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ORIGINAL ARTICLE

Environmental pre-requisites and social interchange: the participation experience of adolescents with autism spectrum disorder in Zurich

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ABSTRACT

Aim: Participation of adolescents with autism spectrum disorder hardly occurs in settings outside of home and school. Little is known about how their participation is influenced by environmental factors. This study explored how and why adolescents with autism spectrum disorder perceive aspects of their environment as facilitators or barriers to their participation outside of home and school.

Method: This explanatory case study explored the participation experiences of adolescents with autism spectrum disorder (15–21 years) from Zurich and surroundings with in-depth interviews and photo-elicitation, using photos made by the participants during activities outside of home and school. Data was analysed with a 7-step procedure.

Result: The presence of two main themes seemed necessary to facilitate participation outside of home and school: "environmental prerequisites to attend activities", which consists of five subthemes, such as "the company of trusted persons" and "the provision of knowledge and information", and "social interchange and engagement", which consists of three subthemes and describes how actual involvement can be supported.

Conclusion: Our findings highlight the influence of trusted persons on adolescents with autism spectrum disorder, and the need to extend the support network for these adolescents to other individuals, services and society so that their participation in activities can be encouraged.

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➤ IMPLICATIONS FOR REHABILITATION

- Adolescents with autism spectrum disorder perceive every kind of participation outside of home and school as social.
- We recommend using the company of trusted persons to encourage adolescents with autism spectrum disorder to actively participate outside of home and school.
- Rehabilitation professionals should promote environment-based approaches to achieve participation of adolescents with autism spectrum disorder.
- Rehabilitation professionals should actively approach, acknowledge and gently guide adolescents with autism spectrum disorder to support engagement in participation.

Introduction

Participation of adolescents with autism spectrum disorder (ASD) hardly occurs in settings out of home and school, which includes public areas, leisure places or places of friends and extended family [1,2]. This means that these individuals are not exposed to a wide range of age appropriate activities that their non-ASD counterparts do experience such as sports, mobility, attending cultural events, shopping, working or socialising with friends [3,4]. Participation, defined by the World Health Organisation as "involvement in life situations" [5, p.10] is extended here to "being engaged in and/or performing meaningful activities in occupational and social roles while attending." [6, p.2]. Participation is generally seen as requiring both attendance, understood as "being there", and involvement, which includes elements of engagement, motivation, persistence, social connection and levels of affect, within the environment [7,8]. For adolescents with ASD, participation is an entry point for learning and social development, as it is interwoven with family, peers, public life and society, all of which are parts of their environment.

Many different definitions of environment are used in the literature. In this paper "environment" is regarded along the lines of the definition provided by the World Health Organisation, which defines the concept as "the physical, social, and attitudinal environment in which people live and conduct their lives" [5, p.5]. Environment, in this definition, has been identified as being an important influential factor on participation, particularly for youth with disabilities [9–12]. Environments act as mediators and they

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can serve dynamically as either barriers or facilitators for participation of adolescents with ASD [6]. It has been established in the field of environmental psychology that, to be optimal for the facilitation of participation, environments firstly need to provide information, such as descriptions of social rules and processes, provide secondly meaningful choices to participate actively, and last facilitate interactions that pursue a restorative character [13,14].

Scientific studies that focussed on a combination of autism, environment and participation have, so far, delivered (mainly) fragmented knowledge [15,16]. More precisely, existing research has largely focussed on particular age groups and settings: adolescents are less researched than children [6] and the majority of studies look at home settings [17–19] and school settings [20,21]. It is clear, then, that the adolescent age group should be given (more) attention. All the more, as, for most adolescents, settings out of home and school are essential to socialise and transit to adulthood [22]. Although adolescents with ASD value friendships and joint activities with youths [1], their reported communal participation rate is low [23]. Additionally, the reported environmental supportiveness for community participation of adolescents with ASD is low as well [3]. Adolescents with ASD might avoid participation experiences because they feel pressured as a result of their efforts to balance the idea of "being different" with the need to "fit in" [24]. Constant pressure is tiresome and contradicts involvement. Research reports a decrease in the development of functioning after leaving high school in adolescents with ASD [25]. This decrease might be a consequence of missing age-appropriate participation experiences [26,27]. The lack of these appropriate experiences might also have negative consequences on independence in work and adulthood [28,29]. In addition, a lack of age-appropriate participation experience can affect health and quality of life in a negative way [27,30–33].

There is growing demand that autism research should incorporate the experiences and values of individuals with ASD themselves [34,35]. At the moment, however, there is, to our knowledge, still only limited literature on the way in which adolescents experience environmental factors, and the way in which these adolescents think these factors influence their participation (this has only been studied in home and school settings) [4,18,21].

In an attempt to fill this knowledge gap, the objective of this study was to gain in-depth insight as to how and why adolescents with ASD perceive aspects of their environment as facilitators or barriers to their attendance and involvement in activities outside of home and school? Given that the interplay between environment and participation is dynamic, we were particularly interested in grasping the turning point when an environmental facilitator becomes a barrier and vice versa, which we described as "tension". Only if we know how the environment affects people with ASD, and how it gives shape to facilitators, barriers and tensions, can we try to support participation of adolescents with ASD by creating strategies to adjust and optimise their environments.

Materials and methods

In order to answer our research question, we conducted a qualitative, case study, while closely adhering to the methodology set out by Yin [36]. More specifically, we focussed on the experiences of adolescents with ASD in a particular geographical area.

The case: the canton of Zurich

The canton of Zürich was selected as case, for two main reasons. First, hardly any research has been conducted in the canton of Zürich regarding environment and participation of people with ASD. Secondly, the situation in the canton of Zürich means that there are likely little to no other (non-ASD related) reasons for a lack of participation. The canton provides a relatively stable, secure and well-defined environment for all who reside there. It provides a high quality of life, as well as an economically prosperous, and multi-cultural setting [37,38]. The social health system covers almost all costs of children's education and therapy. Most adolescents with ASD in the canton of Zürich attend public school and live at home [39]. Public transport functions well in this canton and it aims for equal accessibility for all. We found, however, that, although the canton of Zürich has been working on the implementation of the United Nation convention on the rights of persons with disabilities (ratified by Switzerland in 2014), and has made progress in doing so, the extent of facilities and support for persons with cognitive or social difficulties, like ASD, is still rather limited. A noise reduction area and/or the use of simple language would be beneficial for them. Finally, looking at the manner in which the two local daily newspapers (Neue Zürcher Zeitung and Tagesanzeiger) dealt with autism between 2014 and 2017, which offers a glimpse into the way ASD is dealt with by the community in general, it is apparent that ASD is mainly either idealised (indicated by newspaper features about extraordinary people with ASD and successful work stories of people with ASD in informatics) or as something strange and in need of a solution (indicated by features about diagnostics of ASD and discussions about the causes of autism). There is only limited attention for the day to day reality of living with ASD, and the needs of people with ASD. This, more assertive approach, is only employed by one social media platform [40] and a client organisation for autism (autismus deutsche schweiz, [41]), which launches campaigns for autistic friendly environments in theatres, collaborations with hairdressers and dentists and quiet hours in shopping malls.

