Received: 22 June 2022 | Revised: 21 January 2023 | Accepted: 28 June 2023

DOI: 10.1111/cch.13155

RESEARCH ARTICLE

WILEY

Parents' perceptions: Participation patterns and desires for change for children and adolescents with autism spectrum disorder—A descriptive population-based study from Switzerland

Beate Krieger[1,2] | Barbara Piškur[3,4] | Anna J. H. M. Beurskens[2] | Albine Moser[2,3]

[1]School of Health Professions, ZHAW Zurich University of Applied Sciences, Winterthur, Switzerland

[2]Department of Family Medicine, Maastricht University, Maastricht, The Netherlands

[3]Research Centre for Autonomy and Participation for People with Chronic Illness, Zuyd University of Applied Sciences, Heerlen, The Netherlands

[4]Hasselt University, Faculty of Rehabilitation Sciences, Hasselt, Belgium

Correspondence
Beate Krieger, ZHAW Zurich University of Applied Sciences, School of Health Professions, Katharina Sulzer Platz 9, CH-8401, Winterthur, Switzerland.
Email: beate.krieger@zhaw.ch; krbe@zhaw.ch

Funding information
The authors declare that there was no funding for this research.

Abstract

Background: Low participation in youth with autism spectrum disorder (ASD) has been reported, but age-related and contextual information is rare.

Objective: This study aimed to describe, from parental perspectives, two patterns of participation and parental desires for change of children (age: 5–11) and adolescents (age: 12–17) with ASD in Switzerland.

Method: A cross-sectional design used the German version of the Participation and Environment Measure-Child and Youth to describe and juxtapose the participation results of 60 children and 55 adolescents with ASD in 45 activities at home, school and in the community and parental desires for change.

Results: Participation patterns differed between settings and age groups. Both groups were found to participate most at home, followed by school, whereas community participation was either low or nonexistent. Children were more involved at home than adolescents, while school involvement was higher than participation frequency in both age groups. Community participation frequency was generally low but higher in children than in adolescents, while involvement was similarly low in both groups. Half the parents expressed desire for change with three tendencies: (1) widespread desire for change at home due to high support needs, (2) parents of adolescents expressed more desire for change in all settings than those of children and (3) all parents mainly desired to increase participation frequency and involvement.

Conclusions: This study informs research and social, health and community service providers to further reshape their programmes to meet parental needs and increase the participation of youth with ASD.

KEYWORDS
autism, involvement, parents, participation, PEM-CY, youth

1 | INTRODUCTION

Lower participation rates have been reported across the lifespan for children and adolescents with autism spectrum disorder (ASD), compared with their peers without a disability (Askari et al., 2015; Hilton et al., 2008). Participation is defined within the International Classification of Function, Disability and Health (ICF) as '*involvement in a life situation*'(p 7) (WHO, 2001) and extended here to '*being engaged in and/or performing meaningful activities in occupational and social roles while attending*' (Krieger et al., 2018). This low participation means that children and adolescents with ASD participate less in different age-appropriate activities such as play, self-care, household chords, social media, school field trips, sports, mobility, shopping and socialising with friends (Arnell et al., 2018; Dovgan & Mazurek, 2019). Reduced participation has been also reported for different settings such as the home (Egilson et al., 2018; Sood et al., 2014), school (Wainscot et al., 2008) and community (Egilson et al., 2017; Hilton et al., 2008). Participation, as it is described within the framework of '*family of participation-related constructs*' (fPRC) (Imms et al., 2017, p 3), is understood as a combination of attendance and involvement. Participation serves as a means and an end for children and adolescents to learn and for social development (Adolfsson et al., 2011; Bölte et al., 2019). Participation is also embedded and influenced by the environment, which broadly consists of social and physical structures in which we live (Imms et al., 2017).

National contexts and policies are parts of the environment. For Switzerland, there is a relative paucity of data on the participation of youth with ASD from the parental perspective due to federal laws and sequenced cantonal health-and-social systems. Schools and leisure activities of youth with ASD vary greatly as does the organisation of leisure activities, which is a parental responsibility. A recent bill by the federal council of Switzerland (Bundesrat, 2018) encourages coordination of diverse activities in cooperation with parents and finances new service models for children and adolescents with ASD.

Parents (which is used here as synonym for all main caregivers) have essential knowledge of the daily participation of their children (Arakelyan et al., 2019). They are vitally connected to and often enable the participation of their children at home, at school and in the community. It is argued that parents should be given the mandate to prioritise intervention outcomes and participate in outcome measure reporting for their child, for themselves and for their family (Georgiades & Kasari, 2018). Thus, their perception of participation and desired changes in their children's participation are essential for family-centred service delivery.

One promising measure for combining these aspects is the Participation and Environment Measure-Child and Youth (PEM-CY) (Coster et al., 2011). Constructed as an questionnaire, it assesses parental perspectives on participation patterns of youth, environmental barriers and supports and parents' desires for change in three settings (home, school and community). Parents are asked to rate their children's participation frequency and involvement over the last 4 months in 5 to 10 activity groups in each of the three settings. Examples of activity groups at home are "*personal care management*" or "*indoor play and games*", for school "*field trips and school events*" or "*getting together with peers outside the class*", and for the community "*neighborhood outings*" or "*community events*". For each activity groups, various activities are given. Parents are asked to think of one or two of these activities their children participate in most often and start the ratings (frequency, involvement, and desire of change). With this construction the PEM-CY is suitable to use for children and adolescents between 5 and 17 years of age. It is not normative and flexible enough to refer to parents' perceived priorities. The PEM-CY belongs to the group of patient-reported outcome measures (PROMs), which collect health outcomes directly from the people experiencing them (Churruca et al., 2021). Thus, parent-lead collaborative care planning is feasible with the PEM-CY (Khetani et al., 2015). It also detects participation differences between youth with high functioning ASD as compared with those without ASD (Egilson et al., 2018).

Although PEM-CY-based research investigated samples of youth with ASD with different ages (Egilson et al., 2017; Lamash et al., 2019; Simpson et al., 2018), little systematic research has focused on age-related description of participation patterns in all three settings in children and adolescents with ASD (Ghanouni et al., 2019). Adolescence comprises a transitional period of physical adjustments and role changes within the family and society (Csikszentmihalyi & Larson, 1984; Friedman et al., 2013). Transitions often occur outside-of-school contexts, such as developing peer

Key messages

- This study describes for the first time participation patterns and parental desires for change in youth with autism spectrum disorder (ASD) from German-speaking Switzerland by using the translated and culturally adapted version Participation and Environment Measure-Child and Youth (PEM-CY(G)).
- Service providers need to be aware that participation frequency in children and adolescents with autism spectrum disorder declines from home participation to school participation and is striking low with 50% nonparticipation in the community.
- Parents of children and adolescents with ASD express strong desires for change in home participation. Health professionals need to address specifically the low participation involvement of these children and adolescents and reduce the parental support needs at home.
- In school settings, there are indications that a further focus on social participation can enhance the participation of youth with ASD.
- A combination of earlier involvement, more support from service providers, and increased community supportiveness is recommended to address the low community participation rate of youth with ASD.

relationships, increasing mobility, greater independence and moving into postsecondary education or work. In children with various disabilities, age was positively related to higher participation frequency and involvement at home as assessed with the PEM-CY (Anaby et al., 2014). It is assumed that similar differences also exist in the participation patterns of children and adolescents with ASD, as described within the ICF—core sets for children and adolescents with ASD (Bölte et al., 2019). However, adolescence poses for youth on the autism spectrum specific challenges, for example, increasing loneliness and depression, fewer peer contacts and more social withdrawal in the community and even within the family (Chang et al., 2019; Deckers et al., 2017; Magnuson & Constantino, 2011; Schwartz et al., 2016). These all may affect their participation, and the positive higher participation rate in adolescents compared with children might be questionable. However, an age-related description of the participation pattern is, to our knowledge, still missing.

Thus, the purpose of this study is to describe, from the parental perspective, two age-related patterns (5–11 and 12–17 years of age) of participation and parental desires for change in children and adolescents with ASD from Switzerland. We formulated the following two questions:

(1) What participation patterns are observed in the three settings of home, community, and school for children and adolescents with ASD, as described by parents in the German-speaking part of Switzerland?
(2) What desires for change do parents describe in the participation patterns of their children and adolescents with ASD?

2 | METHOD

2.1 | Design

A population-based cross-sectional study was selected, describing features at a given point in time.

2.2 | Participants

Participants were German-speaking parents who care for one or more children between 5 and 17 years with a recognised medical diagnosis of ASD. In accordance with the design, we decided to take a the self-selected sample for which parents were recruited through invitation letters sent to multiple different pathways in the German-speaking part of Switzerland, such as client and professional organisations and social media. The invitation letter included a link to a webpage with further information. Participation was voluntary, and the given information was anonymous in accordance with the data safety laws of the European Community. Parents consented online with informed consent. This survey received a jurisdictional declaration of nonobjection by the cantonal ethical committee of Zurich (BASEC Request 2018-00238).

