Skólapátttaka og umhverfi 8–17 ára getumikilla barna með einhverfu: Mat foreldra


Efnið: Pátttaka, umhverfi, getumikil börn á einhverfurófi, einhverfa, PEM-CY, mat foreldra
School participation and environment of high-functioning children with autism spectrum disorders, aged 8–17 years

ABSTRACT

Introduction: This study explored the participation patterns and environment supports and barriers for high functioning children with autism spectrum disorder (ASD) within their schools. Information was gathered from parents of 8–17 year old children with and without ASD. The study was conducted in collaboration with the State Diagnostic and Counselling Centre, and is part of a larger research project focusing on the quality of life, participation and environment of disabled children in comparison with Icelandic children in general.

Method: Initially the questionnaire Participation and Environment Measure for Children and Youth (PEM-CY), which combines assessment of children’s participation and the environment, was translated into Icelandic according to author translation guidelines. Thereafter the questionnaire was pilot tested and a web based version was developed. The five types of activities in the school section of the PEM-CY are: Classroom activities; Field trips and school events; School-sponsored teams, clubs and organization; Getting together with peers outside of class, and Special roles at school. Participation is operationalized with three measurement dimensions: frequency, extent of involvement and desire for change. Items in the 'Environment' section examine perceived supports and barriers to participation in school.

The study utilized a descriptive cross-sectional design. Data was obtained from parents of 99 pupils with ASD and 241 pupils in the comparison group. Independent sample t-tests and chi-square tests were used to explore differences between groups. Partial eta square ($\eta^2_p$) was calculated to examine effect sizes specific to differences between the groups. Pearson correlation was calculated to explore the association between extent of desire for change and perceived supportiveness of the environment. Item-level comparisons are presented descriptively using radar plots.

Results: Pupils with ASD participated in fewer school activities and were less involved than their peers in the control group. The greatest differences between the two groups were found in participation frequency on School–sponsored teams, clubs and organizations (29%), as almost half of the pupils with ASD never participated in such activities. In level of involvement within school, differences were observed in four types of activities, with large effect size in Getting together with peers outside of class (1.03) and Classroom activities (0.8). Overall, parents of pupils with ASD were significantly less satisfied with their children’s school participation and desired change in all five school activity types.

A significant difference was observed between parents of children with ASD and control group children for the impact of school environment on participation ($p < 0.001$). The most common barriers limiting participation and also with the largest
group difference included Social, Cognitive and Physical activity demands as well as Relations with peers. Effect sizes for environment summary scores were large with the overall largest group difference found in Environment: support and in Environment: supportiveness total: (1.14). Twice as many parents of pupils with ASD reported that resources needed to support their children’s participation within school were not adequate. The only item that did not show significant difference between the two groups was Personal transportation. A negative correlation was obtained between Desire for change score and Environmental: supportiveness score.

**Conclusions**: Parents of pupils with ASD reported that their children participate less in important school-related activities than did parents of pupils without ASD. Barriers limiting school participation included features of the social and physical environment as well as limited resources. The results of this study enable a better understanding of the school participation of pupils with ASD and the impact of environmental factors on their participation. The results also highlight those aspects that should be prioritized to enable greater participation of pupils with ASD in various school situations.

**Keywords**: Participation, environment, high functioning children with autism spectrum disorders, autism, PEM-CY, parent-report

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