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Participation profiles and the barriers and facilitators that impact on participation of children with Autism Spectrum Disorders living in regional and remote Western Australia

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Abstract

Background: Autism Spectrum Disorder (ASD) is a heterogeneous condition, influencing participation in activity and occupation. Approximately, 1% of Australian children have an ASD diagnosis, with many of these families living in remote and regional areas. Given the environments role in facilitating or hindering participation, there is a need to understand how geographical location impacts the participation profiles of children with ASD.

Objective: This study aims to describe the participation profiles, and environmental barriers and facilitators to participation for children with ASD living in regional or remote Western Australia.

Methods: A total of 32 families completed a questionnaire pack including a socio-demographic questionnaire and the Participation and Environment Measure – Children and Youth.

Results: Children with ASD had reduced participation in community activities. Within the home, children most commonly participated in computer and video games, and in school settings, children participated rarely in non-classroom and extracurricular activities. Parents reported a desire for their children to decrease time spent engaging in video games and increase time spent in the community, socializing, engaging in extracurricular activities, and completing chores. Parents reported a number of barriers to participation across community, home, and school settings.

Conclusion: Children with ASD living in regional areas had restricted participation profiles and a number of barriers to participation as reported by their parents. There is a need for additional support and services in non- metropolitan areas for families of children with ASD to increase participation. This study also highlights the need to expand the definition of participation in the International Classification of Functioning, Disability and Health to include aspects of involvement.

Keywords: Australia; child; rural; occupational participation

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder characterized by impairments in social interaction and communication, restricted, repetitive or stereotyped behaviors and atypicalities in sensory processing (1, 2). Collectively, these symptoms can have significant and variable impacts on the everyday functioning, participation and engagement of children with ASD (3-6). Previous studies have demonstrated that children with ASD experience significantly reduced

activity participation compared to their typically developing peers (3, 5, 6).

The World Health Organization defines participation as involvement in life situations (7), with engagement in occupation recognized as vital for health, development, quality of life and wellbeing (7-11). The International Classification for Functioning – Child and Youth version (ICF-CY) provides a framework to examine participation, describing the complex relationship between the child, their health, participation, and the environment

(7). The ICF-CY also recognizes the influential nature of the environment in facilitating or restricting participation in activities (7). While the ICF-CY has not yet been used to guide research investigating the impact of environmental factors on children with ASD living in non-metropolitan settings, existing literature has illustrated the advantages of using the ICF-CY as a framework to guide research into the factors impacting participation outcomes for children with disabilities (12, 13).

The Australian population is spread over a vast landscape, with 32% of Australians living in inner regional, outer regional, remote, and very remote areas (14). Geographical locations are known to influence the participation profiles of typically developing children (15-17), and in Australia, the unique environmental context of rural areas can present barriers to participation (18). Approximately 1% of Australian children are thought to be impacted by ASD (19), with many of these families living in regional and remote areas. While there is a significant paucity of research investigating families of children with ASD outside of metropolitan areas, research has indicated that families living in non-metropolitan areas experience inadequate access to services and supports (20). Given the reduced access to services, and the unique influences regional and remote areas can have on participation, it is possible that the activity participation profiles of children with ASD are similarly impacted.

To date, the majority of research investigating the participation of children with ASD has been conducted with children living in metropolitan areas, thus, the impact of environmental factors in regional areas for children with ASD remains unknown. There is a need to understand how children with ASD living in regional and remote areas participate. The aim of this study was to describe the parent reported participation profiles of children with ASD living in non-metropolitan areas of Western Australia (WA), and to examine the environmental barriers and facilitators to participation faced by these children.

Method

To understand how parents of children living in regional and remote areas perceive their child's participation, and the associated facilitators and barriers to participation, families of children with ASD were asked to complete a self-report questionnaire pack.

Participants

Families of children with ASD were recruited from a pool who had previously expressed interest in engaging research with Curtin University after participating in a previous study (21). Participants were initially recruited with support from the

Disability Services Commission (DSC) of WA and included all families registered as having a child diagnosed with ASD (21). The pool comprised of 247 families, of these, 54 families lived in a regional or remote area of WA according to the Australia Standard Geographical Classification – Remoteness Areas (ASGC-RA) (22) and were contacted. Participants were over 18 years of age, a primary caregiver of a child aged 5 to 17 years with a diagnosis of ASD, had sufficient English language skills and time to complete the questionnaires. A total of 32 families consented to participate by completing the provided questionnaire pack.

Instruments

Participants completed a questionnaire pack which consisted of a paper-based questionnaire comprised of the Participation and Environment Measure – Children and Youth (PEM-CY) (23) and a Socio-demographic questionnaire.

The PEM-CY is a parent-report assessment tool used to gather data on children's participation, and barriers and supports for participation (23). This assessment was informed by the ICF-CY and explores participation (frequency, involvement, and desired change) in types of activities in three settings (community, home, and school) as well as exploring features and resources impacting upon and supporting participation (23). The PEM-CY utilizes language accessible to parents (7, 23), requiring parents to rate their child's frequency of participation in activities on a scale of 0-7 (0-never, 1-once in the last four months, 2-a few times in the last four months, 3-once a month, 4-a few times a month, 5-once a week, 6-few times a week, and 7-daily). If their child participates in the activity, parents are also asked to classify their child's involvement on a scale of 1 to 5 (1-minimally involved and 5-very involved). The instructions clarify that involvement is separate from independence and can be scored regardless of the support the child may need in the activity. To guide the parents, the instructions provide examples of behavior associated with the scorings 'very involved', 'somewhat involved' and 'minimally involved' (for example; 'very involved' "[...] child is engaged throughout the activity," "[...] shows a lot of initiative/and or interest in and attention to what he/she and others are doing [...]").

The PEM-CY has been reported to have moderate to good internal consistency and test-retest reliability scores of over 0.58 in both trials (24). The PEM-CY is one of few measures that takes into consideration the impact of environment on participation across a variety of environments, including different geographic areas (24).

