

Environment and participation of adolescents with autism spectrum disorder

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CHAPTER 8

Summary



SUMMARY

Adolescence is a period of physical adjustments and role changes within the family and society. Adolescents experience many transitions, often in outside-of-school contexts such as when developing peer relationships, increasing mobility and independence, or moving towards post-secondary education and work. Between 0.65 and 2.5% of the world's population is diagnosed with autism spectrum disorder (ASD). Adolescents with ASD participate significantly less in age-specific living situations. Participation, defined by the World Health Organization as "involvement in a life situation," is embedded in environments such as with families, social clubs or in the community. Everywhere, an individual-environmental transaction occurs. An environmental focus can offer new perspectives to support participation for socially-challenged persons, such as adolescents with ASD. This dissertation aims to elaborate on the role of environments in the participation of adolescents with ASD. Hopefully, the gained insight will benefit adolescents with ASD and improve their participation.

CHAPTER 1

This chapter introduces the topic under research. It characterizes ASD as a lifelong condition, presents global prevalence rates, gives an overview of the poor longitudinal outcomes in major life areas observed in individuals with ASD, and outlines the economic consequences for societies. Next, it argues for a focus on adolescents with ASD. It describes their low participation rates, referring to a classification defined by the WHO in the International Classification of Functioning, Disability, and Health (ICF). By using ICF, supporting and hindering environments for the participation of adolescents with ASD are introduced and explained in the context of the role of parents and families within their immediate social environments.

A problem summary and the presentation of the research gaps follows. This leads to the main aim of deepening our understanding of the role of environments as supportive or hindering to the participation of adolescents with autism spectrum disorder. Two subsequent research questions guided the whole thesis:

1. What is the role of environments as supportive or hindering to the participation of adolescents with ASD as described in the literature and by adolescents themselves?

2. How do parents of adolescents with ASD perceive and describe the role of environments as supportive or hindering to the participation of these youth?

The chapter ends with the presentation of the context of the empirical parts of the study, which is Switzerland, and an overview of the following chapters.

CHAPTER 2

This chapter contains a scoping review aiming to map the existing literature between 2001 and 2018 on supporting and hindering environments for the target group. Sources of scientific evidence were searched in 4 databases. Inclusion criteria were the perspectives of adolescents with ASD, families, or peers, participation in a natural context, and a clear connection between the environment and participation. The review covered scientific publications and identified 5528 articles. After a rigorous 5-step-selection procedure, 31 studies were thematically analyzed, and stakeholders validated the results.

Two sections presented the results: (1) a descriptive summary and (2) a narrative summary with three main themes and ten subthemes. *'Providing security'* showed how parental, physical, and informative environments have either a securing or intimidating effect on adolescents' participation. *'Helping to connect'* delineated how environments like peers and friends, services and staff, family, and attitudes support or hinder social relationships or social activities. *'Tension in participation'* summarized ambiguities regarding the participation of adolescents with ASDs, including topics such as isolation or solitary participation, involvement in disability-related groups, and the dilemma of normalcy and difference.

The scoping review found a complex interrelation between the participation of adolescents with ASD and their environment. These adolescents have a strong desire for positive peer relationship experiences. Security and connection, the most important environmental aspects, represent meaningful, subjectively relevant, and feasible aspects of how the environment can shape participation. This research widens the field regarding working with adolescents with ASD, as it directs attention towards the responsibility of the environment regarding participation.

CHAPTER 3

This chapter describes a study which aimed to understand how and why participants perceive aspects of their environment as facilitators or barriers to their participation outside of home and school in the region of Zurich. Six male adolescents participated in in-depth interviews and took photos during their participation activities. Transcribed interviews and photos were analyzed. Their participation turned out to take place in a variety of areas and to be performed regularly and consistently. The favorite activity among the participants was using public transport. Interestingly, all participants perceived participation as a social act, even when they were solitary activities like attending libraries or hiking.

Results revealed two main themes and 10 subthemes that seemed necessary to facilitate participation: *'Environmental pre-requisites to attend participation'* were imperative to begin participating. These comprised (1) the company of trusted persons, (2) the presence of a nudging drive (with elements of obligation, habituation, interest, and motivation), (3) the provision of knowledge and information, (4) the presence of good vibes, and (5) the design of the physical environment. The second main theme, *'social interchange and engagement'* was related to the occurrence of social reciprocity when adolescents with ASD interacted with people other than their trusted persons during social activities. Three subthemes described how actual involvement could be supported: (1) being approached, (2) becoming a group member, and (3) being acknowledged and gently guided. The results of this study confirmed various themes of the scoping review. The findings highlighted the influence of trusted persons on adolescents with ASD and the need to extend the support network for these adolescents to other individuals, services, and society to encourage their participation in activities.