Participants

Participants had to fulfil several criteria to be eligible for this study. We were looking for adolescents between 15 and 21 years of age, who were diagnosed with ASD (according to ICD-10 standards) by a physician, and who participated in at least one activity outside of home and school without being accompanied by someone. In addition, the adolescents had to have been living in the canton of Zürich for at least 3 years and had to be able to communicate verbally or with assistive devices in local languages. Adolescents were excluded if they attended sheltered housing or workplaces and/or if they were supervised 24 h a day.

Three sampling techniques to find participants were used. Firstly, we conducted a purposive sampling by asking 42 key persons like teachers, physicians, therapists and employers, to approach adolescents with ASD. Although some rejected aiding our study, as they feared it would cause adolescents with ASD too much distress, a total of 38 informants supported this stage of recruitment. Secondly, we conducted self-selection sampling by presenting the project in autism specific social media. Finally, we used snowball sampling and asked adolescents with ASD to attract peers with ASD. Six male and two female participants consented to participate, however, the two females resigned during the photo-collecting phase. The study obtained ethical approval from the Zurich Ethics Committee (25.4.2017 BASEC-Nr.2017-00262). Participants and parents received written and verbal

Table 1. Characteristics of participants.

Participants	1	2	3	4	5	6
Age	16 (pilot)	17	15	16	20	20
Gender	Male	Male	Male	Male	Male	Male
Diagnosis						
ASD	Asperger	Asperger	Asperger	Asperger	ASD	Asperger
Co-morbidity	None	ADHD	None	ADHD	Social anxiety	Migraine
Age at diagnosis	7	8	7	9	6	12
Parents						
Marital status	Separated	Married	Married	Married	Widow	Married
Education mother	Low	Middle	High	High	Middle	Middle
Education father	High	Low	High	High	Low	High
Living condition						
With whom	Mother	Parents	Parents	Parents	Mother	Alone*
location	rural	urban	suburbs	suburbs	rural	urban
School/Work						
Type	Private school	Private school	Regular school	Internship	Apprenticeship (polygraph)	University (informatics)
Support	Individual learning plan	Individual learning plan	Small class	Special needs support	Special needs support	None
Interview place	School garden	Home	Home	Café	Therapy place	University

*Weekends with parents.

information and provided informed consent. Participants gave consent for the publication of their photos. As a sign of gratitude, adolescents received a book voucher.

Data was collected by first using photo-elicitation and then conducting in-depth interviews. The method of photo-elicitation was used as it has been demonstrated to have specific benefits for collection data about deeply emotional experiences, and collecting data from less expressive participants and youth with ASD, as well as from people who have stigmatised conditions, such as mental illness [42,43] and adolescents with ASD [44]. First, photos were gathered: the participating adolescents were instructed to take photos of activities they participated in over a period of two weeks. They were asked to specifically focus on three participation experiences outside of home and school that they liked, disliked and felt a certain tension or unease about. After this period, they selected (at most) 15 photos, coupled them with either a title or a brief written description, and passed them on to the researchers. Second, the experiences of these adolescents with ASD were assessed discussing their experiences using photo-elicitation during in-depth interviews. The interviews were conducted in accordance with an interview guide that had been prepared beforehand, and which had been improved based on feedback obtained from an adult with ASD. The main changes aimed at making the questions in the guide simpler and straightforward. The in-depth interviews started with general questions (e.g. "Please explain this photo") and continued with more probing questions (e.g. "Why did you take this photo?"). Concepts of theoretical assumptions guided further questioning (e.g. "When do you feel you are engaging in participation?" and "Do you feel well-informed during your participation?"). Six participants, including the one from the pilot interview (P1), fulfilled all data collection steps (Table 1). Most participants were coached by their parents (P2, P3, P4, P5) or therapist (P1) during the photo collection process. Overall, data collection yielded 12.75 h of interviews and 69 photos.

Data analysis

The interview data were transcribed verbatim. Data was analysed in seven steps as described by Yin [36]. Each adolescent was seen as one "unit of analysis" [36, p.3]. First, the members of the research team acquainted themselves with the photos and descriptions of each unit of analysis to get a general sense of the data. Next, the research team reflected on how best to code the data without losing the meaning of the interview as a whole. We decided to use four preliminary broad categories ("facilitator", barrier", "tension" and "explanation") to describe (the explanation for) the effect of environments on participation. Technically, aspects of environments were defined as "facilitators" when they provided conditions to feel secure, welcome, socially accepted, experience fun, pleasure or positive self-esteem during participation. Aspects of environments were defined as "barriers" when they provided conditions to intimidate, to provide physical or social distance or exclusion, stress, negative feelings like non-motivation or anxiety or incomprehensiveness resulting in non-participation. Aspects of environments were defined as "tension" when they provided conditions that generated ambivalent or contradictory feelings causing insecurity or unease during participation. Reasons behind an aspect of an environment being placed in one of the three beforementioned categories were categorized as "explanations" The words of one of the participants with ASD (P5) can serve as an example of how the coding process worked in practice: an environmental condition that lead this participant to refrain from using public bathrooms was their smell. We defined the smell of public bathrooms as a "barrier". The same adolescent explained that he imagined such a bathroom as being" dirty and insane". We coded "image of dirt and insanity" within the category "explanation". After defining the four central categories, we read and re-read the data and classified all data that was covered by them, leaving out any data that did not fit at least to one of the categories. This resulted in a total of 1199 coded quotes. Then, the first author and another researcher independently clustered the coded quotes of each participant (unit of analysis) into an individual pattern [36]. For each participant, the two patterns that were created by the two independent researchers were matched [36, p.143], and the team assigned more abstract labels to them, covering the meanings of the coded quotes and at the same time taking care that these labels were analytically mutually exclusive. Subsequently, the complete research team discussed the results, while also keeping in mind the received photos, which expressed engagement and/or restraint from participation. Next, two of the researchers merged ("matched") the six individual patterns into one common pattern. The complete research team then discussed rival explanations as well as theoretical ideas and assumptions that might explain this common pattern and refined the results further. After coming to an agreement, the research team formulated the results with two main themes and 8 subthemes.