A socio-demographic questionnaire used in a previous study (21) obtained information in relation

to aspects of the environment and person (both the caregiver and child with ASD) as identified in the ICF-CY (7). Specifically, this questionnaire asked questions pertaining to the respondent's gender, age, marital status, relationship to the child, household income and status, and other siblings, as well as the child with ASDs' age, gender, diagnosis, and comorbidities. In order to detect any potential bias due to differences between respondents and non-respondents (25), an abbreviated version of the PEM-CY and socio-demographic questionnaire was also developed.

Procedures

Participants were contacted initially via phone or email and provided with information regarding the study and questionnaire pack. Address details were obtained from participants that confirmed that they were willing to participate. The questionnaire pack was posted to participants and included a detailed information sheet and a return paid envelope for the completed questionnaires. Reminder packs were sent three and six weeks after the initial packs were posted if they had not been returned. Non-responders were randomly selected and contacted via phone to complete the abbreviated version of the questionnaire to allow for the non-respondents analysis.

Primary data analysis

Data were coded and managed using SPSS software (26). Univariate analysis utilizing chi-square test (fishers exact) and independent *t*-tests were conducted to describe the socio-demographic characteristics of the sample population and to determine if any socio-demographic differences existed between the study and non-respondent sample.

Analysis was undertaken in accordance with previous research using the PEM-CY (27, 28). The mean and mean standard error of participation (frequency and involvement) was calculated across the types of activities of the PEM-CY to depict the participation profiles. Frequencies of participation were obtained by calculating the mean frequency scores of respondents. The number of respondents who reported that they never participated in the types of activities were also totaled and calculated as a percent of total respondents for the types of activities. Mean involvement for the types of activities was calculated by totaling involvement scores and dividing by the number of respondents who identified their child as not participating in that type of activity.

Desired change was calculated by totaling the number of participants who indicated desired change in frequency, involvement and/or variety or

participation in types of activities and dividing by the number of respondents. The desired change of participation frequencies were also calculated to identify the types of activities that parents desired their child to participate in more or less frequently.

Barriers to participation were calculated by totaling the number of parents who reported features that 'usually makes harder' or having access to resources as 'usually no,' Similarly, supports to participation were calculated through totaling the number of parents who identified that features 'usually help' or having access to resources as 'usually yes.'

Secondary analysis

A secondary analysis using reference data (29) was conducted to determine differences in participation between children with ASD from regional and remote areas and children with ASD in Australia. Secondary analysis was conducted using R (30) and the Basic Statistics and Data Analysis package (31). Reference data were obtained from a recent Australian-based study using the PEM-CY to examine the participation profiles of children and adolescent with ASD in Australia (29). Mean and standard deviations for the children aged 9 to 10 years were extracted from the reference data and summary *t*-tests were used to examine differences between the current sample and the reference data in regard to both frequencies and involvement of participation.

Ethical considerations

All participants were provided with a detailed information sheet regarding participation prior to providing informed consent to participate. The information sheet provided participants with information regarding the aim of the study, voluntary participation, requirements of participation, and opportunity for withdrawal at any stage of the study. Data obtained have been stored securely and will be kept securely for seven years as per the Western Australian University Sector Disposal Authority requirements (32). Ethical approval was obtained from the Human Research Ethics Committee at Curtin University, Perth, Western Australia.

Results

A total of 32 participants completed and returned the questionnaire packs. Socio-demographic information of the parents, their household, and their child with ASD is summarized in Table 1. Additional diagnostic information including comorbidities and impact of diagnosis is summarized in Table 2.

TABLE 1. Socio-demographic and clinical factors

Factor	N (%)
Age of child (mean [SD]) years	11.8 (3.7)
Age of diagnosis, years	
Mean [SD]	5.8 (3.4)
Minimum	1
Maximum	15
Child's gender	
Male	30 (93.8)
Female	2 (6.3)
Age of participant (mean [SD]) years	42.5 (6.4)
Relationship to child	
Mother	29 (90.6)
Father	3 (9.4)
Relationship status	
Married	21 (65.6)
Divorced	2 (6.3)
Widowed	1 (3.1)
Separated	7 (21.9)
Member of unmarried couple	1 (3.1)
Family income	
\$5,000-\$24,999	5 (15.6)
\$25,000-\$49,999	6 (18.8)
\$50,000-\$74,999	4 (12.5)
\$75,000-\$99,999	3 (9.4)
\$100,000-\$149,999	5 (15.6)
\$150,000+	9 (28.1)
Employment status	
Employed full time	5 (15.6)
Employed part time	9 (28.1)
Employed casually	2 (6.3)
Self-employed	5 (15.6)
Home-maker/caregiver	8 (25.0)
Student	1 (3.1)
Missing values	2 (6.3)
Level of education	
Year 10	2 (6.3)
High school	7 (21.9)
TAFE	9 (28.1)
Trade qualification	4 (12.5)
Bachelor's degree	8 (25.0)
Master/doctorate	2 (6.3)
Partner's level of education	
Year 10	5 (15.6)
High school	1 (3.1)
TAFE	2 (6.3)
Trade qualification	9 (28.1)
Bachelor's degree	3 (9.4)
Masters/doctorate	3 (9.4)
Missing/unanswered	9 (28.1)
Regionality	
Inner regional	21 (65.6)
Outer regional	8 (25.0)
Remote	3 (9.4)
Very remote	0 (0.0)
Home type	
Urban house	27 (84.4)
Small farm	5 (15.6)
Number of adults in the household	
1	8 (25.0)
2	15 (46.9)
3	7 (21.9)
4 or more	2 (6.3)
Number of children in the household	
1	4 (12.5)
2	20 (62.5)
3	5 (15.6)
4	3 (9.4)

TABLE 2. Diagnosis and impact of participant's children

Diagnosis	N (%)	Impact			
		None	Minor	Moderate	Major
Autism Spectrum Disorder					
Autistic Disorder	13 (40.6)	0	1	3	9
High Functioning Autism	14 (43.8) ^a	0	2	6	5
Asperger's Syndrome	4 (12.5) ^a	0	0	2	1
PDDNOS	3 (9.4)	0	0	2	1
Comorbidities					
Cognitive/intellectual	11 (34.4)	4	2	3	2
Psychological/ mental health	12 (37.5)	4	1	6	1
Physical/other	15 (50.0)	4	1	6	1

Note. ^a One respondent did not indicate the impact of diagnosis

Non-respondents analysis

Socio-demographic characteristics of the 32 respondents and 10 non-responders were compared in order to determine differences between the responding and non-respondent groups. No differences were found between the respondents and the non-respondents in relation to age of parent (mean = 40.8, SD = 7.1, $p = 0.466$), age of child (mean = 10.8, SD = 41.1, $p = 0.443$), relationship ($p = 0.589$), geographic location ($p = 0.436$), family income ($p = 0.873$), and type of household ($p = 0.401$).

