Community participation group interventions for children and adolescents with neurodevelopmental disabilities: A systematic review; and, Community participation for girls and women living with Rett syndrome

Jaimi Andrews

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Community participation group interventions for children and adolescents with neurodevelopmental disabilities: A systematic review.

And

Community participation for girls and women living with Rett syndrome.

Jaimi Andrews
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Community participation for girls and women living with Rett syndrome

Jaimi Andrews

A report submitted in Partial Fulfilment of the Requirements of the Award of Bachelor of Occupational Therapy Honours, Faculty of Health and Science, Edith Cowan University

Submitted August 2012

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This review and research project would not have been possible without the ongoing support from the Telethon Institute for Child Health Research and Edith Cowan University. In particular, I would like to thank, Dr Sonya Girdler from Edith Cowan University, for her guidance, patience and understanding. The children and families involved in the Australian Rett Syndrome Study should also be acknowledged for their time and dedication in continuing to answer questionnaires. A special thanks to Ms Katherine Bathgate, Dr Jenny Downs and Clinical A/Prof Helen Leonard from the Telethon Institute for Child Health Research for their endless encouragements and contributions. This thesis is dedicated to my wonderful parents who have supported me throughout my life and given me the opportunity to attend university and complete my honours degree.
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Literature Review

Community participation group interventions for children and adolescents with neurodevelopmental disabilities: A systematic review

Jaimi Andrews
I would like to make note that although my systematic review is primarily based on community participation interventions for girls and women with Rett syndrome, due to limited research available, I will be considering other neurodevelopmental intellectual disabilities such as cerebral palsy, Down syndrome, and Autism Spectrum Disorder.
Community participation group interventions for children and adolescents with neurodevelopmental disabilities: A systematic review

Abstract

Objective: To describe the effectiveness of community integration interventions on community participation, self-esteem and quality of life for children and adolescents with a neurodevelopmental intellectual disability.

Method: Electronic searches of five databases and manual searches of reference lists were conducted. Community integration interventions which targeted friendship development, recreation participation, quality of life and self-esteem were included.

Results: Thirteen studies were included in this review. A variety of study designs and interventions were used. Following interventions, all but one study reported significantly increased friendships, five reported increased recreation participation and one reported increased quality of life and self-esteem. Methodological quality of the studies ranged from adequate to strong.

Conclusions: Community integration interventions appear to be effective in supporting the successful inclusion of children and adolescents with neurodevelopmental intellectual disabilities. Future interventions should consider the impact of several factors, such as impairment, personal and environmental factors, in facilitating community participation.

Key words: Neurodevelopmental intellectual disability · Recreation program · Friendship group · Children · Adolescents · Community participation · Quality of life

Author: Jaimi Andrews
Supervisors: Dr Sonya Girdler and Ms Katherine Bathgate
May 2012
Background

The prevalence of neurodevelopmental intellectual disability in Western Australia is 14.3 per 1000 people (Leonard, Petterson, Bower, & Sanders, 2003). Neurodevelopmental disability refers to a condition or disorder which begins in the early stages of development (conception, birth, infancy, and childhood) (Patel & Merrick, 2011). It can result in mild to profound intellectual disability, behavioural problems, impaired speech, social withdrawal and poor gross motor functioning (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012). Types of neurodevelopmental disabilities include Rett syndrome, autism, cerebral palsy, Down syndrome, Asperger's syndrome, and Fragile X syndrome. Due to the nature of these disabilities, they can often have a major influence on daily life (Patel & Merrick, 2011). A clear example of this includes limited ability to participate in community activities such as recreation and friendships (Patel & Merrick, 2011).

For children and adolescents with intellectual disabilities, community participation has the ability to enhance physical and mental wellbeing, promote social inclusion, increase self-worth and improve independence (Laugeson, Frankel, Mogil, & Dillon, 2009; Specht, King, Brown, & Foris, 2002). In addition, participation in recreational activities and friendships can increase overall life satisfaction and contribute to one's quality of life (Budruk & Phillips, 2011; Geisthardt, Brotherson, & Cook, 2002; Specht et al., 2002). Although the importance of community participation has been identified, current research suggests that people living with an intellectual disability will participate in less recreational activities than their peers (Law et al., 2006).