Table 2. Areas of participation (activities or situations).

Participants	1	3	4	5	6	6
"Like to participate"	Bus Train Guitar lesson Shooting club Riding in the car Restaurants	Bus Train Tram Reading in the park Taekwondo	Bus Train Music class Station Cinema Walking the dog	Bus Train Tram Fishing club Volleyball Archery Visiting friend Museum	Bus Train Walking Hiking Fitness club Library Family visits Skiing Workplace	Public dinner Workplace Sports Concert Boat trip University study room**
"Dislike to participate"	Funerals	Disco Parties Bar Public swimming pool	Skiing Shooting club Art	Disco Bar	Public bathroom Long-distance travelling	None
"Tension"	station* busses*	Zoo Museum Cinema	Youth club Church	Shopping Cinema Workplace	Receptions Shopping	Parties University study room**

*During rush hours; **Two different study rooms.

Trustworthiness

Following the recommendations of Guba & Lincoln [45] we used different strategies to guarantee/protect the trustworthiness of this study. Credibility was ensured through data triangulation, an iterative peer-debriefing and a member-check procedure, for which 4 participants reviewed a short summary of their interview (two participants did not respond to this request, even after two reminders). Transferability was guaranteed by providing a well-documented context and research process and displaying photos. A rigorous decision trail and researcher triangulation during analysis contributed to the confirmability and dependability of the study. Finally, for reflexivity, research diaries and research team meeting notes were stored.

Results

The analytical process aimed at answering the research question of how and why adolescents with ASD experience facilitators, barriers, and tension in their environments during attendance and involvement in activities outside of home and school, led to the identification of two main themes. The first main theme "environmental pre-requisites to attend participation" appears to be imperative to start participation. It consists of five subthemes: (1) the company of trusted persons, (2) the presence of a nudging drive; (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", consists of three subthemes: (1) being approached, (2) becoming a group member, and (3) being acknowledged and gently guided. In this section, general aspects about participation of adolescents with ASD in the canton of Zurich are described first, after which general insights into these main themes and subthemes are given together with exemplary comments and photos acquired from specific participants. Facilitators, barriers and tensions are presented for each subtheme both in the written text as well as in the corresponding tables.

Participation of the six male adolescents with ASD in activities outside of home and school in the canton of Zurich turned out to take place in a variety of areas (Table 2), and to be performed regularly and consistently. The favourite activity among the participants was using public transport. Interestingly, all participants perceived participation as a social act. Although this is obvious for group activities such as volleyball, this finding requires explanation when it comes to solitary activities like attending libraries or hiking in an open, vast landscape. For a person with ASD, even the possibility of meeting somebody, during a seemingly less social activity, often feels like a social event and therefore often feels less easy. The following photo (Figure 1) and matching quote illustrate this seemingly counterintuitive feeling.

> "Nearly every Sunday I go for a walk with my mum. Mostly we walk around our village, but sometimes we drive to nice places. Weather does not matter. I love to be in nature and see changes. Always different with all kind of weather. Meanwhile, I know all the paths around our village. Yet, it is still stressful to know that people might come towards us and I have to greet them. Before, when I see them, I would have run away. Now, it is a bit easier, I can stand it, but still … ". (Participant(P)5).

Main theme I: environmental pre-requisites to attend activities

The first main theme comprises five environment-based subthemes that influence whether adolescents with ASD would attend and participate in an activity (Table 3). For these adolescents to attend and participate in new environments, facilitators from all five subthemes must be present, while the presence of any barrier would result in non-participation. Due to the dynamic nature of environments, each facilitator can reach a turning point, which we call *tension,* and as such convert into a barrier.

The first subtheme, *the company of trusted persons,* describes enacted company from well-known and therefore trusted persons with whom adolescents have a long-term relationship, most often parents, grandparents, siblings, a close boyfriend (P4) or girlfriend (P6). In a supportive environment, these trusted persons actively initiate, organise and accompany participation of adolescents with ASD. Adolescents with ASD participate because they wish to be together with their trusted persons and enjoy shared well-being. Company is usually needed for extended periods, as expressed in the following quote (combined with Figure 2):

> "This was taken during the end of year meeting at the fishing club. My father was invited, and I accompanied him. I am now a member of the club for several years, but I always go to the meeting with my parents". (P4)

All new activities that the adolescents with ASD participated in were experienced in the company of trusted persons. Their absence acted as a barrier to participation. Absence of trusted persons can occur as a result of them being constrained by time limits, having a lack of interest or experiencing boredom in shared activities. At times, even the company of trusted persons can be a cause of tension. This occurs, for example, when the mood of a

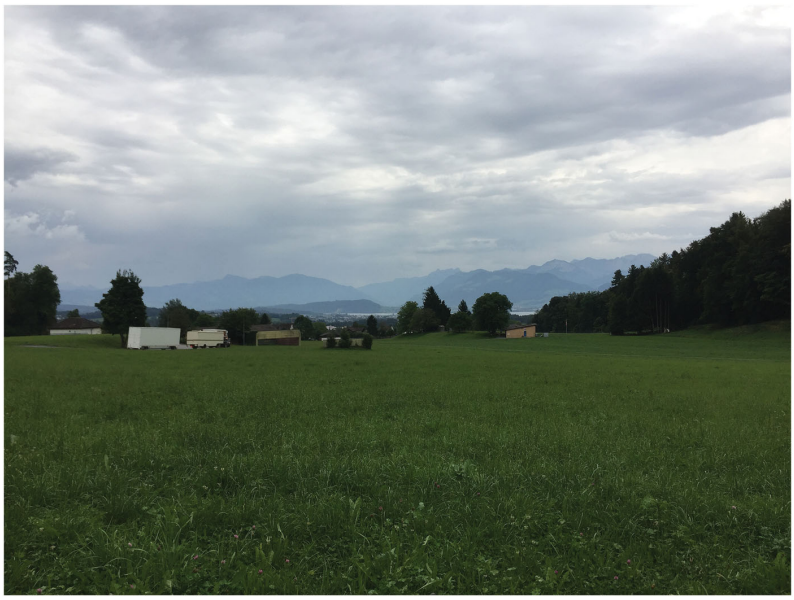

Figure 1. "Sunday walk", data retrieved on Sunday August 27th, 2017 13:28.