Participation

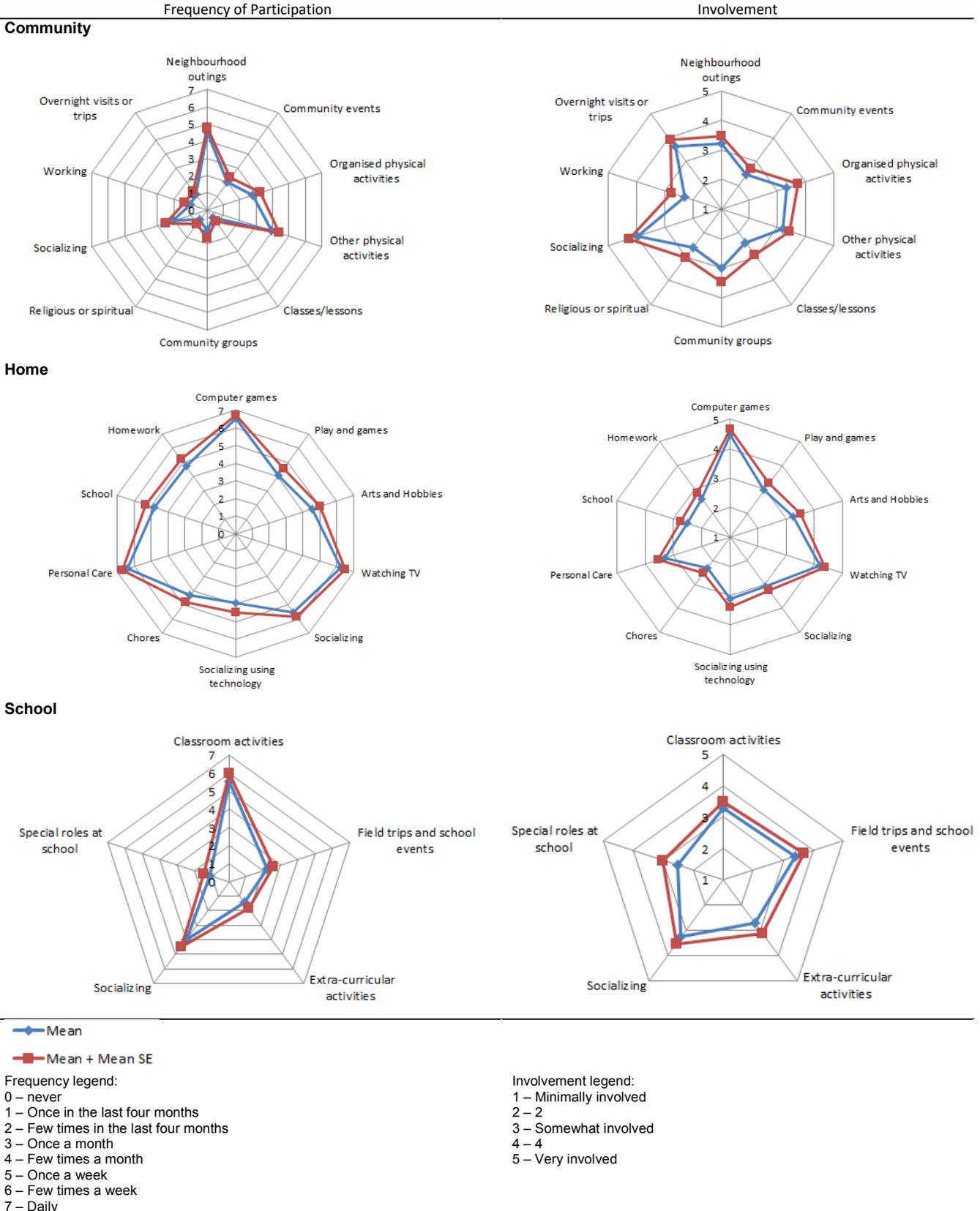
Overall parents reported that their children participated in a range of activities within the home, school, and community settings. Frequency and involvement radar diagrams (Figure 1) depict the engagement in types of activities in the three settings; community, school, and home. The percentage of parents who desired change in frequency, involvement and/or variety of types of activities of the three settings is presented in radar diagrams in Figure 1. The frequency, involvement, and desired change diagrams each include the same activity areas of the three environmental domains.

Community setting

Activity areas frequency

Within the community setting, children most frequently engaged in neighborhood outings (mean = 4.5, mean SE = 0.30) (between a few times a month and once a week) and unstructured physical activity (mean = 3.91, mean SE = 0.46) (few times a month) as shown in Table 3 and Figure 1. Children rarely participated in activities in the community setting, including classes/lessons (mean = 0.56, mean SE = 0.28) (never-once in the last four months), religious and spiritual activities (mean = 0.72, mean SE = 0.3) (never-once in the last four

FIGURE 1. Environmental settings- frequency and involvement in types of activities



months), work (mean = 1.0, mean SE = 0.37) (once in the last four months) and overnight visits or trips (mean = 1.09, mean SE = 0.23) (once in the last four months). Many parents identified their children as

‘never participating’ in some types of activities within the community; classes/lessons (87.5%), religion (78.1%), work (78.1%), organizations (71.9%), and overnight trips (50.0%).