To encourage participation in the community, appropriate interventions and programs need to be developed. To date, very few community participation interventions have been identified for children and adolescents with intellectual disabilities. Instead, there has been a focus on the child’s health needs such as medical care (Dahan-Oliel et al., 2012). However, interventions and programs which target recreational participation and friendships are reported to be more valued by the families of children with an intellectual disability than interventions focusing on health care.
Community participation programs have the ability to increase sports participation and social interaction between children with and without disabilities, and improve academic performance and functional skills (Shukla, Kennedy, & Cushing, 1999; Werts, Caldwell, & Wolery, 1996). In addition, interventions provide typically developing children with an opportunity to gain an understanding about disability (Carter et al., 2004; Schleien, Krotee, Mustonen, Kelterborn, & Schermer, 1987).

When designing a community participation intervention for children and adolescents with a neurodevelopmental intellectual disability, several factors should be considered. The International Classification of Functioning, Disability and Health (ICF) is a holistic, theoretical framework which is often used to describe the relationship between activity and participation, and impairment, personal and environmental factors (World Health Organization [WHO], 2005). Impairment factors which may impact the effectiveness of community participation interventions include cognitive and language ability (Kasari et al., 2005) and severity of intellectual disability (Murphy & Carbone, 2008; Shikaka-Thomas, Majnemer, Law, & Law, 2008). Current literature suggests that young people with a more severe intellectual disability are less likely to participate in community activities (Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011; Majnemer et al., 2008). Clinical symptoms also have the ability to impact the frequency and intensity at which a child can participate in recreational activities and friendships (King et al., 2003; Oates, Bebbington, Bourke, Girdler, & Leonard, 2011).

Personal factors which may impact on engagement in programs targeting community participation include age and gender (Kasari et al., 2005). Depending on the age of the child or adolescent, activity preference and availability of leisure activities may vary. It has been suggested that as the child matures, activity preference will change and activities will become less available (Dusseljee et al., 2011). Gender may also influence participation as research suggests that males
prefer more physical activities, whilst girls prefer sedentary activities (Lorenzi, Horvat, & Pellegrini, 2000).

Environmental factors which may influence participation in community interventions include accessibility, family social demographics, and community support (Becker & Dusing, 2010; Kasari et al., 2005; Murphy & Carbone, 2008). It is important to ensure that the environment is accessible for children and adolescents with intellectual disabilities to allow them to participate successfully. Family social demographics such as socio-economic status can affect a child’s ability to attend interventions due to the cost of specialised equipment (Murphy & Carbone, 2008). Family needs should also be considered as they may have other children or prior commitments (Fennick & Royle, 2003). Negative and discriminatory attitudes of the community can also inhibit children with an intellectual disability seeking out community participation programs (Law, Petrenchik, King, & Hurley, 2007).

Therefore, the objective of this systematic review is to describe the effectiveness of community integration interventions on community participation, self-esteem and quality of life for children and adolescent’s with neurodevelopmental intellectual disabilities.

Methods

Search strategy

A search of the COCHRANE database failed to identify a previous review addressing this objective. Four electronic databases were then searched for this review. Each database was searched from its earliest electronic record (Cumulative Index of Nursing and Allied Health Literature – CINAHL from 1982, MEDLINE from 1966, PsycINFO from 1685, and SPORTDiscus from 1381) until April 2012. The main search terms were grouped into four concepts. The first concept had the following key words with intervention and program added to the end: community-based, friendship,
social skills, group, and peer support. The second concept included Rett syndrome, Down syndrome, autism (autism, autism spectrum disorder), cerebral palsy, neurodevelopmental disability, intellectual disability and mental retardation. The third concept included outcome key words including community participation, activity participation, friend (friendship, friends), leisure, recreation, social interaction, interpersonal, self-esteem and quality of life. The fourth concept included children, adolescent, teenager and young. With assistance from the librarian, all terms were adjusted, exploded and truncated in order to match the database being searched. Forward citation searching using the electronic database, Web of Science, was completed on included articles. Manual searches were conducted on all reference lists of retrieved studies however conference proceedings and grey literature were not searched.