2.3 | Measures

The online questionnaire consisted of the German version of the PEM-CY, demographic questions and questions about the actual manifestations of ASD symptoms. The demographic questions included those considering the family constellation, regional information, education of parents and the actual workload. This indicates the socioeconomic level of the family. We refrained to ask for the annual income and marital status, as this declaration is not common to Switzerland.

Due to the population-based nature of the sample, we estimated that clinical diagnostic features were either unknown to parents or not currently up to date. In Switzerland, until now, the ICD-10 criteria are used for ASD diagnostic. Therefore, we developed an actual ASD-manifestations questionnaire according to ICD-10 diagnostic criteria (e.g. communication, restricted and repetitive behaviour) and reported challenges (e.g. difficulties handling change, sleeping situation, self-injuring behaviour, age-appropriate independence) (Galpin et al., 2018). The 11 manifestations were rated for the last 4 months on a Likert-like scale between 1 and 6. The scales were formulated with qualitative anchors (e.g. 6 = 'Our child can express himself or herself age-appropriately or better' versus 1 = 'The expressive language of our child is very low'). Face and content validity of these manifestations was validated by the feedback of three professionals experienced in the diagnosis of youth with ASD to cover the most essential features of daily behaviour in ASD.

The PEM-CY is a standardised parent-reported assessment of the extent and patterns of participation (diversity, frequency, and involvement) in children and youth between 5 and 17 years and parents' desires for change in 25 activities within three settings. PEM-CY has demonstrated adequate internal consistency and test–retest reliability (Coster et al., 2011). We used a German-translated and cross-culturally adapted version, the PEM-CY(G) (Krieger, Schulze, et al., 2020). After setting the questionnaire up on an online platform (SocSicSurvey.com), five parents of children with ASD provided feedback on comprehensiveness and user-friendliness, and it was changed accordingly. Data collection took place between March and October 2020. Although in Switzerland the COVID-19 lockdown took only 6 weeks and the restrictions afterwards were judged as relatively mild, parents were asked to refer to the time before the lockdown for their answers.

2.4 | Analysis

The quantitative data were analysed using IBM SPSS Statistics (Version 27.1) analytical software. We focused on descriptive statistics due to the descriptive nature of the research questions.

2.4.1 | Demographics

Demographics of parents and youth were summarised, and total numbers, percentages, means and/or medians were calculated for the whole sample and two age groups (5–11 years and 12–17 years). This

age division reflects the difference between primary and secondary schools in Switzerland. Based on the data level, *t*-tests or Whitney–Man Wilcoxon tests were performed to indicate a statistically significant difference level of $p = 0.05$. Parent-reported manifestation of ASD was calculated using the median and quartile range for the whole group and the two subgroups. Calculations were based on Tukey's range tests to account for the ordinal scale used.

2.4.2 | Participation patterns

Participation patterns were analysed by participation diversity, frequency and involvement. We combined recommendations from the PEM-CY user guide with descriptive analysis. For participation diversity, we calculated the average number of activities that youth participated in per setting (home, school and community) and the standard deviation (SD). For participation frequency and involvement, we refrained from calculating average summary scores. Instead, we calculated the median and interquartile range (IQR) for each activity and Mann–Whitney *U*-tests to find significant difference levels of $p = 0.05$ between the two age groups. To compare patterns between participation frequency and involvement, we standardised the medians over 1. The variables analysed from PEM-CY are listed in Table 1.

2.4.3 | Parental desires for change

Per activity, we calculated the percentage of parents opting for each answer, both per setting and an average summary score. Missing data were reported. Narrative comments about desires for change, which

TABLE 1 PEM-CY: Analysed scales and scores across 25 activities in three settings.

	Variable	Scales	Reported scores
Participation pattern	Diversity	Sum of attended (frequency) activities per setting (home: 10 activities; school: 5 activities; community: 10 activities)	Mean of diversity and SD
	Frequency	8-point scale (1 = never; 2 = once in the last 4 months; 3 = few times in the last 4 months; 4 = once a month; 5 = few times a month; 6 = once a week; 7 = few times a week, 8 = daily)	Median of participation frequencies and IQR
	Involvement	5-point Likert scale (1 = minimally involved; 3 = somewhat involved; 5 = very involved	Median of participation involvement and IQR
Change	Desires for change	6-point categorical scale (no change desired; yes, do more often; yes, do less often; yes, be more involved; yes, be less involved; yes, be involved in a broader variety of activities) Space for free comments	Percentages of wished changes Summary scores per setting (mean) Qualitative reporting

Abbreviation: PEM-CY, Participation and Environment Measure-Child and Youth.

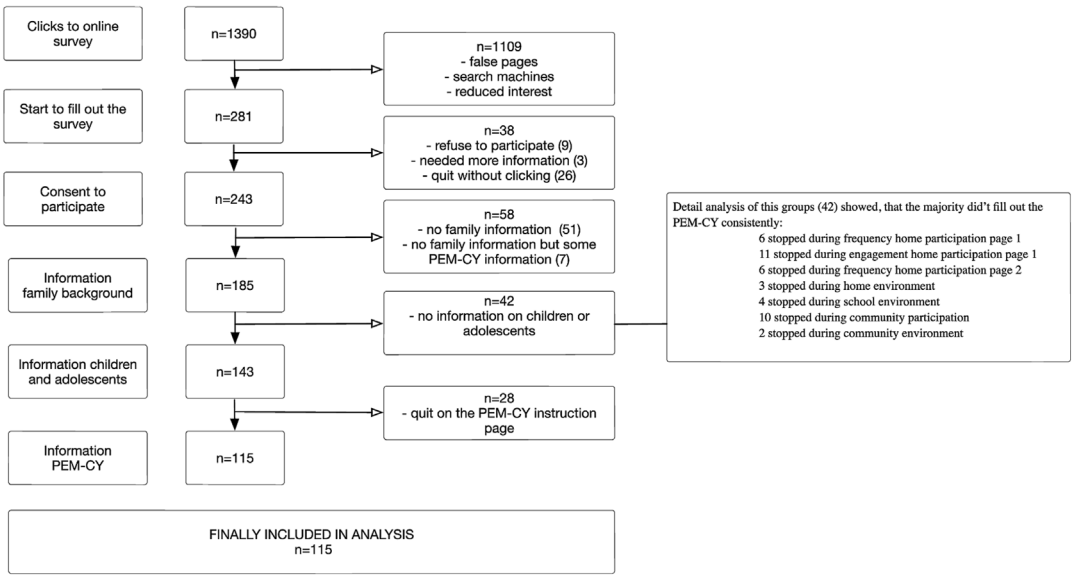

FIGURE 1 Flowchart selection of final cases.

are unique to the German PEM-CY version (Krieger, Schulze, et al., 2020), were analysed alongside each activity with a summative content analysis (Hsieh & Shannon, 2005), which involved counting, comparing and interpreting within the context of the quantitative ratings of parental desires for change.

3 | RESULTS

During the data collection, the online survey received 1390 views, of which 115 were included in the analysis. The flow of eligibility can be found in Figure 1.

TABLE 2 Demographic characteristics of parents answering questions for their children or adolescents with ASD.

	Children with ASD Age 5–11, $N = 60$		Adolescents with ASD Age 12–17, $N = 55$		Total group of youth Age 5–17, $N = 115$	
	n	%	n	%	n	%
Responding persons						
Mother[a]	46	78.0	49	89.1	95	83.3
Father[a]	9	15.3	4	7.3	13	11.4
Both together[a]	4	6.8	2	3.6.	6	5.3
Community type of living						
Urban[a]	9	15.0	5	9.1	14	12.2
Rural[a]	38	63.3	28	50.9	66	57.4
Agglomeration (suburbs)	13	21.7	22	40.0	35	30.4
Family constellation						
Child lives with both parents together	52	86.7	41	74.5	93	80.9
Parents separated; child lives in two households	0	0.0	4	7.3	4	3.5
Parents separated; child lives overly with one parent[a]	5	8.3	6	10.9	11	9.6
Child lives with one parent in a new family[a]	2	3.3	2	3.6	4	3.5
Other or missing[a]	1	1.7	2	3.6	3	2.6
Number of siblings of child with ASD						
No siblings	22	36.7	13	24.1	35	30.7
One sibling[a]	24	40.0	26	48.1	50	43.9
Two or more siblings[a]	14	23.3	15	21.7	29	25.5
Education of mother						
Obligatory[a]	3	5.0	2	2.6	5	4.3
Secondary education (professions)[a]	17	28.4	18	32.7	35	30.4
Tertiary education (academic)[a]	40	66.7	33	63.6	75	65.3
Unknown or missing[a]	0	0.0	0	0.0	0	0.0
Education of father						
Obligatory[a]	1	1.7	1	1.8	2	1.7
Secondary education (professions)[a]	15	25.0	11	20.0	26	22.6
Tertiary education (academic)[a]	42	70.0	39	71.0	81	70.4
Unknown or missing	2	3.3	4	7.2	6	5.3
Further information of the family						
Actual percentage of paid work of mother	33.1[b]	31.32[c]	49.9[b]	33.25[c]	41.1[b]	33.20[c]
Actual percentage of paid work of father	87.1[b]	27.31[c]	80.5[b]	33.76[c]	84.0[b]	30.57[c]
Number of languages spoken in the inner family	1.42[b]	0.72[c]	1.53[b]	1.42[c]	1.47[b]	1.1[c]

Abbreviation: ASD, autism spectrum disorder.
[a]No significant difference at the $p = 0.05$ level.
[b]Mean.
[c]SD.