TABLE 3. Child frequency and involvement in activity as reported by parents

	Frequency		Involvement	
	N ^a	Mean (SE) ^b	N	Mean (SE)
Community				
Neighbourhood outings	32	4.50 (0.30)	30	3.23 (0.25)
Community events	32	2.00 (0.32)	27	2.44 (0.24)
Organized physical activity	31	2.77 (0.49)	19	3.32 (0.41)
Unstructured physical activity	32	3.91 (0.46)	28	3.18 (0.25)
Classes and lessons	32	0.56 (0.28)	10	2.40 (0.54)
Organizations, groups, clubs and volunteer or leadership activities	32	1.25 (0.39)	12	3.00 (0.48)
Religious or spiritual gatherings	32	0.72 (0.30)	10	2.60 (0.43)
Getting together with other children in the community	32	2.06 (0.43)	18	3.94 (0.31)
Working for pay	32	1.00 (0.37)	10	2.30 (0.45)
Overnight visits or trips	32	1.09 (0.23)	18	3.61 (0.30)
Home				
Computer/video games	32	6.53 (0.18)	31	4.48 (0.20)
Indoor play and games	32	4.09 (0.49)	27	2.96 (0.29)
Arts, crafts, music and hobbies	32	4.56 (0.46)	29	3.24 (0.29)
Watching TV, videos and DVDs	32	6.22 (0.30)	31	4.19 (0.19)
Getting together with other people	32	5.5 (0.34)	30	3.07 (0.19)
Socializing using technology	32	3.94 (0.51)	28	3.11 (0.29)
Household chores	32	4.34 (0.48)	30	2.30 (0.21)
Personal care management	32	6.41 (0.27)	30	3.30 (0.24)
School preparation	32	4.78 (0.52)	28	2.50 (0.23)
Homework	32	4.72 (0.49)	27	2.59 (0.25)
School				
Participate in classroom activities	32	5.56 (0.43)	29	3.28 (0.19)
Field trips and school events	31	2.23 (0.33)	29	3.41 (0.26)
School teams, clubs and organizations	32	1.44 (0.43)	16	2.69 (0.41)
Getting together with peers outside of class	32	4.00 (0.48)	27	3.26 (0.26)
Special roles at school	32	1.09 (0.36)	15	2.53 (0.47)

Note. ^aNumber of responses; ^bStandard Error

Activity areas involvement

While the frequencies of participation was low in the types of activities in the community setting, the mean involvement was above 'somewhat involved' for six of the 10 types of activities investigated (Figure 1, Table 3). Parents reported that in four types of activities (socializing, overnight trips, organized physical activity, and organizations) their children were above 'somewhat involved' (mean = 3.94, 3.61, 3.32, 3.00, respectively) despite participating in these activities less than monthly.

Activity areas desired change

Overall parents desired change in their children's participation in activities in the community setting as shown in Figure 2 and Table 4. Almost half (46.9% – religion) to three quarters (75% – community events and classes/lessons) of parents desired change in participation in the types of activities their children were involved in. No parents included in the study indicated a desire for their children to participate less

frequently in any of the investigated community activity areas. Between 15.6 and 43.8 percent of parents reported that they wanted their children to participate more frequently in the investigated community activity areas.

Barriers and supports

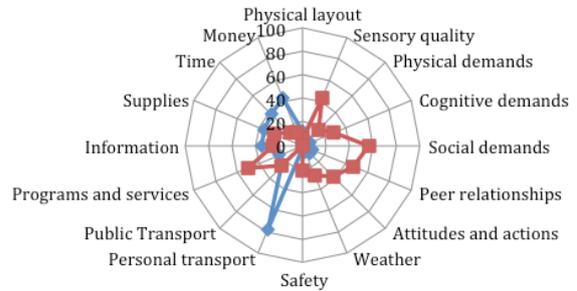
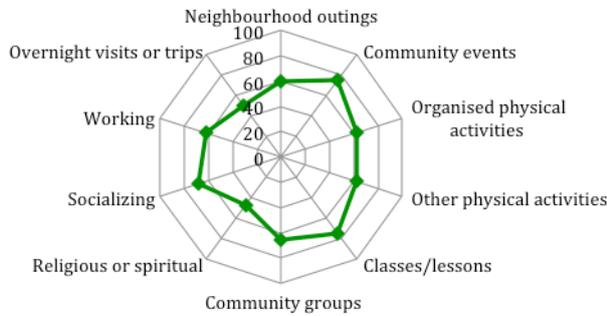
Parents identified features and resources in the community setting which supported and restricted their children's participation (Figure 2). Supports to participating in the community setting were personal transport (78.1% of parents) and having sufficient money (43.8%) and time (37.5%) to support their children. A high proportion of parents identified social demands of activities (56.3%), programs and services (50.0%), and peer relationships (46.9%), as being barriers to their children's participation in activities in the community setting.

FIGURE 2. Environmental settings –percentage of parents who desire change in participation and perceived barriers and facilitators to participation.

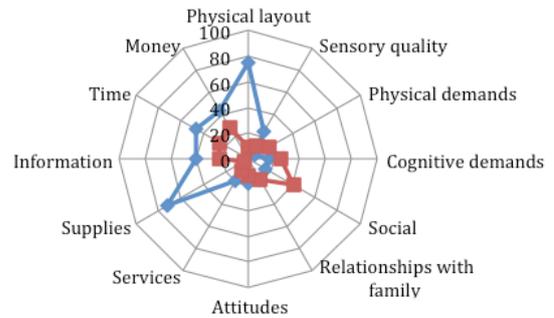
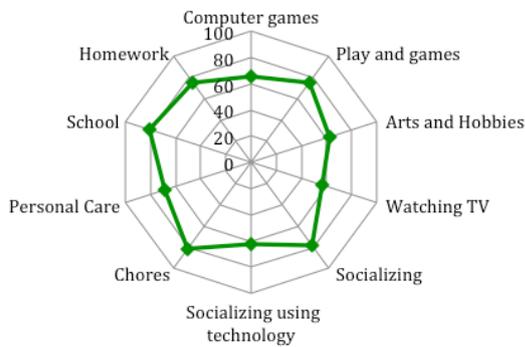
Desired change regarding frequency, involvement or variety of participation (%)

Perceived items as barriers or facilitators (%)