**Inclusion and exclusion criteria**

*A priori* criteria for inclusion of studies were applied initially to titles and abstracts and then full text articles if the abstract did not provide sufficient information. Studies were included if the community integration intervention was delivered in a group and was aimed at targeting community participation, self-esteem and/or quality of life. Interventions were also not limited to being administered by a specific health profession or discipline. Participants in the studies were restricted to children and adolescents aged five to 18 years with a neurodevelopmental disorder resulting in intellectual disability such as Rett syndrome, Down syndrome, cerebral palsy and autism. For the remainder of this review, neurodevelopmental intellectual disability will be referred to as intellectual disability. Studies were excluded if the interventions were delivered individually or were primarily targeted at parents. Participants which had an acquired neurodevelopmental disability or physical disability were also excluded for this review. Quantitative, qualitative and mixed-method studies were included. Studies reported in any other languages beside English were excluded.
Assessment of methodological quality

Two reviewers independently assessed the quality of each study using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers developed by Kmet and colleagues (2004). This quality assessment form contains a 14-item quantitative checklist. Guidelines and instructions have been provided to assist the reviewers to answer the questions and calculate a final score. The reviewers used a scoring system to determine the quality of the paper, which could be described as strong (score of >80%), good (70-80%), adequate (50-70%) or limited (<50%) (Lee, Packer, Tang, & Girdler, 2008). Any discrepancies found between reviewers were resolved through discussion.

Data extraction

Data was independently extracted from selected studies using the following headings: study objective, study design, subject and sample size, intervention used, data collection method, outcome measures, results, discussion and limitations. Once data was extracted, the level of evidence was determined on the National Health and Medical Research Council guidelines (National Health and Medical Research Council [NHMRC], 1999).

Results

Search strategy and selection criteria

Electronic searches located a total of 396 articles using the key terms (see Figure 1). The titles and abstracts were reviewed and 325 articles were found not to meet the inclusion criteria and 13 articles were unable to be obtained. The full-text of the remaining 58 articles were reviewed and nine were found to meet inclusion criteria. Reference lists and citations from web of science were
Community participation for girls and women with Rett syndrome

manually searched which identified a further four studies for inclusion. Overall 13 studies were included in this systematic literature review.

An overview of the included 13 articles is presented in Table 1. Study designs included: four randomised control trials (RCT) (Drysdale, Casey, & Porter-Armstrong, 2008; Frankel et al., 2010; Kasari, Rotheram-Fuller, Locke, & Gulsrud, 2012; Laugeson et al., 2009), one, one-way repeated measures design (Siperstein, Glick, & Parker, 2009), seven quasi-experimental designs (time series, multiple baseline, pre-test-posttest) (Barry et al., 2003; Carter et al., 2004; Fennick & Royle, 2003; Haring & Breen, 1992; MacKay, Knott, & Dunlop, 2007; Schleien et al., 1987; Schleien, Mustonen, & Rynders, 1995), and one mixed methods study (Becker & Dusing, 2010). Within the 13 articles, a variety of interventions were reported. Three were described as recreation programs (Fennick & Royle, 2003; Schleien et al., 1987; Siperstein et al., 2009), two were friendship clubs/groups (Carter et al., 2004; Haring & Breen, 1992), two were community art programs (Becker & Dusing, 2010; Schleien et al., 1995), two were social skills groups (Barry et al., 2003; MacKay et al., 2007), two were friendship training groups (Frankel et al., 2010; Laugeson et al., 2009), one was a PEER-mediated group (Kasari et al., 2012) and one was a community skills group (Drysdale et al., 2008). Overall, 468 young people participated in these interventions: 214 were young people with Autism Spectrum Disorder including Autism and Asperger's syndrome (Barry et al., 2003; Carter et al., 2004; Drysdale et al., 2008; Fennick & Royle, 2003; Frankel et al., 2010; Haring & Breen, 1992; Kasari et al., 2012; Laugeson et al., 2009; MacKay et al., 2007; Schleien et al., 1987; Schleien et al., 1995), one with Down syndrome (Becker & Dusing, 2010), 62 with a non- specified intellectual disability (Drysdale et al., 2008; Haring & Breen, 1992; Siperstein et al., 2009) and 191 were typically developing peers (Barry et al., 2003; Becker & Dusing, 2010; Haring & Breen, 1992; Kasari et al., 2012; Schleien et al., 1987; Schleien et al., 1995; Siperstein et al., 2009). All but one study (Drysdale et al., 2008), reported on friendships, five reported on recreational and activity participation (Becker & Dusing, 2010; Fennick & Royle, 2003; Schleien et al., 1987; Schleien et al.,
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1995; Siperstein et al., 2009), five reported on social skills (Barry et al., 2003; Haring & Breen, 1992; Kasari et al., 2012; Laugeson et al., 2009; MacKay et al., 2007), and one reported on quality of life and self-esteem/confidence (Becker & Dusing, 2010).