Table 3. Main theme I: environmental pre-requisites to attend activities.

Subthemes	Facilitators	Barriers	Tension
Company of trusted persons	• Trusted persons with long-term relationships • Persons initiate, prepare, organise and accompany • Persons provide enjoyment of being together	• Missing familiar person • Pursue different interests and refrain from shared joy	• Trusted persons are less reliable or capable • Inability to initiate or organise
Presence of a nudging drive	• Aims and obligations are communicated • Authentic learning activities • Meets adolescent's interest and their active approval • Activities involving regular, manageable motor skills	• Aims or obligations are not provided • Fail to address adolescent's interests • Construction of artificial or difficult activities	• Presence of competing volitional factors to participate
Provision of knowledge and information	• Insight into organisational processes and rules • Spatial orientation • Structure, regularity, frequency, intensity grading of participation • Security through feeling of preparedness	• Underestimating preparation to get informed • Inability to provide structure, regularity or adaptation to the adolescent's learning process • Underestimating needs for sameness and security	• Unforeseeable situations with problems • Participating too early without enough routine or preparation
Presence of positive vibes	• Friendly, kind social climate • Funny persons are less intimidating • Lightness and ease	• Moody, rough, impolite or offensive social climate • Openly sad situation • Conflicting situation • Stress	• A lapse in a generally positive, friendly atmosphere.
Design of the physical environment	• Possibilities of influencing physical features • Availability of diverse spaces that are well labelled • Prevention of density through architecture and regulations	• Uncontrollable physical features • No quiet places • Unforeseen density	• The sum of physical environmental aspects • Fatigue and stress accelerate the perception of physical features negatively

sister turns negative during a social activity, or when parents fail to provide organisational support for their shared activity. One participant's dog (P4) provided comfort and company, but the dog's presence could not initiate the participation of his owner in new participation areas.

Presence of a nudging drive is the second subtheme that affects whether an adolescent with ASD would attend and participate in an activity. It comprises elements of obligation, habituation, interest and motivation and addresses adolescents' volition for participation. Understanding obligations and/or the aims of an activity was as important for adolescents with ASD in supporting their participation as meeting their interests was. To facilitate this understanding, it is essential that other people within the environment clearly communicate these obligations and aims. For

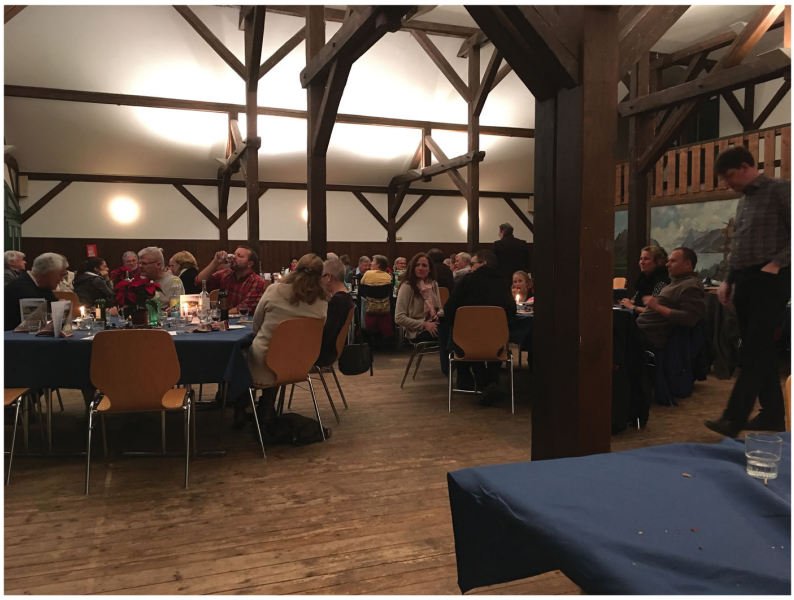

Figure 2. "Fish club", data retrieved on Wednesday December 6th, 2017, 20:39.

example, one participant mentioned in connection with his membership in the fishing club. He didn't like to clean the communal pond. But he was informed that it was obligatory for all members to clean it once a year. He also understood the aim of this activity: a clear pond for the fishes. This nudged him to participate in cleaning the pond (a not always pleasant experience). Authentic situations in general, such as job-shadowing, also encouraged participation (P3–P5). If adolescents were interested in the activities and actively consented to engaging in them, participation also increased. Activities that involve the performance of regular, manageable motor skills, including walking a dog and exercising at a gym, also functioned as nudges to facilitate participation. It was experienced as a barrier to participation if obligations or aims were not communicated or interests were not met. Artificial activities, such as occur in roleplays, were also mentioned as being not supportive. Competing volitional factors, for example when an activity was uninteresting but obligatory, or when motivation was connected with one's energy level, generated tension in the motivation of adolescents with ASD to participate in activities (see Figure 3)

> "It is a tension. On one hand, it is nice to get an invitation and to be together with people that I already know a bit. On the other hand, it is exhausting to go home late .... I have to learn to use less energy to hang out with others. My girlfriend has helped me a lot to this end. But yes, it is exhausting." (P6)

Provision of knowledge and information, the third subtheme, expresses the need of adolescents with ASD for insight and understanding into the structural and social framework of the activities they might be participating in, as well as acquaintance with organisational processes and rules, such as those associated with using the tram (explained in the quotation below). It also includes spacial orientation regarding any (social) activity prior to attending. One adolescent explained why he likes using the trams (see Figure 4) in the inner city of Zurich:

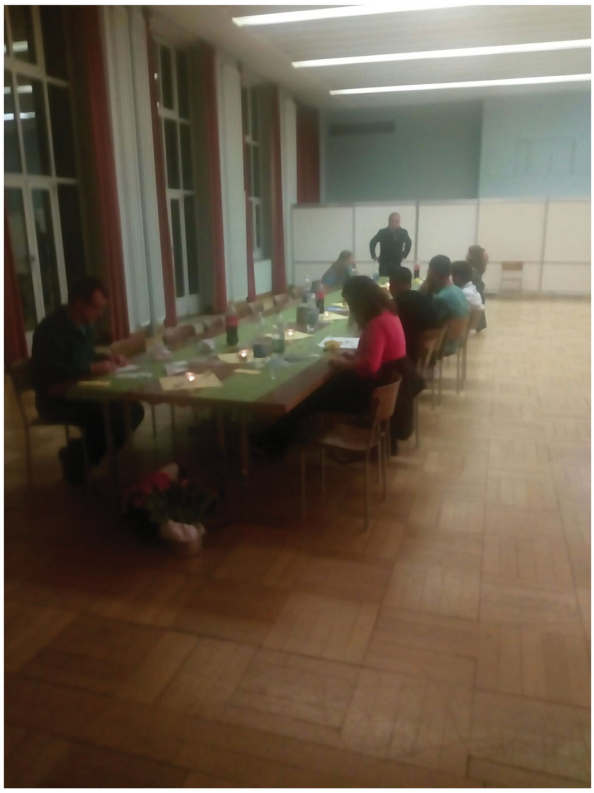

Figure 3. "Caritative event", data retrieved on Thursday October 17th, 2017, 18:26.

> "In the inner city I prefer to use the trams. They use tracks ... so everything is given to the drivers ... so they travel mostly the same routes. Thus, I do not have to rack my brain as to where I am ... as with busses. Everything is given and much easier. You only have to watch the timescale. It is easy. You just must follow the coloured lines; each tram has a different number and colour. The 3 and 11 is green, the 13 yellow, the 2 red. The 4 is blue ... you see - easy to understand. I know them all." (P2)

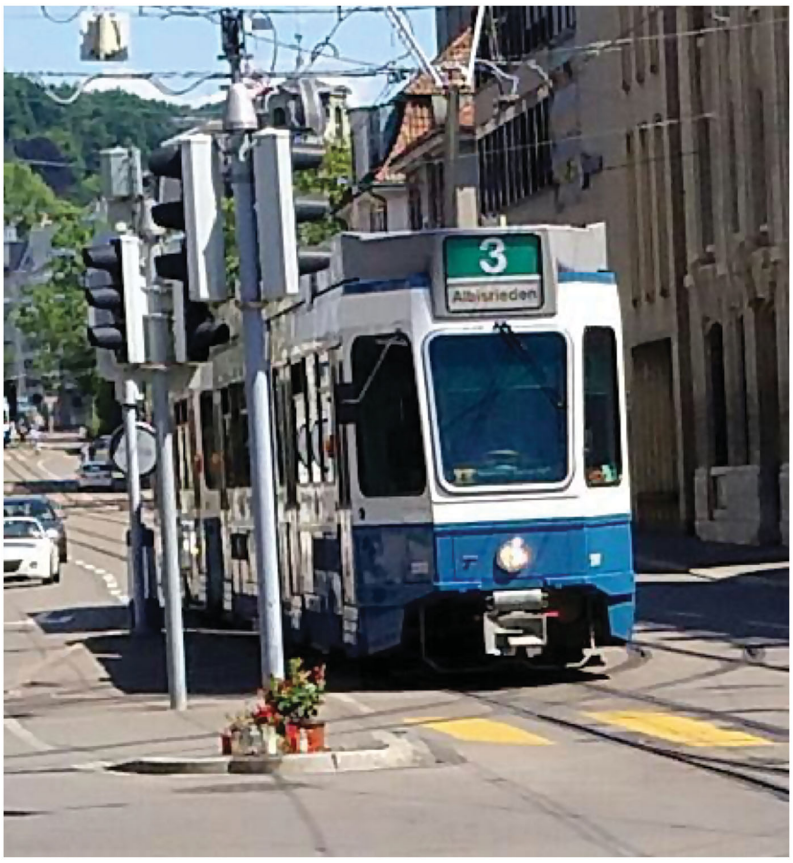

Figure 4. "Tram Zurich", data retrieved on Friday July 7th, 2017 m 13:10.

Structural aspects, such as regularity, frequency and grading of intensity were supportive to the participation of adolescents with ASD in activities, because the feeling of being knowledgeable provided them with a sense of security and relaxation. One participant summarised his activity of serving at the fish market explaining that he loves to participate when he is knowledgeable:

> "I like doing when I know how to do it. At the annual fish market, we serve always the same: fish and chips, all kind of beverages, I know them all .... I like this. I serve once a year at one day ... serving fish and chips and beverages and money and all this ... and I can keep the tips." (P4).

Adolescents with ASD perceived it as a barrier if others underestimated their need for (extensive) preparation to get informed about and get acquainted with the norms and rules that exist in the activity in question. Considering their desire for knowledge and information, adolescents with ASD often refused attending unfamiliar activities, as they missed the sameness and security. In addition, facilitators became situational tensions when adolescents faced unexpected problems. One adolescent explained that attending receptions was a situational tension for him, as he would meet unknown persons, he hadn't had a chance to prepare to meet. Participation in activities during which there was insufficient time to prepare on the spot for new unforeseeable interactions, or to reflect on the circumstances and changes at hand also generated tensions in connection with provision of knowledge and information.

Presence of positive vibes is the fourth of the environmental prerequisites for adolescents with ASD. It describes a generally helpful climate that facilitates participation. One adolescent explained why he liked attending the shooting club (see Figure 5):

> "What affects me is the attitude of people. ... for example, in a club ... if somehow the people are always in a bad mood, then my interest for it fades away and I feel like I am out of place. For example, in the shooting club, I feel fine. The atmosphere is friendly and nice. They talk in a friendly way, and you see how well they treat each other ... well I can't explain this more in detail; it is not easy. But I like to be there." (P1)

> Friendliness, facilitated through a certain lightness, promoted the participation of adolescents with ASD. In such an atmosphere, they felt there were fewer expectations on them and they experienced less stress. The latter was also experienced in funny situations. Rough, impolite, and offending social atmospheres intimidated adolescents with ASD and acted as barriers. Likewise, adolescents felt incompetent in reacting appropriately to sad or conflict-laden situations. Tension occurred when there was a lapse in a generally positive atmosphere, such as when a moody person was present and expressed negative vibes.