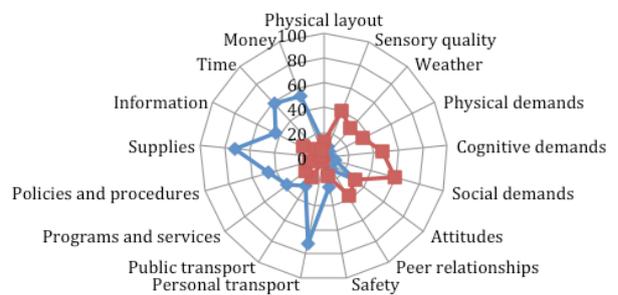
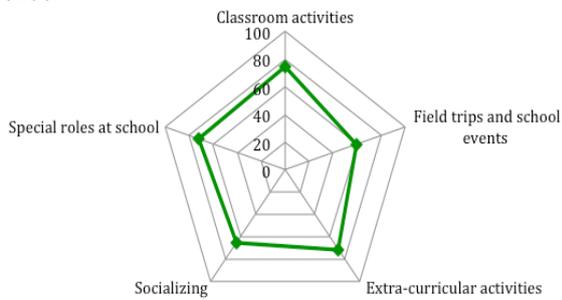
Community



Home



School



◆ % of parents who desired change

◆ Facilitators
■ Barriers

TABLE 4. Parent/care-giver desire for change in participation, overall, frequency and involvement

	Overall change	Frequency		Involvement		Variety
	(%)	Reduce (%)	Increase (%)	Reduce (%)	Increase (%)	Increase (%)
Community						
Neighbourhood outings	59.4	0	43.8	0	25	3.1
Community events	75	0	37.5	0	34.4	12.5
Organized physical activity	64.5	0	32.3	0	22.6	16.1
Unstructured physical activity	62.5	0	34.4	0	28.1	12.5
Classes and lessons	75	0	31.3	0	15.6	12.5
Organizations, groups, clubs and volunteer or leadership activities	65.6	0	21.9	0	18.8	9.4
Religious or spiritual gatherings	46.9	0	15.6	0	9.4	6.3
Getting together with other children in the community	68.8	0	43.8	0	15.6	3.1
Working for pay	62.5	0	34.4	0	9.4	6.3
Overnight visits or trips	51.6	0	25.8	00	9.7	6.5
Home						
Computer/video games	65.6	34.4	3.1	12.5	0	25
Indoor play and games	75	0	43.8	0	15.6	21.9
Arts, crafts, music and hobbies	62.5	0	3.7	0	15.6	15.6
Watching TV, videos and DVDs	56.3	34.4	3.1	3.1	3.1	9.4
Getting together with other people	78.1	3.1	59.4	3.1	25	12.5
Socializing using technology	62.5	6.3	28.1	0	25	3.1
Household chores	81.3	0	56.3	0	34.4	9.4
Personal care management	68.8	0	31.3	3.1	37.5	3.1
School preparation	81.3	6.3	37.5	0	40.6	6.3
Homework	75	0	37.5	0	34.4	9.4
School						
Participate in classroom activities	75	3.1	25.0	0	43.8	6.3
Field trips and school events	59.4	0	31.3	0	31.3	9.4
School teams, clubs and organizations	71.9	0	25.0	0	25	15.6
Getting together with peers outside of class	65.6	3.1	37.5	0	21.9	9.4
Special roles at school	71.9	0	28.1	0	15.6	15.6

Home setting

Activity areas frequency

As shown in Figure 1 and Table 3, within the home setting, children most frequently participated in computer and video game activities (mean = 6.53, mean SE = 0.18, between a few times per week and daily), personal care (mean = 6.41, mean SE = 0.27, between a few times per week and daily) watching TV (mean = 6.22, mean SE = 0.3, between a few times per week and daily), and getting together with other people (mean = 5.5, mean SE = 0.34, between once and few times a week). The frequencies of participation in types of activities in the home setting were generally higher than in other settings with the lowest mean frequency being 3.94 (socializing using technology, just below a few times a month). Within the home setting, the percentage of parents who identified their children as never participating in the types of activities was low. More parents reported that their children never participated in socializing using technology (28.1%), school preparation (21.9%), chores (18.8%), homework (18.8%), and

indoor play (18.8%) than other types of activities within the home setting.

Activity areas involvement

Children were reported as being 'somewhat involved' or higher in six of the 10 types of activities in the home setting (Figure 1, Table 3): computer games (mean = 4.48, mean SE = 0.2), watching TV (mean = 4.19, mean SE = 0.19), personal care (mean = 3.30, mean SE = 0.24), arts (mean = 3.24, mean SE = 0.29), socializing using technology (mean 3.11, mean SE = 0.29), and getting together with other people (mean = 3.07, mean SE = 0.19). Low involvement (below 3 – somewhat involved) was reported for work or chore-based activity types as follows; homework (mean = 2.59, mean SE = 0.25), school preparation (mean = 2.5, mean SE = 0.23), and chores (mean = 2.30, mean SE = 0.21).

Desired change

A high percentage of parents reported that they desired change in their children's participation in the types of activities (Figure 2, Table 4). Between 56.3

(TV) and 81.3 (school prep and chores) percent of parents desired change in their children's participation in the types of activities in the home setting, including frequency, involvement, and variety. More than half of parents desired their children to participate more frequently in socializing (59.4%) and chores (56.3%). A high percentage of parents (34.4%) desired that their children reduce the frequencies of participating in the activity areas of computer games and watching TV.

Barriers and supports

Three quarters of parents reported that the physical layout of their home supported their children's participation as shown in Figure 2. Despite a high proportion of parents identifying sufficient money, time and, availability of information, as barriers to their child's participation (28.1, 25.0, and 21.9%) more parents viewed these aspects as supporting their child's engagement (43.8, 46.9, and 40.6%). Over one quarter of parents reported that the cognitive demands of activities were a barrier to their child's participation.

School setting

Activity areas frequency

Children in this study most commonly participated in classroom activities with mean frequencies of participation between once a week and few times a week (mean = 5.56, mean SE = 0.43) as shown in Figure 1. In contrast, children very rarely participated in non-classroom types of activities including field trips (mean = 2.23, mean SE = 0.33, between a few times in the last four months and once a month), extra-curricular school activities (mean = 1.44, mean SE = 0.43, between a few times in the last four months and once in the last four months) and school roles (mean = 1.09, mean SE = 0.36, just above once in the last four months). Many parents reported that their children never participated in special school roles (71.9%) and extra-curricular activities (65.5%). Six parents reported that their children never participated in social activities at school (18.8%).