Quality of studies

The methodological quality of selected studies is presented in Table 1. Overall, methodological quality of the 13 included studies ranged from adequate to strong. There appeared to be no relationship between the type of intervention protocol and the quality of the research. For most articles, the study design, objective, method of subject selection, subject/comparison characteristics and outcome measures were clearly described. Random allocation of subjects and blinding of investigators varied, depending on the study design. Due to the nature of the interventions, it was impossible to blind subjects. Very few articles reported effect sizes, confounding variables or the variance of outcome measures. Other shortcomings included poorly reported sample sizes and assessors were therefore left to make their own conclusions. Generally, the analytical methods were justified appropriately and the results and conclusion sections were reported in detail.

Interventions

The intention of this review was to examine research which reported on various types of community participation interventions, however, the majority of the interventions targeted friendships rather than recreational and leisure interventions. Even though it has been reported that both friendship and leisure participation is important in promoting quality of life and health and well-being for children with intellectual disabilities (Potvin, Prelock, & Snider, 2008), only four of the 13 studies incorporated both friendship facilitation and recreational participation into their programs (Carter et al., 2004; Fennick & Royle, 2003; Schleien et al., 1987; Siperstein et al., 2009).
Of the 13 included articles, seven were specifically designed to target friendship facilitation (Barry et al., 2003; Carter et al., 2004; Frankel et al., 2010; Haring & Breen, 1992; Kasari et al., 2012; Laugeson et al., 2009; MacKay et al., 2007). The aim of these interventions was to develop friendships, teach appropriate social skills for friendship development (conversation and initiation skills), and promote inclusion in peer groups. Three studies (Fennick & Royle, 2003; Schleien et al., 1987; Siperstein et al., 2009) used a recreational program to promote recreational participation in well-known sports and preferred activities, and also encourage friendship development. Finally, two studies (Becker & Dusing, 2010; Schleien et al., 1995) were described as community art programs. These aimed to enhance basic art skills, encourage friendship development and promote participation in art activities such as dancing, singing, acting, and arts and crafts.

The settings of the interventions included two in a school classroom (after-hours) (Frankel et al., 2010; Laugeson et al., 2009), two during recess and lunch at school (Haring & Breen, 1992; Kasari et al., 2012), six in a community setting (leisure centre, museum, performing arts centre, university campus) (Barry et al., 2003; Becker & Dusing, 2010; Fennick & Royle, 2003; Schleien et al., 1987; Schleien et al., 1995; Siperstein et al., 2009) and three in both a classroom and community setting (Carter et al., 2004; Drysdale et al., 2008; MacKay et al., 2007).

Comparison groups varied for all four RCT’s. The two friendship training groups (Frankel et al., 2010; Laugeson et al., 2009) were evaluated against 12-week delayed treatment group. The PEER mediated group (Kasari et al., 2012) was compared against a no-treatment group. Lastly, the community skills programme (Drysdale et al., 2008) evaluated the difference between three groups: classroom training, classroom training and community outings, and a no-treatment group.
Outcomes

Four broad outcomes (friendships, recreational participation, quality of life and self-esteem) were evaluated for this systematic literature review (see Table 1).