CHAPTER 4

This chapter presents research aiming to translate and cross-culturally adapt the Participation and Environment Measure- Child and Youth (PEM-CY) into German in a way that culturally represented the PEM-CY constructs of *'participation'* and *'environment'* in Switzerland, Germany, and Austria. Colleagues and the developers followed adapted cultural equivalence guidelines. Fifteen parents of children and adolescents with disabilities from these three countries participated in three rounds of

think-aloud interviews. Data were analyzed by content analysis using semantic, idiomatic, experiential, and conceptual equivalence.

Results showed adaptations mainly focused on experiential and conceptual equivalence with conceptual equivalence being the most challenging to achieve. Examples of experiential equivalence included adapting the examples of activities in the PEM-CY to reflect those typical in German-speaking countries. Conceptual equivalence mainly addressed aspects of “involvement” and “environment” and was reached through adaptations such as enhanced instructions and structures and additional definitions.

To conclude, the study presents a culturally adapted version of PEM-CY (German) available for research, practice, and further validation.

CHAPTER 5

This chapter presents a study that aimed to describe parental perspectives on the participation patterns of children and adolescents with ASD at home, at school, and in the community of children as well as parental desires to change these patterns. 60 parents of children and 55 parents of adolescents with ASD in the German-speaking part of Switzerland participated in this cross-sectional study. An online survey contained the PEM-CY(G) and demographic and health-related questions. Data were analyzed descriptively and thematically for both age groups, which did not differ significantly ($p = 0.5$) regarding the type of residence and parents' education level. The manifestation of autistic symptoms indicated that both groups represented a less severe sample of the autistic spectrum.

Results showed different participation patterns in all settings and both age groups. Both participated most often at home, but high percentages of parents desired changes, such as in *'getting together with others'* and *'household chores'* or *'personal care management'*. The younger group was more involved at home than the older group. The school participation of both groups varied greatly, and parents' desires for change referred frequently to *'getting together with other children of class'*. Community participation in both age groups was low, and in half of the activities it was non-existent. Parents primarily desired more participation frequency in *'getting together with other peers in the community'*, and *'structured and unstructured physical*

activities'. Overall, parents of adolescents with ASD expressed a stronger desire for change in all three settings than parents of children with ASD. Parents of both age groups wanted higher participation frequency and involvement for all activities, with two exceptions: *'gaming'* and *'watching films.'* To conclude, this research informed the scientific community and social, health, and community service providers about how to reshape their programs to meet parental needs and supports for the participation of children and adolescents with ASD.

CHAPTER 6

This chapter aimed to describe parental perspectives on environmental supports and barriers, combined with parental contextual strategies in three settings (home, school, community). Data collected in the same cross-sectional study as described in chapter 5 was used and analyzed similarly quantitatively and qualitatively. Results revealed that half of the parents in Switzerland perceived more environmental supports than barriers for their children's participation as assessed by the PEM-CY (G). Supports included aspects such as *'services,' 'information,' 'time,'* and *'money.'* In contrast, environmental aspects such as *'physical layout,' 'sensory quality,' 'demands of activities,' 'relationships,'* or *'attitudes'* were seen as significant barriers to participation. In both age groups, *'sensory aspects'* and *'social demands of activities'* were the greatest barriers in all three settings. This was explicitly the case in the community setting, where environments are more flexible and less predictable. The other half of parents did not describe environmental aspects clearly as barriers or as supports for their children's participation.

Parental contextual strategies comprised 41% of all comments regarding *'people,'* thus being a social aspect. Another 37% of strategies were associated with *'activities.'* *'Time,' 'objects,'* and *'places'* were far less mentioned but were as well. Most parental strategies were used in all settings and were similar across both age groups. To conclude, despite parents seeing more supports than barriers in their children's environments, barriers were described as less tangible and less changeable by parents. Parental perspectives on participation and their contextual strategies need to be considered in environment-based interventions to support the social participation of children and adolescents with ASD. This can simultaneously reduce caretaking-related strain in parents of children and adolescents with ASD.

CHAPTER 7

This chapter first provides a summary of the most relevant and interesting discussion points obtained from the literature review and the four empirical studies to answer the research question. Seven important environments for the participation of adolescents with ASD were identified. Then, the chapter reflects on the theoretical lenses used throughout the dissertation and the understanding gained about the participation of adolescents with ASD. Next, the seven identified environments which represent our insight about the role of the environment for their participation are discussed. Methodological considerations follow before the chapter ends with recommendations

CHAPTER 9

This chapter presents in layman's terms the scientific impact of the research and its achieved and anticipated relevance for practice, teaching, service implementations, and society to support the participation of adolescents with ASD and their families.