Activity areas involvement

Children were at least 'somewhat involved' in three of the five types of activities in the school setting. These types of activities were field trips (mean = 3.41, mean SE = 0.26), classroom activities (mean = 3.28, mean SE = 0.19) and socializing (mean = 3.26, mean SE = 0.26) (Figure 1, Table 3). Children were reported as being less than 'somewhat involved' in both extra-curricular school activities (mean = 2.69, mean SE = 0.41) and special roles at school (mean = 2.53, mean SE = 0.47).

Desired change

Between 25.0 and 37.5% of parents indicated that they would like their children to participate more frequently in the types of activities in the school setting (Figure 2, Table 4).

Barriers and supports

A large proportion of parents reported that the attitudes of others impacted their children's participation. Almost one-third (31.3%) of parents reported that attitudes were a support, with a further one-third (31.3%) reporting that attitudes restricted participation (Figure 2). Parents reported the physical (34.3%), cognitive (46.9%), and social demands (59.4%) of activities were barriers to their children's participation in the school setting. Parents also perceived the sensory qualities (40.6%) and peer relationships (31.3%) as barriers to participation in the school setting. Parents viewed personal transport (71.9%) as a support to their children's participation. More than half of the parents identified that they had sufficient time (59.4%) and money (53.1%) to support their children's participation at school.

Comparisons to reference sample

Secondary analysis comparing frequencies and involvement in activity in children with ASD revealed that children living in regional and remote areas had reduced frequency and involvement in participation compared to the reference data in a number of domains (Table 5).

In the community, frequencies of participation among children with ASD were reduced in classes and lessons and involvement was reduced in both community outings and classes and lessons compared to the reference data. In the home, children in the current study had reduced frequencies of participation in arts, craft, music and hobbies and chores, and had both reduced frequency and involvement in indoor play and games. In schools, children from regional and remote areas had reduced frequencies of participation in both schools, teams, clubs and organization, and were less likely to get together with peers outside of school compared to the reference group.

Discussion

The children with ASD in the current study participated in a range of activities in the home, school and community settings. However, their parents reported participation restrictions and desired a change in their children's participation in a range of activities. Parents also identified several barriers and supports to their children's participation in their environments.

The participation profiles of the children in this study showed infrequent participation in a range of

activities that would be considered typical for their age including socializing, community groups, extra-curricular activities, and community events. This may

have negative effects on health, well-being, and development (7, 10). Participation in activities has been shown to be important for children as it

TABLE 5. Secondary analysis comparing outcomes to reference sample

	Current sample		Reference sample ^b		Significance	
	Frequency Mean (SD) ^a	Involvement Mean (SD)	Frequency Mean (SD)	Involvement Mean (SD)	Frequency <i>p</i>	Involvement <i>p</i>
Community						
Neighbourhood outings	4.50 (1.70)	3.23 (1.38)	4.83 (1.48)	3.3 (1.22)	0.32	0.80
Community events	2.00 (1.80)	2.44 (1.25)	1.91 (1.45)	3 (1.14)	0.79	0.04*
Organized physical activity	2.77 (2.72)	3.32 (1.77)	2.98 (2.55)	3.52 (1.24)	0.70	0.64
Unstructured physical activity	3.91 (2.62)	3.18 (1.33)	4.66 (1.88)	3.61 (1.08)	1.14	0.12
Classes and lessons	0.56 (1.61)	2.40 (1.71)	1.47 (2.25)	3.72 (1.28)	0.01*	0.04*
Organizations, groups, clubs and volunteer or leadership activities	1.25 (2.18)	3.00 (1.65)	0.88 (1.84)	3.17 (1.42)	0.38	0.74
Religious or spiritual gatherings	0.72 (1.69)	2.60 (1.35)	1.36 (2.04)	2.47 (1.28)	0.07	0.77
Getting together with other children in the community	2.06 (2.42)	3.94 (1.30)	2.62 (1.98)	3.46 (1.09)	0.23	0.15
Working for pay	1.00 (2.09)	2.30 (1.42)	1.31 (2.25)	2.44 (1.13)	0.46	0.77
Overnight visits or trips	1.09 (1.30)	3.61 (1.29)	1.22 (1.27)	3.68 (1.18)	0.61	0.83
Home						
Computer/video games	6.53 (1.02)	4.48 (1.09)	6.42 (1.49)	4.85 (0.5)	0.62	0.07
Indoor play and games	4.09 (2.79)	2.96 (1.51)	5.15 (2)	3.77 (1.21)	0.05*	0.01*
Arts, crafts, music and hobbies	4.56 (2.61)	3.24 (1.55)	5.61 (1.6)	3.83 (1.13)	0.04*	0.06
Watching TV, videos and DVDs	6.22 (1.70)	4.19 (1.05)	6.62 (0.77)	4.37 (0.9)	0.20	0.38
Getting together with other people	5.5 (1.95)	3.07 (1.05)	6 (1.44)	3.07 (1.17)	0.18	1.0
Socializing using technology	3.94 (2.91)	3.11 (1.52)	3.85 (2.54)	3.37 (1.39)	0.87	0.41
Household chores	4.34 (2.74)	2.30 (1.15)	5.45 (1.99)	2.47 (1.29)	0.037*	0.48
Personal care management	6.41 (1.52)	3.30 (1.29)	6.88 (0.73)	3.02 (1.27)	0.10	0.29
School preparation	4.78 (2.92)	2.50 (1.23)	5.52 (2.41)	2.39 (1.45)	0.19	0.68
Homework	4.72 (2.76)	2.59 (1.31)	5.53 (2.23)	2.52 (1.22)	0.13	0.80
School						
Participate in classroom activities	5.56 (2.42)	3.28 (1.00)	6.55 (1.4)	3.15 (0.98)	0.03*	0.53
Field trips and school events	2.23 (1.84)	3.41 (1.40)	2.09 (1.32)	3.62 (1.01)	0.69	0.45
School teams, clubs and organizations	1.44 (2.41)	2.69 (1.62)	2.5 (2.46)	3.33 (1.29)	0.03*	0.15
Getting together with peers outside of class	4.00 (2.70)	3.26 (1.38)	5.37 (2.46)	3.37 (1.28)	0.01*	0.71
Special roles at school	1.09 (2.04)	2.53 (1.81)	0.76 (1.7)	2.74 (1.45)	0.40	0.67

Note. ^aStandard deviation; ^breference sample derived from (29); *significant effect

provides the opportunities for skill mastery and promotes development, quality of life, and wellbeing (9-11). High levels of participation including frequency and variety are associated with positive outcomes in a range of areas including academic achievement, interpersonal functioning, and well-being (11).