Friendships

Despite using a variety of outcomes measures, all but one study reported significant changes in friendships following interventions. Friendships interventions were evaluated in three RCT studies (Frankel et al., 2010; Kasari et al., 2012; Laugeson et al., 2009), with two (Frankel et al., 2010; Laugeson et al., 2009) using a delayed treatment group, and one (Kasari et al., 2012) with a no-treatment group. Significant improvements in quality and quantity of friendships and play dates were found using a variety of friendship measures including friendship quality scale (Laugeson et al., 2009), quality of play questionnaire (Frankel et al., 2010; Laugeson et al., 2009), social network survey and observations/ interviews (Kasari et al., 2012). A significant decrease in loneliness was also reported using social inclusion scales including the loneliness scale, piers self-concept scale and the pupil evaluation inventory (Frankel et al., 2010). Three of four pretest-posttest studies (Barry et al., 2003; Carter et al., 2004; Fennick & Royle, 2003; Schleien et al., 1987) evaluating friendship interventions reported significant increases in quality, quantity and interaction of friendships. This may have resulted from the reliance on observations to assess friendships (Fennick & Royle, 2003), whilst the other three studies used observations as well as informal interviews and formal social inclusion measures (attitude acceptance scale (Schleien et al., 1987), social support scale, and loneliness scale (Barry et al., 2003). A significant increase in positive friendships and interactions outside of school was reported following the intervention period in two multiple baseline designs (Haring & Breen, 1992; Schleien et al., 1995), one time series design (MacKay et al., 2007), one repeated measures design (Siperstein et al., 2009) and one mixed methods study (Becker & Dusing, 2010). In these studies, friendships were measured using observations (Becker
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Dusing, 2010; Haring & Breen, 1992; Schleien et al., 1995), informal interviews (MacKay et al., 2007), and the peer hang-out-with and friendship inventory (Siperstein et al., 2009).

Recreational participation

Participation in recreational activities was examined in five studies (Becker & Dusing, 2010; Fennick & Royle, 2003; Schleien et al., 1987; Schleien et al., 1995; Siperstein et al., 2009). Two pretest-posttest designs reported a significant increase in sports participation using observations as an outcome measure following a recreational program (Fennick & Royle, 2003; Schleien et al., 1987). Although these two studies reported a significant improvement in recreational participation, only one was assessed as having a strong methodological quality, questioning the strength of the findings (Fennick & Royle, 2003). One repeated measures design (Siperstein et al., 2009) and mixed methods study (Becker & Dusing, 2010) also yielded similar results to the pretest-posttest studies using the adapted sports skills assessment (Siperstein et al., 2009) as well as observations (Becker & Dusing, 2010). In addition, Siperstein and colleagues (2009) found a strong relationship between sports skills and building friendships (p = 0.01) and Becker and colleagues (2010) reported that following the recreational intervention, a young girl with Down syndrome had increased motivation to attend other community programs. Another study also reported a significant change in activity participation in informal activities following a friendship club, even though its initial aim was to promote friendships (Carter et al., 2004).

Community participation skills

A three-armed RCT study aimed at evaluating the effectiveness of a community skills intervention (Drysdale et al., 2008) reported a highly significant difference (p = 0.007) between the two intervention groups and the control group in shopping skills. Although shopping skills increased for both intervention groups, no significant difference was found between the classroom only intervention group and the classroom and community intervention group for the shopping task. The
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methodological quality of the study was found to be strong due to the large sample size and random allocation of young people to groups.

Quality of life and self-esteem

Only one study reported significant improvements in quality of life and self-esteem (Becker & Dusing, 2010). The Pediatric Quality of Life Inventory (PedsQL), a reliable and valid measure (Varni, Seid, & Kurtin, 2001), was used to measure quality of life whilst subject and parent feedback were used to measure self-esteem. However, the adequate methodological quality of the study may limit the ability for the findings to be generalised. The effect size could not be calculated for this study as the total number of subjects was not specified.