The design of the physical environment, the last of the five subthemes of the first main theme that need to be fulfilled for adolescents with ASD to attend and participate in an activity, addresses the effects of physical features of settings, including noise, light, touch, smell, temperature, and vibration. The sense of space and density experienced by the adolescents with ASD also falls under this factor. Sensory features affected all participants, but individuals' experiences with them were different,

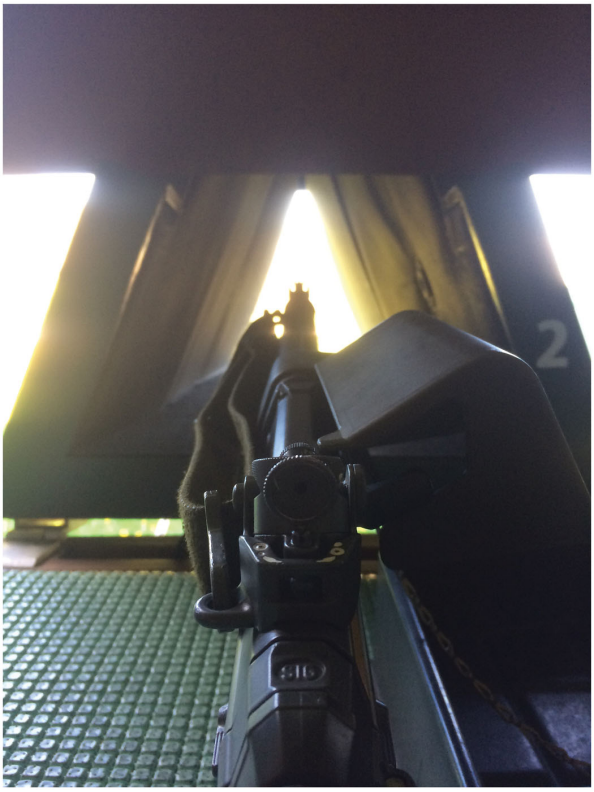

Figure 5. "Shooting club", data retrieved on Tuesday July 18th, 2017, 13:24.

Figure 6. "Study room", data retrieved on Thursday October 19th, 2017, 18:26.

nonetheless. Sensitivity to physical features that were present at activities was dynamic and could be influenced by an adolescent's level of fatigue, habituation and personal maturation. Having agency over the sensory input they experienced supported the participation of adolescents with ASD. Sound and noise were most often described by adolescents as features that affected their concentration negatively and caused restlessness. Physical features could hinder participation of adolescents even when they felt passively exposed to them. An example of this given by one of the participants in this study was the vibrations of a nearby highway that affected sleep and provoked headaches (P6). These vibrations reduced the number of sleepovers at his girlfriend's home, which resulted in him spending less time with her. All participants described having enough space as being a pleasant and important feature for their participation, and they often evaluated rooms in terms of the sense of space they offered, as shown in Figure 6. Well-labelled spaces, such as libraries or shooting clubs, were preferred as they allow overview and orientation.

> "This is one of my preferred study places at the university. It is spacious. Talking is allowed. Mostly I am there at 8 in the morning and I can choose a place to sit. Few persons, 2 or 3 of them, are there at that time. This is pleasant, as it is quiet. If possible, I would sit in the same place, as there is an electrical outlet and I can oversee the entrance". (P6)

Adolescents with ASD felt that crowds strongly minimised their personal space. Crowds also affected their agency by limiting their free movement. Some adolescents considered crowds as barriers as crowds increase the chances of being touched unpredictably. For one participant, the anonymity in cities was relaxing (P6). Although physical context mattered in terms of attendance of and participation in activities, we found that the extent of differences in the individual experiences with physical context did not allow specific features to be clearly distinguished as facilitators or barriers.

Overall, all five environmental prerequisites (subthemes) had to be present for participants of this study for them to attend new activities. Once attendance is secured, the presence of some of the prerequisites, such as the company of trusted persons, was less necessary for participation and they could attend alone. All participants indicated that they were able to use public transport on their own, after initially requiring company. Only five other activities were performed without company, namely attending a gym (P5), sports groups (P1, P2, P6), individual music lessons (P1, P3), vocational-related lectures (P4, P5, P6), and visiting a museum (P4).

Main theme II: Social interchange and engagement

The second aspect that is crucial for participation of adolescents with ASD, and which provides insight into the question of how and why adolescents with ASD experience facilitators, barriers, and tension in their environments while they are attending and participating in activities outside of home and school, concerns social interchange and engagement. This aspect is related to the occurrence of social reciprocity when adolescents with ASD interact with persons other than their trusted persons during social activities. Such encounters include meeting persons occasionally (e.g. street, library, bathrooms), meeting acquaintances of others (e.g. concerts, university, receptions), passing break times with colleagues, and attending group events (e.g. university, work,

Table 4. Main theme II: social interchange and engagement.

Subtheme	Facilitators	Barriers	Tensions
Being approached	• Proactive behaviour • Being asked • Patience for answers	• Lack of pro-active approach • Lack of invitation • Lack of explanation	• Overstraining approaches • Gazing problems
Becoming a group member	• Organised group session • Clear rules for communication • Les priority of talking	• Large, informal groups • Irregular meetings • Quick conversations	• Pace (velocity) • Feeling inhibited in reacting
Being acknowledged and gently guided	• Provide positive feedback • Indicating gently what to do • Acceptance • Expression of gratitude for presence	• Negative feedback • Low tolerance • Stigmatised judgement	• Small issues can set off feelings of inappropriateness

leisure). Since adolescents with ASD were often uncomfortable about these situations, they were less likely to take photos. However, they explained the situations extensively in the interviews. Engagement in such social situations is a balancing act, which is reflected in the fact that this type of social interaction was the cause of most of the "tensions" that were indicated by participants. Three subthemes were identified within the second main theme (Table 4).