Parents identified both barriers and supports to their child's participation. Various physical, social, and cognitive demands associated with activities were identified as significant barriers to participation among children with ASD. Similar barriers have been observed among adolescents with ASD when examining participation in physical activity, leading to the conceptualization of participation among adolescents with ASD as being 'conditional' (33). This model of conditional participation proposes that willingness to participate in physical activity among adolescents with ASD requires various interconnected requirements to be met, including

predictability, freedom of choice, competence and confidence, motivation and adjustment to external demands (33). Based on the barriers to participation observed in the current study, it is possible that this concept of 'conditional participation' may also extend into participation in other domains including the home, school, and community. Determining and addressing these conditions among children with ASD within the home, school and community may support improvements in participation.

In both the community and school settings, personal transport was perceived as an important factor supporting participation, as well as sufficient time and money. While not within the scope of the current study, these findings may have critical implications for participation among children with ASD in low-economic areas. Further, transport in this context is often associated with significant distances. The impact on family functioning when

participation requires a parent to spend a lot of time driving one child should be further explored.

A recent Australian-based study using the PEM-CY to examine the participation profiles of children with ASD (29) showed a similar restricted participation profile to the current study, at least descriptively speaking. However, when comparing the results, frequencies and involvement in activities were reduced in children with ASD from regional and remote areas in a number of domains (29). Findings from the current study are also similar to a systematic review which found that leisure participation of children with ASD is restricted (34). This review found that major environmental factors reducing participation in children with ASD are a lack of services and community programs, reduced access to equipment and built environments (34). As reported by parents in the current study, it is likely that these environmental factors are contributing to, and exacerbating existing participation restrictions in this population living in regional and remote areas. Intervention and additional supports and opportunities should be considered in regional and remote areas for children with ASD to increase participation range and frequency in order to ensure optimal skill development and quality of life.

This study highlights the importance of expanding the construct and definition of participation in the ICF-CY to go beyond frequency, and to include involvement (23, 35-37). A holistic understanding of participation can only be obtained by incorporating both objective measures of frequency alongside subjective measures of involvement and engagement. Parental report also confirms the importance of considering involvement when measuring children's participation (38). Incorporating involvement while assessing participation may also provide important information about desired activities, guiding interventions aiming to enhance not only participation but also enjoyment and quality of life (35).

This study also highlights the discord between frequencies of participation and involvement across all three of the settings. This was evident in some activities such as homework and personal care which had high-mean frequencies and low-mean involvement. This may reflect children's low motivation or enjoyment in chore or work-based activities (28). Conversely, this study identified several activities including overnight visits or trips and socializing where despite a low-mean frequencies of participation (less than monthly) children were more than 'somewhat involved.' These were both activities which more than half of the parents desired change in their child's participation (including increasing frequencies of participation). This finding

can be further understood by examining the role of barriers to participation in these types of activities. For example, half of the parents (50%) reported that access to programs and services were a significant barrier to their child participating in these activities, with peer relations and social demands also playing significant roles. These results indicate that there is a critical need for increased services and supports for families and children with ASD to support community engagement. This lack of services and opportunities for organized leisure activities is consistent with previous research with rural communities (39-41). These findings also expose an area for future investigation and potential intervention regarding increasing participation frequency.

Strengths and limitations

This study consisted of a relatively small sample size, restricting the ability to generalize results to a wider regional/remote population. However, it must be noted that the pool of participants included in this study was taken from a larger sample believed to be representative of the population pertaining to families with children with ASD as recorded by the DSC. Therefore, results from this study can, with caution, be interpreted as representative of the larger sample of families with ASD living in non-metropolitan areas of WA. This study was also restricted by the complexity of the PEM-CY. However, no significant differences between the respondent group and the non-responders represent a notable strength of the study. This study provides novel information regarding the participation profiles and barriers and supports to participation of children with ASD living in non-metropolitan areas.

Conclusion

This study highlights the influential role of environmental factors in supporting and restricting participation for children living in regional and remote areas of WA. The results of this study should guide further research into interventions and solutions in these areas to increase participation of children with ASD. In addition, this study draws attention to the limited range of activities that the studied sample participate in, which was amplified by the limited resources and services in regional and remote areas.

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Conflicts of interest

The authors report no conflicts of interest.