Discussion

This systematic review found adequate to strong evidence that community integration interventions appear to be effective in promoting the inclusion of children and adolescents with an intellectual disability.

Findings from this review have highlighted that there are potentially many ways to continue to improve the effectiveness of community participation interventions. Several studies which reported that interventions were delivered in an integrated setting with typically developing peers as well as children with intellectual disabilities were more beneficial than interventions which included only children with intellectual disabilities. Participation in community activities with typically developing peers was important for children with intellectual disabilities as it enhanced normalisation, increased recreational opportunities and encouraged positive friendships (Becker & Dusing, 2010; Carter et al., 2004; Fennick & Royle, 2003; Haring & Breen, 1992; Kasari et al., 2012; Schleien et al., 1987; Siperstein et al., 2009). In studies which only involved children and adolescents with intellectual disabilities (Barry et al., 2003; Carter et al., 2004; Frankel et al., 2010;
Laugeson et al., 2009), it was noted by observers and parents that future programs should include typically developing peers.

Controversy exists in relation to the most appropriate setting for community participation interventions. While some research has found that skills learnt in the classroom were transferred to the playground and not the community (Kasari et al., 2012), other research reported that skills learnt in both the classroom and community, were generalised to the community setting (Carter et al., 2004; MacKay et al., 2007). In comparison, Drysdale and colleagues (2008) found no difference between the classroom setting and the community setting in relation to skill transfer. However the results from this study should be interpreted with caution as only two community outings were undertaken and the study had a small sample size ($n = 12$). Therefore further research is needed.

Another important finding was the importance of considering children activity preference within the programs. Three studies identified that it was important to consider activity preferences of children and adolescents with intellectual disabilities as it significantly increased positive participation in recreational activities (Carter et al., 2004; Fennick & Royle, 2003; Schleien et al., 1987).

In relation to the ICF, several factors which may impact community participation interventions were identified. For impairment factors, clinical symptoms and severity of disability were discussed. Fennick and colleagues (2003) reported that limitations in the ability to communicate significantly impacted on a young persons ability to form friendships. A number of studies also reported that children and adolescents with a more severe intellectual disability, were less likely to recognise friendships (Kasari et al., 2012; MacKay et al., 2007), improve community living skills (Drysdale et al., 2008) or participate in the program as a whole (Siperstein et al., 2009).

Both age and gender emerged as personal factors which could potentially impact on participation in programs. Four studies (Laugeson et al., 2009; MacKay et al., 2007; Schleien et al., 1987; Siperstein et al., 2009) purposefully formed similar age and sex groups to facilitate similar
age and sex friendships. In one study (Siperstein et al., 2009), an older group of children were excluded from the recreational program as it was felt that older children would have different recreational preferences compared to those younger.

Potential environmental factors which could impact participation in community programs for young people with intellectual disability included family social demographics, accessibility, and social support from the community. Several strategies, surrounding family social demographics, were offered to increase participation and attendance in the program including incentives such as paid parking and cost effective programs (Laugeson et al., 2009; MacKay et al., 2007; Siperstein et al., 2009). Other strategies included grouping children based on the parents' and childs’ availability, prior commitments and geographic location (Fennick & Royle, 2003; MacKay et al., 2007). Several interventions utilised environmental modifications tailored to the young person’s needs including assistive equipment and modifications of sports to encourage positive friendships between children with and without intellectual disabilities (Becker & Dusillg, 2010; Carter et al., 2004; Fennick & Royle, 2003; Laugeson et al., 2009; MacKay et al., 2007; Schleien et al., 1987; Schleien et al., 1995). Four studies considered community support as an important factor, therefore teachers and typically developing peers learnt strategies to encourage community awareness and promote community inclusion for children with intellectual disabilities (Barry et al., 2003; Fennick & Royle, 2003; Kasari et al., 2012; Schleien et al., 1995).

