimes yes, sometimes no</th>
<th>Usually no</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Children with ASD</td>
<td>Children without ASD</td>
<td>Children with ASD</td>
</tr>
<tr>
<td>1. Services in the home</td>
<td>74.5 (73)</td>
<td>94.4 (219)</td>
<td>19.4 (19)</td>
</tr>
<tr>
<td>2. Supplies in the home</td>
<td>76.5 (75)</td>
<td>93 (214)</td>
<td>23.5 (23)</td>
</tr>
<tr>
<td>3. Information</td>
<td>59.8 (58)</td>
<td>89.1 (205)</td>
<td>35.1 (34)</td>
</tr>
<tr>
<td>4. Time</td>
<td>45.9 (45)</td>
<td>71.2 (166)</td>
<td>46.9 (46)</td>
</tr>
<tr>
<td>5. Money</td>
<td>53.6 (52)</td>
<td>77.7 (181)</td>
<td>33 (32)</td>
</tr>
</tbody>
</table>

Values are % (n).

^a 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.

Egilson, Jakobsdóttir & Ólafsdóttir, 2017
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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