3.1 | Participants

The demographics of the 115 parents are listed in Table 2. Overall, 60 parents reported on children (5–11 years of age), while 55 reported on adolescents (12–17 years of age). Statistically, the two groups did not differ significantly ($p = 0.5$) with regard to responding parents, community type of residence and education level of parents. Nearly half of respondents used two languages in the inner family. However, the family constellation differed statistically: Parents of adolescents lived more often in separated households, and the paid working hours of mothers of adolescents were higher than those of mothers of children.

The demographics of the children and adolescents with ASD are listed in Table 3. The two age groups differed statistically in the average age of diagnosis, number diagnosed with Asperger's syndrome and the number of friends and informal friends (per social media) they meet with per week. About 15%–20% of parent answers for informal friendships and social media contacts were missing.

TABLE 3 Demographic characteristics of children and adolescents as described by parents.

	Children with ASD Age 5-11y; N = 60		Adolescents with ASD Age 12-17y; N = 55		Total group of youth Age 5-17y; N = 115	
	n	%	*n*	%	*n*	%
Gender						
Male[a]	51	85.0	41	74.5	92	80.0
Female[a]	9	15.0	14	25.5	23	20.0
Type of ASD						
Autism spectrum disorder[a]	16	26.7	11	20.0	27	23.5
Early onset autism[a]	10	16.7	8	14.5	18	15.7
Asperger syndrome	23	38.3	33	60.0	56	48.7
Atypical autism[a]	5	8.3	3	5.5	8	7.0
Other not specified	6	10.0	0	0.0	6	5.2
Age of diagnosis	5.6[b]	2.12[c]	8.5[b]	3.41[c]	7.0[b]	3.15[c]
Main co-morbidity						
No co-morbidity	34	56.7	19	34.5	53	46.1
ADHD[a]	11	18.3	12	21.8	23	20.0
Anxiety[a]	1	1.7	4	7.3	5	4.3
Epilepsy[a]	0	0.0	1	1.8	1	0.9
Depression[a]	1	1.7	4	7.3	5	4.3
Motor dysfunction[a]	4	6.7	2	3.6	6	5.2
Others or unknown	6	10.0	11	20.0	14	14.8
Schooling						
Regular setting without adjustments[a]	8	13.6	8	14.8	16	14.2
Regular setting (minor adjustments)[a]	20	33.9	13	24.1	33	29.9
Regular setting (special adjustments[a]	9	15.3	6	11.1	15	13.3
Private school[a]	7	11.9	13	24.1	20	17.7
General separate school[a]	13	22.0	8	14.8	21	18.6
Home or boarding school[a]	1	1.7	2	3.8	3	2.7
Vocational apprenticeship	0	0.0	3	5.6	3	2.7
None or misssing[a]	1	1.7	3	5.6	4	3.6
Friendships (outside school)						
Personal friends meeting per week	1.4[b]	2.04[c]	0.7[b]	0.94[c]	1.1	1.64[c]
Informal peers meeting per week[a]	2.74[b]	4.64[c]	3.0	4.22[c]	2.8	4.41[c]
Peers meeting via social media per week	0.6[b]	1.81[c]	3.1	4.33[c]	1.8	3.55[c]

Abbreviation: ASD, autism spectrum disorder.
[a]No significant difference at the $p = 0.05$ level.
[b]Mean.
[c]SD.

TABLE 4 Actual manifestation of ASD during the last 4 months

	Children with ASD Age 5–11 $n = 66$		Adolescents with ASD Age 12–17 $n = 55$		Total number of youth Age 5–17 $n = 115$	
	Median	IQR	Median	IQR	Median	IQR
1. Ability of expressive language	5	3.5–6	6	5–6	6	4–6
2. Use of communication aids	6	5–6	6	6–6	6	5–6
3. Intellectual abilities	6	5–6	6	4–6	6	4–6
4. Self-harming behaviour	6	4.5–6	6	5–6	6	5–6
5. Reaction to changes	3	1–4	3	1–4	3	1–4
6. Repetitive behaviour	4	2–5	4	3–5	4	2–5
7. Restricted behaviour	4	3–5	4	2–5	4	3–5
8. Selective eating	4	2–5	4	3–6	4	2–5
9. Sleeping situation	3	2–5	4	3–6	4	2–5
10. Interaction with other children	3	3–4	4	2–4	4	2–4
11. Age appropriate independence	3	2–4	4	2–5	3	2–4

Note: The highest number (6) indicates not been affected, lowest number (1) indicates being strongly affected as judged by parents. Calculations based on Tukey's range tests.
Abbreviations: ASD, autism spectrum disorder; IQR, interquartile range.

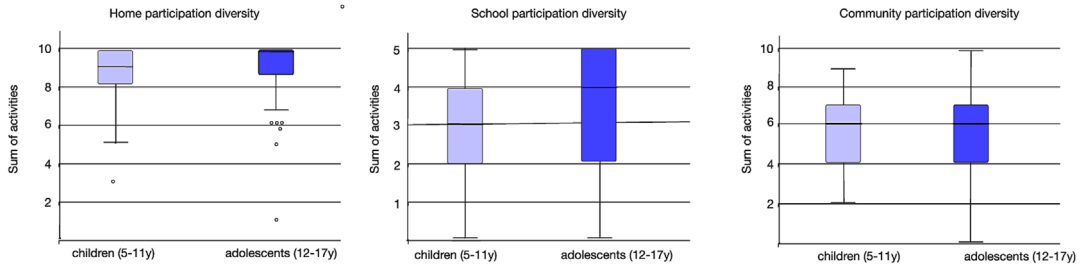

FIGURE 2 Participation diversity.

The manifestation of ASD symptoms gave insight into the spectrum of autistic features in the sample (see Table 4). '*Expressed language ability*', '*use of communication aids*', '*intellectual abilities*' and '*no self-harming behaviour*' were rated highly in both groups, indicating a less severely affected autistic sample. '*Reaction to changes*', '*repetitive behaviour*', '*restricted behaviour*' and '*selective eating pattern*' were rated in the middle range for both subgroups. In contrast, '*sleeping situation*', '*interaction with other children*' and '*age-appropriate independence*' scored in both groups in the middle range. However, in all these three manifestations, adolescents with ASD presented more spread than children with ASD. Only '*reaction to changes*' was given with a high spread in both groups.

3.2 | Participation patterns

3.2.1 | Diversity

The distribution of diversity, visualised by box plots (Figure 2), gives graphical insight into the overall number of activities children and adolescents participated in across each setting (regardless of the frequency). In 10 home activities, the average diversity for children and adolescents was relatively high (children: $M = 8.7$, $SD = 1.38$; adolescents: $M = 8.8$, $SD = 1.74$). The box plots show how adolescents' diversity in home activities was influenced by a few individuals with relatively low diversity rates. In five school activities, children participated middle diverse and children slightly less diverse than adolescents (children: $M = 3.0$, $SD = 1.56$; adolescents: $M = 3.4$, $SD = 1.46$). However, the box plots indicated that 75% of adolescents participate in two to five activities at school. Of the 10 possible activities in the community, both groups participated in half of all possible activities on average (children: $M = 5.5$, $SD = 1.7$; adolescents: $M = 5.3$, $SD = 2.3$).

3.2.2 | Participation frequency and involvement in children with ASD

At home, children participated mostly with a high frequency. '*Indoor play and games*' and '*personal care management*' were the most

frequent activities, while '*socialising using technology*' and '*school preparations*' were the least frequent. In half of all activities, including '*getting together with other people*', parents reported high involvement. Although '*personal care management*' was done frequently, the corresponding involvement was in the middle range. According to the parents, children showed the lowest involvement in '*school preparations*'.

At school, children's participation frequency varied greatly. '*Getting together with other children outside the class*' was the pursuit with the highest frequency, while '*school-sponsored teams, clubs, and organisations*' and '*special roles at school*' were the least frequent. For all activities, school participation involvement was judged in the middle range.

In the community, children's participation could be divided into two groups: activities with high participation frequency (e.g. '*neighbourhood outings*', '*unstructured physical activities*' and '*getting together with other children*') and activities with rare or no participation (e.g. '*classes and lessons*', '*overnight visits and trips*'). With two exceptions ('*unstructured physical activities*' and '*getting together with other children in the community*'), children's involvement rate was low for all activities in the community. Table 5 and Figure 3 show the

TABLE 5 Participation frequency and involvement in 45 activities in children and adolescents with ASD.