References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Arlington, VA: American Psychiatric Publishing; 2013. Available from: <http://dsm.psychiatryonline.org.dbgw.lis.curtin.edu.au/content.aspx?bookid=556§ionid=41101757#103436574>
- Rogers S. Common conditions that influence children's participation. In: Case-Smith J, O'Brien J, editors. Occupational therapy for children. 6th ed. Missouri, MN: Mosby Elsevier; 2010:146-92.
- Hilton C, Crouch M, Israel H. Out-of-school participation patterns in children with high-functioning autism spectrum disorders. *Am J Occup Ther* 2008;62:554-63.
- Orsmond G, Kuo H. The daily lives of adolescents with an autism spectrum disorder: discretionary time use and activity partners. *Autism* 2011;15:579-99.
- Reynolds S, Bendixen R, Lawrence T, Lane S. A pilot study examining activity participation, sensory responsiveness, and competence in children with high functioning autism spectrum disorder. *J Autism Dev Disord* 2011;41:1496-506.
- Shattuck P, Orsmond G, Wagner M, Cooper B. Participation in social activities among adolescents with autism spectrum disorder. *PLoS One* 2011;6:1-9.
- World Health Organisation. International classification of functioning, disability and health: children and youth version. Geneva: World Health Organisation; 2007.
- De Winter M, Baerveldt C, Kooistra J. Enabling children: participation as a new perspective on child-health promotion. *Child Care Health Dev* 1999;25:15-23.
- King G, Law M, King S, Rosenbaum P, Kertoy M, Young N. A conceptual model of factors affecting the recreation and leisure participation of children with disabilities. *Phys Occup Ther Pediatr* 2003;23:63-90.
- Law M. Participation in the occupations of everyday life. *Am J Occup Ther* 2002;56:640-9.
- Rose-Krasnor L, Busseri M, Willoughby T, Chalmers H. Breadth and intensity of youth activity involvement as contexts for positive development. *J Youth Adolesc* 2006;35:385-499.
- Andrews J, Falkmer M, Girdler S. Community participation interventions for children and adolescents with a neurodevelopmental intellectual disability: A systematic review. *Disabil Rehabil* 2015;37:825-33.
- Foley K-R, Dyke P, Girdler S, Bourke J, Leonard H. Young adults with intellectual disability transitioning from school to post-school: A literature review frames within the ICF. *Disabil Rehabil* 2012;34:1747-64.
- Australian Bureau of Statistics. Australian Social Trends, cat. no. 4102.0 Canberra. 2008. Available from: <http://www.abs.gov.au>
- Australian Bureau of Statistics. Children's participation in sport and leisure time activities, Australia 2003-2012; 2012.
- Australian Bureau of Statistics. Children's participation in cultural and leisure activities, Australia; 2012 Apr.
- Lee J, Macdonald D. Rural young people and physical activity: understanding participation through social theory. *Social Health Illn* 2009;31:360-74.
- Cleland V, Hughes C, Thornton L, Squibb K, Venn A, Ball K. Environmental barriers and enablers to physical activity participation among rural adults: A qualitative study. *Health Promot J Austr* 2015;26:99-104.
- Autism Queensland. CRC for living with Autism Spectrum Disorders; 2013. Available from: www.autismqld.com.au/page/333/CRC-for-Living-with-Autism-Spectrum-Disorders
- Hussain R, Tait K. Parental perceptions of information needs and service provision for children with developmental disabilities in rural Australia *Disabil Rehabil* 2015;37:1609-16.
- Horlin C, Falkmer M, Parsons R, Albrecht M, Falkmer T. The cost of autism spectrum disorders. *PLoS One* 2014;9:1-11.
- Department of Health and Ageing. Australian Standard Geographical Classification - Remoteness Area (ASGC-RA): Australian Government - Department of Health and Ageing; 2007. Available from: <http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/RA-intro#>
- Coster W, Law M, Bedell G, Khetani M, Cousins M, Teplicky R. Development of the participation and environment measure for children and youth: Conceptual basis. *Disabil Rehabil* 2012;34:238-46.
- Coster W, Bedell G, Law M, Khetani M, Teplicky R, Liljenquist K, et al. Psychometric evaluation of the participation and environment measure for children and youth. *Dev Med Child Neurol* 2011;53:1030-7.
- Kelley K, Clark B, Brown V, Sitzia J. Good practice in the conduct and reporting of survey research. *Int J Qual Health Care* 2003;15:261-6.
- IBM Company. IBM SPSS Statistics 19 (version 19); 2010.
- Bedell G, Coster W, Law M, Liljenquist K, Kao Y-C, Teplicky R, et al. Community participation, supports and barriers of school age children with and without disabilities. *Arch Phys Med Rehabil* 2013;94:315-23.
- Law M, Anaby D, Teplicky R, Khetani M, Coster W, Bedell G. Participation in the home environment among children and youth with and without disabilities. *Br J Occup Ther* 2013;76:58-66.
- Simpson K, Keen D, Adams D, Alston-Knox C, Roberts J. Participation of children on the autism spectrum in home, school and community. *Child Care Health Dev* 2017;44:99-107.
- R Core Team. R: A language and environment for statistical computing. Vienna: R Foundation for Statistical Computing; 2016. Available from: <https://www.R-project.org/>
- Arnholt A, Evans B. BSDA: Basic Statistics and Data Analysis: R Package version 1.2.0; 2017. Available from: <https://CRAN.R-project.org/package=BSDA>
- State Records Commission. Western Australian University Sector Disposal Authority. Perth; 2013.
- Arnell S, Jerlinger K, Lundqvist L. Perceptions of physical activity participation among adolescents with autism spectrum disorders: A conceptual model of conditional participation. *J Autism Dev Disord* 2018;48:1792-802.
- Askari S, Anaby D, Bergthorson M, Majnemer A, Elsabbagh M, Zwaigenbaum L. Participation of children and youth with autism spectrum disorder: A scoping review. *Rev J Autism Dev Disord* 2015;2:103-14.
- Falkmer M, Oehlers K, Granlund M, Falkmer T. Can you see it too? Observed and self-rated participation in mainstream schools in students with and without autism spectrum disorders. *Dev Neurorehabil*. 2015;18:365-74.
- Granlund M. Participation – challenges in conceptualization, measurement and intervention. *Child Care Health Dev* 2013;39(4):470-3.
- Maxwell G, Augustine L, Granlund M. Does thinking and doing the same thing amount to involved participation? *Empirical*

explorations for finding a measure of intensity for a third ICF-CY qualifier. *Dev Neurorehabil* 2012;15:274-83.

38. Bedell G, Khetani M, Cousins M, Coster W, Law M. Parent perspectives to inform development of measures of children's participation and environment. *Arch Phys Med Rehabil* 2011;92:765-73.
39. Craike MJ, Symons C, Eime RM, Payne WR, Harvey JT. A comparative study of factors influencing participation in sport and physical activity for metropolitan and rural female adolescents. *Ann Leis Res* 2011;14:355-68.
40. Hardy LL, Kelly B, Chapman K, King L, Farrell L. Parental perceptions of barriers to children's participation in organised sport in Australia. *J Paediatr Child Health* 2010;46:197-203.
41. Smith B, Grunseit A, Hardy L, King L, Wolfenden L, Milat A. Parental influences on child physical activity and screen viewing time: a population based study. *BMC Public Health* 2010;10:593.