Being approached, the first subtheme, focusses on how communication, and specifically talking with each other, starts. Adolescents with ASD described how they wished to be talked to by others. The university student (P7) comments on this:

> "It is more likely that I stand alone than somebody approaches me. I am one out of ten in a mass of 1000 persons who stands alone. It feels like being fool….It would be easier for me if they approached me." (P7)

All participants described it as facilitating, when verbal interaction was initiated by others, particularly with small comments or short questions. And, as the adolescents required time to reflect on how to respond correctly, the people who engaged with them had to be patient. During initial social interactions, adolescents required additional time to focus on the question of how and where to gaze. Finding the right balance between gazing at and looking away from the other was most challenging. Barriers for social interchange and engagement in participation that were perceived by all participants were not being approached actively by others: and being pressed to react timely. One adolescent (P3) described the effort that it took him to talk and how hurt he was when others interrupted him. In general, tension arose when adolescents felt overstrained by the approaches of others or when they got the impression that their reaction to an approach was wrong. The following quote shows how quickly such tension can arise:

> "At the moment somebody replied, "I don't understand?" I became immediately insecure and doubted my capabilities. What mistake did I make? Did I not explain it well enough?". (P5)

Becoming a group member, the second subtheme, refers to the benefits of regular, well-organised groups in providing a venue for social interaction. Clear rules provide ease to adolescents with ASD, as exemplified by volleyball, in which there are lots of regulations, including the standing positions. For some participants, group work that was offered in vocational settings was a facilitator to start getting to know others (P2, P4, P6). However, for one participant, group work was overwhelming (P5). While talking in social situations was considered difficult, performing activities alongside others was perceived to be easier. Some adolescents explained that they started engagement without speaking. Informal or large groups as well as quick conversations were considered barriers to social interaction. The fact that they were engaging with their surroundings internally, but were unable to show this externally, which is easily misinterpreted as a sign of non-interest or absence, was described as a "tension".

Being acknowledged and gently guided is the third and last subtheme of the second main theme "social interaction and engagement". It combines other peoples' acknowledgement of the presence and slightly different needs of these adolescents and of the challenges they face in a particular environment on the one hand, and gentle support or guidance being offered to them on the other. A positive affirmation (e.g. "good to see you here"), for example, facilitates participation. For instance, one participant (P6) mentioned that he felt acknowledged by receiving a disability allowance at the university, allowed him to reserve a seat in the auditorium. Most adolescents with ASD expressed fear of being stigmatised as being weird or stupid. It is therefore understandable that they found it supporting to get gentle real time advice on how to behave according to expectations as explained in the following quote and illustrated with Figure 7:

> "I like when people gently tell me what I have to do in such a situation. Somebody proposed me to sit behind a table. It would be perfectly okay…. I like when they do such proposals and tell me what I should do in a gently way. I didn't know that it is decent to sit in receptions." (P5)

Only one adolescent preferred "tougher" feedback, pointing out his weaknesses and instances in which he did not pick up on reactions, as it broadened his awareness (P5). To all the others, even minor negative responses could turn a facilitator into a tension, as explained by one participant about his experiences in work shadowing in a kitchen (P1):

> "I had to hack a box of parsley, and they did it mega [extremely] fast …I stressed myself mega and still needed more time as them…. It was already a powder and they asked me to make it still smaller. I tried so hard but at the end they just said "not bad". I was a bit glad about my result, but I don't know why they could not acknowledge my hard work and good performance." (P1)

After this experience the participant decided that he was not interested in working in a professional kitchen anymore.

Social encounters were strenuous for adolescents with ASD. They struggled to understand the social processes that occurred during social interchange and engagement. A quote from one adolescent (P5) explained his dilemma with greeting neighbours in the garden:

> "Before, I did not say hello. Later, I started saying hello all the time. Now I think there are fine rules I don't know, and I think a lot about them. Should I great him immediately when I see him? Or when he looks at me? Or when he is close? How close? Do I disturb him? I feel disturbed when I am greeted. Why does he not feel that way? Or does he? How can I know?" (P5)

Overall, social participation was rarely relaxing and joyful for adolescents with ASD.

Figure 7. "Reception", data retrieved on Wednesday September 20th, 2017, 19:17.

Discussion

The goal of this study was to find out how and why adolescents with ASD perceive aspects of their environment as facilitators or barriers to their attendance and involvement in activities outside of home and school. We found that participants experienced each of these participation experiences as a social act. Two main themes were found to be paramount to achieve participation: first, five environmental prerequisites are necessary to achieve attendance of adolescents with ASD in activities: (1) the company of trusted persons, (2) the presence of a nudging drive, (3) the provision of knowledge and information, (4) the presence of good vibes, and (5) a certain design of the physical environment. Secondly, we found three environmental strategies to achieve involvement and social engagement, after attendance is achieved: (1) being approached, (2) becoming a group member, and (3) being acknowledged and gently guided. These two main themes in effect provide new insights concerning participation of adolescents, as they provide the first realistic example of the consecutive processes of the attendance and engagement of adolescents with ASD as described by Imms et al. [7]. Both main themes describe environmental conditions for participation of adolescents with ASD in a new manner.

In this section, we further discuss (the implications of) the findings, focusing on the 3 most important subthemes, two belonging to the theme *environmental pre-requisites to attend activities*, and one to the theme *involvement and social engagement*.

The company of trusted persons was one of the most important environmental prerequisites that influenced attendance. Participants in this study were heavily dependent on family members for company and experienced joy in sharing activities with them. This result is in line with studies on children with physical disabilities [46,47]. While adolescents with different kinds of disabilities consider authentic friendships, role models, opportunities to participate, and family support as the most meaningful environmental aspects for their participation [12], our results only support this finding for the last of these four aspects. While Kramer et al. [11] show that in the developmental phase of adolescence, youth normally replace the company of family with peers, adolescents with ASD consider doing this much less or not at all. While other adolescents value the quality of participation based on engaging alongside peers [11], the adolescents in this study valued being alongside trusted persons, especially family members. In the context of the canton of Zurich, hardly any service targets the participation of adolescents with ASD outside of home and school. Support depends heavily on family resources like time and finances. However, limited time, or financial, motivational or stigmatized restraints may result in a lack of family engagement [48,49]. Furthermore, spending a lot of time with family might limit participation alongside peers. To relieve families, a widening companionship provided by other confidential and trusted persons, like relatives, peers or service staff, seems to be essential to support participation of adolescents with ASD outside of the home and outside of school. In the field of work participation, companionship is recommended [50,51] which is implemented successfully in the canton of Zurich considering work participation but not in other fields.