		Participation frequency 8-point scale (1 = never to 8 = daily)			Participation involvement 5-point scale (1 = minimally to 5 = very)		
		Children Age 5–11 Median (IQR)	Adolescents Age 12–17 Median (IQR)	Sig. dif. $p = 0.05$*	Children Age 5–11 Median (IQR)	Adolescents Age 12–17 Median (IQR)	Sig. dif. $p = 0.05$*
Home	1. Indoor play and games	8 (7–8)	5 (2–7)	.000*	5 (4–5)	3.5 (3–4)	.001*
	2. Arts, crafts, music and hobbies	7 (7–8)	7 (4–8)	.168	4 (3–5)	3.5 (3–5)	.205
	3. Computer and video games	7 (6–8)	8 (7–8)	.037*	5 (4–5)	5 (4–5)	.892
	4. Watching TV, videos and DVDs	7 (7–8)	7 (7–8)	.765	5 (4–5)	5 (4–5)	.181
	5. Getting together with other people	7 (6–8)	7 (5–8)	.414	4 (3–5)	3 (2–4)	.002*
	6. Socialising using technology	5 (1–6)	7 (4–7)	.000*	3 (2–4)	3 (1.5–4)	.865
	7. Household chores	7 (5–7)	7 (6–7)	.524	3 (1–3)	2 (1–3)	.188
	8. Personal care management	8 (8–8)	8 (8–8)	.878	3 (2–3)	3 (2–4)	.281
	9. School preparation	5 (1–7)	7 (2–8)	.069	1 (1–3)	1.5 (1–3.5)	.466
	10. Homework	7 (3–8)	7 (5–8)	.945	3 (1–3)	2 (1–3.5)	.440
School	1. Classroom activities	3 (1–6)	7 (6–8)	1.00*	3 (3–4)	3 (3–4)	.142
	2. Field trips and school events	3 (1–4)	3 (2–4)	.580	3 (2–4)	3 (1.5–3.5)	.190
	3. School-sponsored teams, clubs and organisations	1 (1–1)	1 (1–5)	.029*	1.5 (1–3)	2 (1–3)	.595
	4. Getting together with peers outside of class	7 (3–8)	6 (2–7)	.394	3 (3–4)	3 (2–4)	.055
	5. Special roles at school	1 (1–5)	3 (2–6)	.237	3 (2–4)	3 (1–4)	.358
Community	1. Neighbourhood outings	6 (5–7)	5.5 (4–7)	.062	3 (3–3)	3 (2–4)	.276
	2. Community events	3 (1.5–4)	2 (1–4)	.368	1 (1–3)	1 (1–4)	.122
	3. Organised physical activities	5 (1–6)	3 (1–7)	.848	3 (1–3.5)	1 (1–2)	.042*
	4. Unstructured physical activities	7 (6–7)	6 (5–7)	.017*	4 (3–4.5)	3 (1–4)	.003*
	5. Classes and lesions (not school-sponsored)	1 (1–6)	1 (1–6)	.639	1 (1–2)	1 (1–4)	.019*
	6. Organisations, groups or volunteer leader activities	1 (1–1)	1 (1–3)	.067	1 (1–2)	1 (1–3)	.709
	7. Religious or spiritual activities	1 (1–3)	1 (1–3)	.739	1 (1–2)	3 (1–3)	.479
	8. Getting together with other children (community)	5 (3–5)	2 (1–5)	.001*	4 (2–4)	3 (1–3)	.001*
	9. Work for pay	1 (1–1)	1 (1–1)	.117	1 (1–1)	1 (1–2)	.631
	10. Overnight visits and trips	1 (1–2)	1 (1–2)	.120	1 (1–1)	1 (1–3)	.165

Abbreviations: ASD, autism spectrum disorder; IQR, interquartile range.
*Mann–Whitney *U*-test significance for $p = 0.05$.

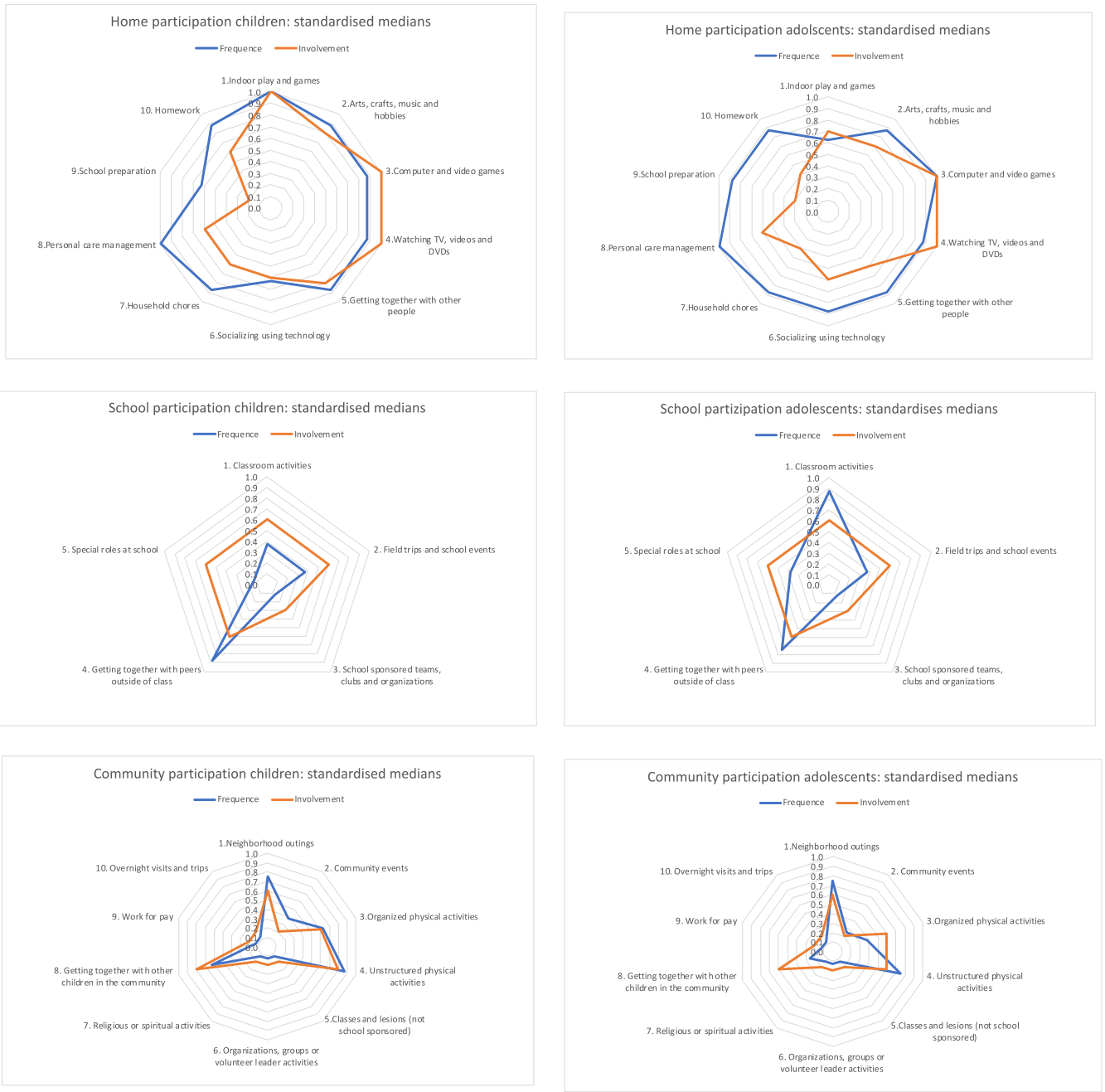

FIGURE 3 Participation frequency and involvement pattern in three settings and two age groups.

frequency and involvement of both age groups in all 45 activities in all three settings.

3.2.3 | Participation frequency and involvement in adolescents with ASD

Overall, the participation frequency of adolescents with ASD in home activities was high. Except for '*indoor play and games*', half of the adolescents participated a few times a week or daily in all activities. Hence, the participation involvement varied: while two activities ('*computer and video games*' and '*watching TV, videos or DVDs*') were rated with high involvement, three others ('*household chores*', '*school preparations*' and '*homework*') were rated with very low involvement.

At school, two activities ('*classroom activities*' and '*getting together with other children outside the class*') showed high participation frequency for adolescents, while the three remaining showed a huge variability. The reported involvement rates clustered around the middle values.

In the community, the participation frequency for adolescents with ASD in *'neighbourhood outings' and 'unstructured physical activities'* was relatively high, while it was low (e.g. *'getting together with*

other children in the community') or are not at all existent (e.g. *'classes and lesions'*, *'organisations, groups or volunteer leader activities'*) in most other activities. Participation involvement presented a similar pattern to participation frequency. Within the IQRs, high involvement was never reported for adolescents with ASD.

3.2.4 | Distribution of frequency and involvement in three settings and two age groups

The combined frequency and involvement in all three settings are displayed graphically with spider diagrams in Figure 3. Both groups participated in most of the activities at similar rates at home, but the involvement rate was lower for adolescents in most activities. At school, the pattern even looks different visually. While children had a low participation frequency (with one exception: '*getting together with peers outside of class*') with a high involvement rate, adolescents combined a high participation frequency in two activities with involvements rates similar to children. In the community, participation frequency and involvement are low in most activities for children and adolescents. There was only one difference: Adolescents with ASD participated slightly less frequently in '*community events*' and '*organised physical activities*' and much less frequently in '*getting together with other children in the community*', while their involvement patterns were similar to those of children.

3.3 | Parental desires for change

Overall, three tendencies were found for parental desires: First, parents of both age groups desired more change in participation at home (children: 51%; adolescents: 61%) than at school (children: 36%; adolescents: 42%) and in the community (children: 34%; adolescents: 48%). Second, parents of adolescents with ASD expressed higher desires for change in all three settings compared with those of children. Third, the majority of desired change referred to more frequent and more involved participation (with two exceptions: '*computer and video games*' and '*watching TV, videos and DVDs*', which parents commented with challenges to limiting gaming time [e.g. '*It's difficult to get him off of it, we hide the tablet*'] and wanting fewer conflicts). The percentages of parental desires are listed in Table 6. If more than 33.0% of parents reported desires for a change, it is highlighted in the table in bold. Parents wrote 529 voluntary comments (home: 141/139; school: 51/34; community: 51/57).

3.3.1 | Parental desires for change in home participation

A third of parents of children and half of those of adolescents desired a higher participation frequency in '*getting together with other people*'. Parents' desires ranged from a stronger interest in socialising, to more involvement (e.g. '*He is a bystander, not nearly there*') and less conflicting social situations (e.g. '*We want more times together, positive experiences, friendly activity with brother*'). Half of all parents desire a higher participation frequency in '*household chores*'. They want greater initiative from their children, more interest and fewer escalations (e.g. '*Getting our son to do this is extremely demanding, energy and time consuming*'). Over half of the parents of children desired more frequent participation in '*personal care management*'. They wanted their children to have a greater drive to become independent and have more independent performance (e.g. '*He doesn't do all these things by himself, we brush his teeth … and help with getting dressed*'). In both groups, parents wanted fewer daily conflicts around care management. Frequency and involvement in '*school preparation*' were also chosen often and comments referred to wanting greater initiative and better organisational or planning skills (e.g. '*The backpack is always packed in exactly the same way, which is difficult when you have to carry something additionally*'). Parents of adolescents desire more insight into the purpose of homework and reduction in conflict potential (e.g. '*A lot of refusal, screaming and aggression, wish there was less homework*').

3.3.2 | Parental desires for change for school participation

For the school setting, a third of parents of children and half of parents of adolescents wanted higher participation frequency in '*getting together with peers outside of class*'. Three aspects were mentioned: missing contact with peers, more shared activities with peers (e.g. '*He is also limited, as he cannot yet do everything his peers can do without supervision*') and more social flexibility in the children with ASD (e.g. '*Mostly she chooses one child, with whom she spends all time. It would be nice if she could open up also to others*'). Only parents of adolescents also wanted more involvement in this activity.

3.3.3 | Parental desires for change for community participation

For community participation, one third in both age groups desired more frequent participation in '*organised physical activities*' and wished that their children could deal better with demands (e.g. '*I wished he could better adhere to the rules*'). Missing opportunities or being excluded from experiences were also mentioned (e.g. '*He was excluded from swimming course because he was too restless*'). Nearly half of parents of adolescents wanted more frequent participation in '*unstructured physical activities*'. They commented that adolescents needed to be persuaded and were dependent on company. Almost half of all parents desired more frequent participation in '*getting together with other children*' in the community. Parents commented on missing friends in the community due to various reasons. Parents also formulated desires about the attitudes of peers' parents (e.g. '*Acceptance exits only with those children, whose parents accept my autistic son and do not classify him as' abnormal 'and' weird*').

TABLE 6 Percentage of parental desires for change in participation.

			No changes desired		Yes, changes desired[a]									
		Number of parents per age-group <12/>12[b]	*'It is ok so'*		Frequency *'Yes, do more often'*		Frequency *'Yes, do less often'*		Involvement *'Yes, be more involved'*		Involvement *'Yes, be less involved'*		Other activities *'Yes, be more involved in a broader variety of activities'*	
			<12	>12	<12	>12	<12	>12	<12	>12	<12	>12	<12	>12
Home	1. Indoor play and games	58/50	67.2	50.0	12.5	**34.0**	3.4	0	5.2	16.0	1.7	2.0	12.1	14.0
	2. Arts, crafts, music and hobbies	58/50	67.2	48.0	12.8	**36.0**	0	2.0	13.8	6.0	1.7	0	10.8	16.0
	3. Computer and video games	58/51	55.2	30.0	0	2.0	20.7	**40.0**	0	4.0	22.4	**34.0**	10.3	18.0
	4. Watching TV, videos and DVDs	58/51	63.8	47.1	1.7	3.9	15.5	27.5	3.4	3.9	19.0	21.6	3.4	11.8
	5. Getting together with other people	58/51	41.4	24.0	**34.5**	**52.0**	5.2	0	22.4	22.0	3.4	2.0	5.2	10.0
	6. Socialising using technology	58/51	57.9	49.0	28.1	**31.4**	3.5	3.9	10.5	17.6	1.8	3.9	8.8	5.9
	7. Household chores	58/51	24.1	27.5	**56.9**	**51.0**	0	0	29.3	**33.3**	0	0	5.2	9.8
	8. Personal care management	58/51	27.6	43.1	**48.3**	23.5	0	2.0	**43.1**	**33.3**	0	2.0	8.6	5.9
	9. School preparation	57/50	31.6	36.0	**49.1**	**42.0**	0	0	28.1	**34.0**	0	2.0	3.5	4.0
	10. Homework	55/49	45.5	34.7	32.7	**46.7**	0	0	25.5	32.7	5.5	2.0	3.6	8.2
	Summary home mean (%)		**48.15**	**38.94**	**27.66**	**32.21**	**4.83**	**7.53**	**18.13**	**20.28**	**5.55**	**6.92**	**7.21**	**10.36**
School	1. Classroom activities	53/52	56.6	46.2	24.5	23.1	1.9	7.7	18.9	26.9	1.9	1.9	7.5	5.8
	2. Field trips and school events	55/50	65.5	60.0	20.0	26.0	0	0	12.7	12.0	7.3	7.3	7.3	6.0
	3. School-sponsored teams, clubs and organisations	55/50	73.1	73.1	15.4	15.4	0	0	9.6	11.5	0	0	7.7	3.8
	4. Getting together with peers outside of class	52/52	52.7	34.0	**34.5**	**52.0**	1.8	0	12.4	32.0	1.8	1.8	3.6	4.0
	5. Special roles at school	51/48	76.5	75.0	15.7	14.6	0	2.1	2.0	8.3	0	0	7.8	4.2
	Summary school mean (%)		**64.88**	**57.64**	**22.02**	**26.22**	**0.74**	**1.96**	**11.12**	**18.14**	**2.2**	**2.2**	**6.78**	**4.76**
Community	1. Neighbourhood outings	58/50	69.0	78.0	19.0	10.0	1.7	0	8.6	4.0	1.7	2.0	5.2	10.0
	2. Community events	58/50	71.2	76.0	20.3	12.0	0	0	6.8	4.0	0	0	10.2	10.0
	3.Organised physical activities	58/50	60.3	50.0	**31.0**	**34.0**	0	0	17.2	10.0	0	0	5.2	12.0
	4. Unstructured physical activities	58/50	58.6	48.0	25.6	**44.0**	3.4	2.0	17.2	10.0	0	0	6.9	8.0
	5. Classes and lesions	56/49	64.3	59.2	19.6	26.5	0	0	12.5	12.2	0	2.0	5.4	8.2
	6. Organisations, groups or volunteer leader activities	53/49	62.3	69.4	26.4	20.4	0	0	7.5	6.1	0	0	15.1	8.2
	7. Religious or spiritual activities	52/48	75.0	83.3	7.7	6.3	0	0	13.5	4.2	0	0	7.	6.3
	8. Getting together with other children	55/50	47.3	30.0	**45.5**	**48.0**	0	0	10.9	20	5.5	0	7.3	18.0

(Continues)

TABLE 6 (Continued)

	Number of parents per age-group <12/>12[b]	No changes desired		Yes, changes desired[a]									
		'It is ok so'		Frequency 'Yes, do more often'		Frequency 'Yes, do less often'		Involvement 'Yes, be more involved'		Involvement 'Yes, be less involved'		Other activities 'Yes, be more involved in a broader variety of activities'	
		<12	>12	<12	>12	<12	>12	<12	>12	<12	>12	<12	>12
9. Work for pay	48/47	89.6	61.7	8.3	27.7	0	0	4.2	4.3	0	0	4.2	10.6
10. Overnight visits and trips	54/49	57.4	61.2	31.5	24.5	1.9	1.9	3.7	2.0	1.9	2.0	11.1	14.3
Summary community mean (%)		**65.5**	**61.66**	**23.5**	**25.3**	**0.70**	**0.39**	10.18	**7.68**	**0.36**	**0.60**	**7.83**	**10.56**

Note: Due to the multiple answer options, percentage refers to the overall of received answers.