Another factor that was found to be central for the attendance of adolescents with ASD in activities outside of home and school, is the *provision of knowledge and information*. This factor concerns orientation and preparedness, which, as cognitive maps, both provide informative security [13,14]. However, information and knowledge are not the same. "Information" refers to facts which are organised to describe situations or conditions. They are (or can be) made explicit and represented – seen in a philosophical way – outside of the mind [52]. This explicitness provides adolescents with ASD with security. Visual maps, written out train schedules and clear signage at stations are examples of (explicitly represented) information. Contrary to "information", "knowledge" refers to beliefs, perspectives, judgements, know-how and methodologies [52]. Although it is based on information, it comprises experiences of activities and social interactions and is seen by social scientists as being socially constructed. Due to the social communication problems, which are inherent to ASD, this social construction of knowledge seems specifically difficult for adolescents with ASD. In turn, this difficulty might be one of the reasons why persons with ASD often indicate that they feel that others stereotype them as being "weird or stupid" [53], as they feel a lack of knowledge or insight. For adolescents in this study, using public transport was an overall pleasant experience. Pupils in the canton of

Zurich are obligatorily trained to use the public transport system, which provides a reliable traffic environment, promotes a favourable attitude towards independent travel, and is adapted to young passengers [54]. Participants' attitudes towards independent travel (for school as well as for work and leisure) and their independence have greatly improved as a result of having gained knowledge. In addition, parents of Swiss adolescents with ASD are relieved from daily driving tasks. This situation would not have been possible without an approach concerning city planning and policy making that is specifically oriented towards independent travel.

As all adolescents with ASD mentioned their wish to be approached several times within one interview, we interpreted "being approached" as the most important subtheme concerning "involvement and social engagement. Our study indicates that adolescents with ASD experienced the adversity of social interactions as the primary issue concerning active involvement in activities. Instead of teaching these adolescents how to approach others [55,56], which is currently a common practice, but poorly facilitates generalisation into natural contexts, this study offers an interactional solution, in line with Sirota [57]. Namely, active participation in a reciprocal social world, in which adolescents with ASD are approached, prompted and gently guided. A pro-social attitude, similar to a family's natural behavior of questioning children with ASD during mealtime [58], is needed in larger social circles. Unfortunately, although people without ASD generally do not experience difficulties in initiating conversations, they currently do not seem to do so regularly with adolescents with ASD. It is therefore recommended that more awareness about this need is created among the public at large. In addition, negative attitudes towards autism [59] are frequently reported and these might be softened by an increase in knowledge and awareness about the subject as well [60,61]. A less medicalised perception of autism, as pursued by some autism-friendly companies, might be another way to achieve more positive attitudes [49].

Challenges and limitations

The strength of this study lies in the use of a case study design with the canton of Zurich as concrete case. The case study design fits our research objective and enables the examination of environment, hardly described for autism [59]. As strongly supported by others [7,9], participation occurs within a contextualised setting and participation outside of home and school can be contextually bounded.

In contrast to what was done in other studies [3,62] we deliberately bypassed the word "community", as a clear definition and common understanding of this term does not exist. It is often used to refer to different entities, such as neighbourhood, religious community, living area, quarter, internet community, region. In addition, no single word exists in German that conveys the same as the term "community". We therefore decided to use the term "outside of home and school". Indeed, participants understood that this term included participation in public places like cinema, sport arenas, public transport as well as visiting friends or relatives in private homes. Therefore, we recommend using this term for further studies.

As a research population, adolescents with ASD are hard-to-reach [63,64]. They hesitate to participate in new activities, and they need the support of trusted persons to continue. Two female participants left the study because they lacked such support. Despite recruitment support from thirty-eight key persons, the number of participants was low. It is not enough to simply ask adolescents with ASD to participate. Knowledge about the environmental prerequisites (first main theme) should be applied to assure attendance of adolescents with ASD in research projects. We recommend that consideration be given to "company of trusted persons", "the presence of a nudging drive", and "provision of knowledge and information" when conducting future research projects that include adolescents with ASD, if needed by employing assistants. This would benefit both future research projects as well as participating adolescents with ASD as they were keen to have their voices heard and felt proud to succeed participating in a research project [63].

Given the small sample size, our results cannot be generalised to the broader population of adolescents with ASD. The sample did, however provide us with a rich amount of data with consisting of 69 photos and nearly 13 h of interviews. Since our data was exclusively provided by male participants, results might not be fully transferrable to the experiences of female adolescents with ASD, as they tend to participate in different environments and activities, to interact with different people, and have different communication styles than males [65,66]. In addition, our inclusion criterium of needing to participate in at least one activity without company, might mean that our results do not fully apply to adolescents with severe language or cognitive impairments, as they might be influenced by other environmental aspects as well.

Photo-elicitation is an established method for conducting studies among persons in the autistic spectrum [44,67]. Using this method is appropriate for such studies as it allows people with ASD to engage with something visually, which is what they are generally good at. On the other hand, however, the use of photo-elicitation in this study did have some additional (unintended) side effects. First, the participants hardly took any pictures of people. Second, understandably, no photos were taken in environments the participants felt altogether too uncomfortable to attend in the first place (leading to very few barriers being described). These shortcomings, especially the second, are likely a result of participants' ASD and should be taken into account in future research among this population [4].

Directions for future practice and research

If the canton of Zurich and other geographical regions want to enhance the societal participation of adolescents with ASD, the creation of more autism-friendly environments is essential, just as environmental interventions are prioritised for other youths with disabilities [68,69]. More concretely, services and governments could address the environmental need of people with ASD for company, knowledge and information and positive vibes in social environments. Furthermore, a campaign to inform the general public of how adolescents with ASD can be included is recommended. Although set up by an individual entrepreneur, the website by Janneke Koekhoven serves as a fine example for such campaigns [70].

Further research should explore the extent to which different environmental features support the participation of adolescents with ASD and which environmental changes are needed. Which changes are most conducive to improvement, might differ from country to country, depending on the social, economic, healthcare and welfare situations that exist. Additionally, successful strategies that can be employed by parents to make social environments more attractive for their adolescent children with ASD need to be further explored and systematically described, in order to achieve attendance and involvement in participation.

Conclusions

This study, focussing on the case of Zurich, Switzerland, provides unique context-bound insight into two aspects of the way in which and the reasons why environments influence the participation of adolescents with ASD outside of the home and school. While the first main theme concerns environmental prerequisites that promote attendance, the second main theme concerns reciprocal strategies to initiate or increase the social involvement of adolescents with ASD. The influence of trusted persons for the participation of adolescents with ASD is highlighted, combined with a plea to relieve these trusted persons through broadening the support network to peers, services and the society in general.

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