[a]More than 33.00% of desired changes per item are highlighted in bold.

[b]Age groups: <12 children from 5 to 11 years of age; >12 adolescents from 12 to 17 years of age.

4 | DISCUSSION

The goal of this study was to examine, from parents' perspectives, the participation patterns of children and adolescents with ASD and the connected parental desires for change in participation in the German-speaking part of Switzerland. Based on the results of this study, we suggest that the participation patterns of children and adolescents with ASD differ between the three settings and between the age groups. While both groups participate most often at home, followed by school, community participation for both age groups is low or, in half of the activities, nonexistent. Children with ASD are more involved at home than adolescents with ASD, while school involvement exceeds activity frequency in both age groups. In community participation, frequency is lower in adolescents than in children, but involvement is similarly low in both groups.

Half of participating parents expressed desires for change. We suggest three tendencies: First, parents had the most desire for change in the home setting. Second, parents of adolescents expressed more desire for change in all three settings than did parents of children. Third, parents of both age groups wanted in all activities a higher participation frequency and involvement, with two exceptions: gaming and watching films.

We will discuss and juxtapose our results across the three settings. In our sample, participation frequency at home is similar to those of other youth with and without disabilities (Lamash et al., 2019; Law et al., 2013; Simpson et al., 2018). For most participants, engagement in activities such as dressing or playing occurs daily. However, parents in this present study expressed strong desires for change: Apart from gaming and watching films, they wanted all activities at home to be more frequent and more involved. Their comments showed that participation in home activities included daily struggles with remembering, motivating, initiating, supporting physically and dealing with emotions and the need for sameness. Parents desired more independence, more insight into activities' necessity and more engagement. Parents perceived children's involvement to be higher in self-chosen activities (such as play, TV, video, and socialising) than in obligatory and externally demanded ones (such as self-care, household chores or homework). It is argued that from the perspective of children and adolescents, these activities are work (Chapparo & Hooper, 2002) as they are externally and socially motivated. Children and adolescents with ASD are intrinsically motivated, more specifically, by their special interests or preferences (Winter-Messiers, 2007), which less often cover self-care or household tasks. Further, reduced social motivation is reported to be challenging for learning age-appropriate tasks in persons with ASD (Factor et al., 2016). Parents' daily struggles to achieve routinisation while simultaneously enhancing their children's performance is tiresome, exhausting and unacknowledged (Bagatell, 2016; Larson, 2006; McAuliffe et al., 2020). When asked about research needs, parents of children with ASD described high needs in the home setting (Clark & Adams, 2020). A paucity of research covering interventions for activities such as household chores or self-care in ASD is notable (Flynn & Healy, 2012; Kuhaneck Miller et al., 2015) and might

also reflect poor intervention practice. It is noteworthy that in children with ASD under 5 years of age (Khalifa et al., 2020), home participation involvement has been reported to be higher than in this present study. As a higher involvement rate makes acquiring new activities and increasing participation frequency easier, an earlier focus on these tasks and an intervention focus on these activities is recommended.

School participation, as suggested by our results, increases in frequency and involvement with age. Compared with data from Australia (Simpson et al., 2018) or Israel (Lamash et al., 2019), the participation frequency of children with ASD in our sample is smaller. This might be explained by different schooling systems in Switzerland. Students take lunch at home or in the day home for school children; therefore, after-school-based projects are seldom. Two more aspects of our results are further notable: First, while children with ASD socialised in frequency and involvement highly with other children outside classes, this drops drastically in adolescents with ASD. These results align with the widely described social loneliness and withdrawal of adolescents with ASD (Deckers et al., 2017; Houghton et al., 2022; Lasgaard et al., 2010). Second, the commends of parents regarding desires for change refer mainly to socialising with peers. Results suggest that socialising with peers outside the classroom is rarely supported by school services and is never a school priority, although students with ASD are reported to benefit from peer buddies motivated by school personnel (Laghi et al., 2018). Similar tensions leading to frustration with school services are reported by other researchers: Services do not grow with children's needs (Ho et al., 2018), and more pedagogical support for social participation is recommended (Ghanouni et al., 2019). However, the overall percentage of parental desires considering school participation was much lower in our sample than in comparable samples (Simpson et al., 2018). We assume that Swiss parents do not desire many changes because, by and large, they value the efforts and academic achievements of schooling services for their children with ASD. We further assume that Swiss parents do not see socialising as the main task of school service.

The community participation of children and adolescents with ASD in our study is as low as described elsewhere (Egilson et al., 2017; Lamash et al., 2019; Simpson et al., 2018). Valuing community participation as a universal right for all persons with disabilities (UN General Assembly, 2007), the percentages of nonparticipation in our Switzerland sample (comparable with a study from Australia, Simpson et al., 2018) are alarming. We propose three strategies to address missing community participation: first, early mobility into the community (Kersten et al., 2020). Parents describe in this research how they need to push their children with ASD gently to achieve development. Parents actively create opportunities for practice in the community, in which their children can scaffold skills for independent mobility (Kersten et al., 2020; Krieger et al., 2022). Considering the high amount of time, adolescents with ASD need to regain self-esteem, a sense of belonging or confidence (Song et al., 2021); starting community involvement at an early developmental stage is reported to be more favourable (Khalifa et al., 2020). Second, to reduce parental burden, service providers can focus their aims towards the community participation of children and adolescents with ASD such as leisure or mobility (Krieger, Piškur, et al., 2020). Youth with ASD value interacting with friends (Chen et al., 2016), and participation in the community is associated with more friendships and social relationships with peers, even after controlling for intelligence quotient and help managing internalising problems (Dovgan & Mazurek, 2019). Third, a high number of caregivers indicated that the community did not support their children's participation (Devenish et al., 2020; Egilson et al., 2017; Lamash et al., 2019). Some authors suspect that community supportiveness may be more important for involvement than child characteristics (Devenish et al., 2020). Museums can remove barriers to participation, sports organisations can provide inclusive programmes and youth clubs can be tailored to the needs of youths with ASD.

Three strengths of this study are notable. First, it presents for the first time estimates of the participation patterns of children and adolescents with ASD in Switzerland, combined with parental desires for change. A second strength is the description of two groups of youth with ASD, while others focus only on children (Devenish et al., 2020) or adolescents (Lamash et al., 2019) separately. The last strength is the combination of qualitative and quantitative data about the desires of parents, which was possible due to a new feature in the PEM-CY (G) (Krieger, Schulze, et al., 2020). It allowed better insight into the daily routines and experiences of parents caring for children with ASD.

Methodologically, we deliberately choose a purely descriptive analysis, as the results should be informative to health care providers and policy developers not acquainted with the PEM-CY construct. Despite the relatively high number of participants for Switzerland (with 3000 estimated individuals with ASD between 5 and 17 years of age (Bundesrat, 2018) in all four regional languages), we further believe that the sample is too diverse to present well-shaped inferential results. In line with others (Simpson et al., 2018), we judged that neither participation frequency nor participation involvement is scaled in the PEM-CY adequately to perform inferential statistics or regression analysis.

Several limitations of this study require consideration. First, as for all parent reports, the possibility of underrating or overrating is inherent. Parents may be unaware of their children's friendships at school or on social media. Second, we are aware of a possible selection bias. Filling in the PEM-CY is challenging and often missing data sets are described (Chien et al., 2020). After consenting, we had an enrollment rate of 85% and a completion rate of 73%, indicating that we lost a third of participants after reading the instructions and while completing the PEM-CY. Third, there might be a volunteer bias in the way we recruited participants. Regarding family constellation, workload and the number of spoken languages in the family, the sample of this study data fits those from official statistics (Bundesamt für Statistik, 2017). However, good German literacy and at least 45 min to fill in the survey were mandatory. Considering that 22% of Switzerland's residents are foreigners (Bundesamt für Statistik, 2017), we might have some missing data. Our sample had few severely affected children and adolescents with ASD. It is possible that parents

of these children were less likely to participate in the survey due to care responsibilities. Fourth, psychometric properties of the used cultural adapted version of PEM-CY(G) were not yet established. However, others translated and adapted versions of PEM-CY reported an internal consistency between 0.55 and 0.86 (Chien et al., 2020; Jeong et al., 2016), which were similar to the original version (Coster et al., 2011). Fifth, as inherent for a cross-sectional study design, causality cannot be attributed and a direct connection between the two age groups cannot be supposed. Many possible factors such as medical diagnoses, developmental phases and number or type of received interventions may account for observed differences. For more insight, longitudinal research into the trajectory from childhood and adolescence into adulthood in individuals with ASD is needed to disentangle participation from developmental, personal-medical factors and received services. One step in this direction is the use PEM-CY as PROM to report about services and interventions.

5 | CONCLUSIONS AND FURTHER DIRECTIONS

The parents in this study indicate that their children and adolescents with ASD participate most often in home activities, but reduced participation involvement and high parental support needs lead to a high amount of parental desire for change at home. This might be crucial to improving current service provisions. Parents also acknowledge higher participation patterns for children and adolescents with ASD in school settings but ask to further prioritise social participation at school. Finally, parents describe a striking low participation pattern for children and adolescents with ASD in the community. This can inform research and social, health and community service providers to further reshape their programmes to meet parental needs.

INFORMED CONSENT STATEMENT

We obtained informed consent from all participants prior to filling out the online survey.

AUTHOR CONTRIBUTIONS

B. K. conceived the study and its design, carried out the data collection, performed the preliminary statistical analyses and drafted the manuscript. B. P. contributed to the study design and the interpretation of the data and gave feedback on the manuscript. A. B. contributed to the study design, supervised the final statistical analysis and contributed to the interpretation of the data and the draft of the manuscript. A. M. contributed to the study design, ethical standards and the interpretation of the data and helped to draft the manuscript. All authors read and approved the final manuscript.

ACKNOWLEDGEMENTS

We would like to express our sincere thanks to CanChild for the permission to use the PEM-CY(G), Dr. Andreas Bänziger for setting up the questionnaire on the online platform and providing support while we extracted and analysed data and Simon Renzler for advising on statistical analysis. We thank all organisations and individual persons for supporting data collection. And most of all, we are deeply grateful to the participating parents of children and adolescents for their time and efforts to share their daily experiences and provide insights into their desires for change. Thanks also for Maastricht University for funding the open acess publication.

CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions. The data that support the findings of this study are available from the corresponding author upon reasonable requests.

ETHICS STATEMENT

All procedures performed in the study involving human participants were in accordance with the ethical standards of the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This survey received a jurisdictional declaration of nonobjection by the cantonal ethical committee of Zurich (BASEC Request 2018-00238).

ORCID

Beate Krieger https://orcid.org/0000-0002-8759-9698
Barbara Piškur https://orcid.org/0000-0002-5788-958X
Anna J. H. M. Beurskens https://orcid.org/0000-0002-8914-7150
Albine Moser https://orcid.org/0000-0003-4073-2890

REFERENCES

Adolfsson, M., Malmqvist, J., Pless, M., & Granlund, M. (2011). Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disability and Rehabilitation*, *33*(13–14), 1230–1244. https://doi.org/10.3109/09638288.2010.526163

Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L., & Teplicky, R. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Archives of Physical Medicine and Rehabilitation*, *95*(5), 908–917. https://doi.org/10.1016/j.apmr.2014.01.005

Arakelyan, S., Maciver, D., Rush, R., O'hare, A., & Forsyth, K. (2019). Family factors associated with participation of children with disabilities: A systematic review. *Developmental Medicine and Child Neurology*, *61*(5), 514–522. https://doi.org/10.1111/dmcn.14133

Arnell, S., Jerlinder, K., & Lundqvist, L. O. (2018). Perceptions of physical activity participation among adolescents with autism Spectrum disorders: A conceptual model of conditional participation. *Journal of Autism and Developmental Disorders*, *48*(5), 1792–1802. https://doi.org/10.1007/s10803-017-3436-2

Askari, S., Anaby, D., Bergthorson, M., & Majnemer, A. (2015). Participation of children with autism: What do we know? *International Journal of Developmental Neuroscience*, *47*(Part_A), 98. https://doi.org/10.1016/j.ijdevneu.2015.04.268

Bagatell, N. (2016). The routines and occupations of families with adolescents with autism spectrum disorders. *Focus on Autistic Behavior*, *31*(1), 49–59. https://doi.org/10.1177/1088357615587503

Bölte, S., Mahdi, S., de Vries, P. J., Granlund, M., Robison, J. E., Shulman, C., Swedo, S., Tonge, B. J., Wong, V., Zwaigenbaum, L., Segerer, W., & Selb. M. (2019). The gestalt of functioning in autism spectrum disorder: Results of the international conference to develop final consensus international classification of functioning, disability and health core sets. *Autism*, *23*(2), 449–467. https://doi.org/10.1177/1362361318755522

Bundesamt für Statistik. (2017). *Familien in der Schweiz: Statistischer Bericht 2017* (pp. 1–110). Bundesamt für Statistik.

Bundesrat. (2018). Bericht des Bundesrates: Autismus-Spektrum-Störungen: Massnahmen für die Verbesserung der Diagnostik, Behandlung und Begleitung von Menschen mit Autismus-Spektrum-Störungen in der Schweiz.

Chang, Y. C., Chen, C. H., Huang, P. C., & Lin, L. Y. (2019). Understanding the characteristics of friendship quality, activity participation, and emotional well-being in Taiwanese adolescents with autism spectrum disorder. *Scandinavian Journal of Occupational Therapy*, *26*(6), 452–462. https://doi.org/10.1080/11038128.2018.1449887

Chapparo, C. J., & Hooper, E. (2002). When is it work? Perceptions of six year old children. *Work*, *19*(3), 291–302.

Chen, Y.-W., Bundy, A., Cordier, R., Chien, Y.-L., & Einfeld, S. (2016). The experience of social participation in everyday contexts among individuals with autism spectrum disorders: An experience sampling study. *Journal of Autism and Developmental Disorders*, *46*(4), 1403–1414. https://doi.org/10.1007/s10803-015-2682-4

Chien, C. W., Li-Tsang, C. W. P., Cheung, P. P. P., Leung, K. Y., & Lin, C. Y. (2020). Development and psychometric evaluation of the Chinese version of the participation and environment measure for children and youth. *Disability and Rehabilitation*, *42*(15), 2204–2214. https://doi.org/10.1080/09638288.2018.1553210

Churruca, K., Pomare, C., Ellis, L. A., Long, J. C., Henderson, S. B., Murphy, L. E. D., Leahy, C. J., & Braithwaite, J. (2021). Patient-reported outcome measures (PROMs): A review of generic and condition-specific measures and a discussion of trends and issues. *Health Expectations*, *24*(4), 1015–1024. https://doi.org/10.1111/hex.13254

Clark, M., & Adams, D. (2020). Listening to parents to understand their priorities for autism research. *PLoS ONE*, *15*(8), 1–20. https://doi.org/10.1371/journal.pone.0237376

Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Gleason, K., & Kao, Y.-C. (2011). Psychometric evaluation of the participation and environment measure for children and youth. *Developmental Medicine and Child Neurology*, *53*(11), 1030–1037. https://doi.org/10.1111/j.1469-8749.2011.04094.x

Csikszentmihalyi, M., & Larson, R. (1984). *Being adolescent conflict and growth in teenager years*. Basic books.

Deckers, A., Muris, P., & Roelofs, J. (2017). Being on your own or feeling lonely? Loneliness and other social variables in youths with autism spectrum disorders. *Child Psychiatry and Human Development*, *48*(5), 828–839. https://doi.org/10.1007/s10578-016-0707-7

Devenish, B. D., Sivaratnam, C., Lindor, E., Papadopoulos, N., Wilson, R., McGillivray, J., & Rinehart, N. J. (2020). A brief report: Community supportiveness may facilitate participation of children with autism spectrum disorder in their community and reduce feelings of isolation in their caregivers. *Frontiers in Psychology*, *11*, 583483. https://doi.org/10.3389/fpsyg.2020.583483

Dovgan, K. N., & Mazurek, M. O. (2019). Relations among activity participation, friendship, and internalizing problems in children with autism spectrum disorder. *Autism*, *23*(3), 750–758. https://doi.org/10.1177/1362361318775541

Egilson, S., Jakobsdóttir, G., & Ólafsdóttir, L. B. (2018). Parent perspectives on home participation of high-functioning children with autism spectrum disorder compared with a matched group of children without autism spectrum disorder. *Autism*, *22*(5), 560–570. https://doi.org/10.1177/1362361316685555

Egilson, S., Jakobsdóttir, G., Ólafsson, K., & Leósdóttir, T. (2017). Community participation and environment of children with and without autism spectrum disorder: Parent perspectives. *Scandinavian Journal of Occupational Therapy*, *24*(3), 187–196. https://doi.org/10.1080/11038128.2016.1198419

Factor, R. S., Condy, E. E., Farley, J. P., & Scarpa, A. (2016). Brief report: Insistence on sameness, anxiety, and social motivation in children with autism Spectrum disorder. *Journal of Autism and Developmental Disorders*, *46*(7), 2548–2554. https://doi.org/10.1007/s10803-016-2781-x

Flynn, L., & Healy, O. (2012). A review of treatments for deficits in social skills and self-help skills in autism spectrum disorder. *Research in Autism Spectrum Disorders*, *6*(1), 431–441. https://doi.org/10.1016/j.rasd.2011.06.016

Friedman, N. D. B., Warfield, M. E., & Parish, S. L. (2013). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry*, *3*(2), 181–192. https://doi.org/10.2217/npy.13.13

Galpin, J., Barratt, P., Ashcroft, E., Greathead, S., Kenny, L., & Pellicano, E. (2018). 'The dots just don't join up': Understanding the support needs of families of children on the autism spectrum. *Autism*, *22*(5), 571–584. https://doi.org/10.1177/1362361316687989

Georgiades, S., & Kasari, C. (2018). Reframing optimal outcomes in autism. *JAMA Pediatrics*, *172*(8), 716–717. https://doi.org/10.1001/jamapediatrics.2018.1016

Ghanouni, P., Jarus, T., Zwicker, J. G., Lucyshyn, J., Chauhan, S., & Moir, C. (2019). Perceived barriers and existing challenges in participation of children with autism spectrum disorders: 'He did not understand and no one else seemed to understand him.' *Journal of Autism and Developmental Disorders*, *49*(8), 3136–3145. https://doi.org/10.1007/s10803-019-04036-7

Hilton, C. L., Crouch, M. C., & Israel, H. (2008). Out-of-school participation patterns in children with high-functioning autism spectrum disorders. *American Journal of Occupational Therapy*, *62*(5), 554–563. https://doi.org/10.5014/ajot.62.5.554

Ho, H., Fergus, K., & Perry, A. (2018). Looking back and moving forward: The experiences of Canadian parents raising an adolescent with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *52*(May), 12–22. https://doi.org/10.1016/j.rasd.2018.05.004

Houghton, S., Kyron, M., Lawrence, D., Hunter, S. C., Hattie, J., Carroll, A., Zadow, C., & Chen, W. (2022). Longitudinal trajectories of mental health and loneliness for Australian adolescents with-or-without neurodevelopmental disorders: The impact of COVID-19 school lockdowns. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *63*(11), 1332–1343. https://doi.org/10.1111/jcpp.13579

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2017). Participation, both a means and an end: A conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine and Child Neurology*, *59*(1), 16–25. https://doi.org/10.1111/dmcn.13237

Jeong, Y., Law, M., Stratford, P., DeMatteo, C., & Kim, H. (2016). Cross cultural validation and psychometric evaluation on the participation and environment measure of children and youth in Korea. *Disability & Rehabilitation*, *38*(22), 2217–2228. https://doi.org/10.3109/09638288.2015.1123302

Kersten, M., Coxon, K., Lee, H., & Wilson, N. J. (2020). 'In their own time': Parents gently push their autistic youth towards independent community mobility and participation. *Journal of Autism and Developmental Disorders*, *50*(8), 2806–2818. https://doi.org/10.1007/s10803-020-04384-9

Khalifa, G., Rosenbaum, P., Georgiades, K., Duku, E., & Di Rezze, B. (2020). Exploring the participation patterns and impact of environment in preschool children with ASD. *International Journal of Environmental*

Research and Public Health, *17*(16), 1–15. https://doi.org/10.3390/ijerph17165677

Khetani, M., Cliff, A., Schelly, C., Daunhauer, L., & Anaby, D. (2015). Decisional support algorithm for collaborative care planning using the participation and environment measure for children and youth (PEM-CY): A mixed methods study. *Physical & Occupational Therapy in Pediatrics*, *35*(3), 231–252. https://doi.org/10.3109/01942638.2014.899288

Krieger, B., Moser, A., Morgenthaler, T., Beurskens, A. J. H. M., & Piškur, B. (2022). Parent's perceptions: Environments and the contextual strategies of parents to support the participation of children and adolescents with autism spectrum disorder—A descriptive population based study from Switzerland. *Journal of Autism & Developmental Disorders*, 1–23. https://doi.org/10.1007/s10803-022-05826-2

Krieger, B., Piškur, B., Schulze, C., Jakobs, U., Beurskens, A., & Moser, A. (2018). Supporting and hindering environments for participation of adolescents diagnosed with autism spectrum disorder: A scoping review. *PLoS ONE*, *13*(8), e0202071. https://doi.org/10.1371/journal.pone.0202071

Krieger, B., Piškur, B., Schulze, C., Moser, A., & Beurskens, A. (2020). Environmental pre-requisites and social interchange: The participation experience of adolescents with autism spectrum disorder in Zurich. *Disability & Rehabilitation*, *43*(26), 3789. https://doi.org/10.1080/09638288.2020.1753248

Krieger, B., Schulze, C., Boyd, J., Amann, R., Piškur, B., Beurskens, A., Teplicky, R., & Moser, A. (2020). Cross-cultural adaptation of the participation and environment measure for children and youth (PEM-CY) into German: A qualitative study in three countries. *BMC Pediatrics*, *20*(1), 492. https://doi.org/10.1186/s12887-020-02343-y

Kuhaneck Miller, H., Madonna, S., Novak, A., & Pearson, E. (2015). Effectiveness of interventions for children with autism spectrum disorder and their parents: A systematic review of family outcomes. *American Journal of Occupational Therapy*, *69*(5), 6905180040p1-14. https://doi.org/10.5014/ajot.2015.017855

Laghi, F., Lonigro, A., Pallini, S., & Baiocco, R. (2018). Peer buddies in the classroom: The effects on spontaneous conversations in students with autism spectrum disorder. *Child and Youth Care Forum*, *47*(4), 517–536. https://doi.org/10.1007/s10566-018-9449-y

Lamash, L., Bedell, G., & Josman, N. (2019). Participation patterns of adolescents with autism spectrum disorder compared to their peers: parents' perspectives. *British Journal of Occupational Therapy*, *83*(2), 78–87. https://doi.org/10.1177/0308022619853518

Larson, E. (2006). Caregiving and autism: How does children's propensity for routinization influence participation in family activities? *OTJR: Occupation, Participation and Health*, *26*(2), 69–79. https://doi.org/10.1177/153944920602600205

Lasgaard, M., Nielsen, A., Eriksen, M. E., & Goossens, L. (2010). Loneliness and social support in adolescent boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *40*(2), 218–226. https://doi.org/10.1007/s10803-009-0851-z

Law, M., Anaby, D., Treplicky, R., Kehtani, M., Coster, W. J., & Bedell, G. M. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy*, *76*(2), 58–66. https://doi.org/10.4276/030802213X13603244419112

Magnuson, K. M., & Constantino, J. N. (2011). Characterization of depression in children with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics : JDBP*, *32*(4), 332–340. https://doi.org/10.1097/DBP.0b013e318213f56c

McAuliffe, T., Cordier, R., Chen, Y. W., Vaz, S., Thomas, Y., & Falkmer, T. (2020). In-the-moment experiences of mothers of children with autism spectrum disorder: A comparison by household status and region of residence. *Disability and Rehabilitation*, 1–15. https://doi.org/10.1080/09638288.2020.1772890

Schwartz, J., Huntington, N., Toomey, M., Laverdiere, M., Bevans, K., Blum, N., Bridgemohan, C., Saini, M., Stoddart, K. P., Gibson, M., Morris, R., Barrett, D., Muskat, B., Nicholas, D., Rampton, G., Zwaigenbaum, L., Halloran, M., Sweeney, J., Doody, O., … Cobigo, V. (2016). The routines and occupations of families with adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *31*(3), 49–59. https://doi.org/10.1080/17518423.2016.1236844

Simpson, K., Keen, D., Adams, D., Alston-Knox, C., & Roberts, J. (2018). Participation of children on the autism spectrum in home, school, and community. *Child: Care, Health and Development*, *44*(1), 99–107. https://doi.org/10.1111/cch.12483

Song, W., Shea, L., Nonnemacher, S. L., & Salzer, M. S. (2021). Community participation comparison between adults on the autism spectrum and adults in the general population. *Journal of Autism and Developmental Disorders.*, *52*, 1610–1621. https://doi.org/10.1007/s10803-021-05059-9

Sood, D., LaVesser, P., & Schranz, C. (2014). Influence of home environment on participation in home activities of children with an autism spectrum disorder. *The Open Journal of Occupational Therapy*, *2*(3), 1–20. https://doi.org/10.15453/2168-6408.1082

UN General Assembly. (2007). Convention on the right of persons with disabilities: Resolution adopted by the general assembly, 24 January 2007. A/RES/61/106.

Wainscot, J. J., Naylor, P., Sutcliffe, P., Tantam, D., & Williams, J. V. (2008). Relationships with peers and use of the school environment of mainstream secondary school pupils with Asperger syndrome (high-functioning autism): A case-control study. *International Journal of Psychology and Psychological Therapy*, *8*(1), 25–38.

WHO. (2001). *International classification of functioning, disability and health (ICF)*. World Health Organization.

Winter-Messiers, M. A. (2007). From tarantulas to toilet brushes: Understanding the special interest areas of children and youth with Asperger syndrome. *Remedial and Special Education*, *28*(3), 140–152. https://doi.org/10.1177/07419325070280030301

How to cite this article: Krieger, B., Piškur, B., Beurskens, A. J. H. M., & Moser, A. (2023). Parents' perceptions: Participation patterns and desires for change for children and adolescents with autism spectrum disorder—A descriptive population-based study from Switzerland. *Child: Care, Health and Development*, 1–16. https://doi.org/10.1111/cch.13155