Limitations of this systematic review should be clarified. Firstly, only four electronic databases were used to search the literature. However, these databases were those most likely to identify research examining the objective of this review. Secondly, very few studies (Drysdale et al., 2008; Frankel et al., 2010; Siperstein et al., 2009) reported effect sizes, making it difficult to compare the relative effectiveness of the individual interventions. Thirdly, parent proxy report was used in several studies of young people with moderate to severe disabilities. This could potentially affect the findings from these studies as it may be difficult for parents to accurately report on their
child's quality of life. Finally, assessment of the methodological quality revealed that four studies (Becker & Dusing, 2010; Carter et al., 2004; Fennick & Royle, 2003; Haring & Breen, 1992) were of adequate quality. This points to the need for more robust methodologies in this area of research.

Overall, this systematic literature review highlights the need to develop and evaluate more interventions which aim to increase leisure participation, friendships, quality of life and self-esteem of young people with intellectual disability. When planning interventions, impairment, personal and environmental factors should be considered. Programs should also aim to be flexible, promote activity preference, encourage active participation and provide enjoyment for all young people (Becker & Dusing, 2010; Murphy & Carbone, 2008). Only 13 articles met the inclusion criteria for this systematic review, indicating that further research is required in this area. The findings from this systematic review will encourage health professionals to facilitate and advocate for the development of community participation interventions for children and adolescents with intellectual disabilities.
References


Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: Randomized controlled trial of social skills at school for children with autism spectrum
Community participation for girls and women with Rett syndrome.


Community participation for girls and women with Rett syndrome


Figure 1 Flow chart of study selection

Titles and abstracts identified screened
n = 396
Excluded n = 325
Unable to obtain/ further information required to make assessment n = 13

Full copies retrieved and assessed for eligibility
n = 58
Excluded n = 49
Age n = 16
No intervention n = 3
Outcomes not relevant n = 8
Individual/paired interventions n = 11
ABI or physical disability n = 6
Foreign language n = 3
Systematic review n = 2

Studies obtained from Web of Science n = 2
Studies identified from reference list n = 2

Publications meeting inclusion criteria and included in review n = 13
<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Design/number of subjects</th>
<th>Subjects</th>
<th>Intervention group</th>
<th>Control group</th>
<th>Outcome measures</th>
<th>Results</th>
<th>* Methodological quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frankel 2010 USA</td>
<td>RCT (n = 68)</td>
<td>Children with high functioning ASD and their parents 7-11y</td>
<td>Children’s friendship training group (n = 35) 12 weekly sessions Classroom (after-hours) Children and parents (separated)</td>
<td>Delayed intervention group (n = 33)</td>
<td><strong>Friendships</strong></td>
<td>Significant change (p &gt; 0.05) in play dates (number, behaviour); child’s self-control and assertiveness Significant change (p &lt; 0.025) in loneliness, ↑ popularity</td>
<td>Strong quality (score = 24/28) Investigators and subjects not blinded. Large sample size, analytical variance described. Random allocation, and results/conclusion sufficiently reported.</td>
</tr>
<tr>
<td>Mackay 2007 UK</td>
<td>Quasi-experimental (n = 46)</td>
<td>Children with high functioning ASD 6-16y</td>
<td>Social skills group 12-16 weekly sessions 8 per group 6 groups; 3 x 6-11y, 3x 12-16y Classroom (after-hours) &amp; community outings</td>
<td>-</td>
<td><strong>Friendships</strong></td>
<td>-</td>
<td>Good quality (score = 20/28). Sample size and confounding variables partially reported. Investigators blinded, no random allocation and variance not reported. Random allocation, and results/conclusion sufficiently reported.</td>
</tr>
<tr>
<td>Laugeson 2008 USA</td>
<td>RCT (n = 33)</td>
<td>Teenagers with ASD 13-17y</td>
<td>Parent assisted social skills group (n = 17) 12 weekly sessions 7 per group Classroom (after-hours) Children and parents (separated)</td>
<td>Delayed intervention group (n = 16)</td>
<td><strong>Friendship</strong></td>
<td>↑ hosted get togethers, better quality friendships (p = 0.05) <strong>Social skills</strong></td>
<td>Good quality (score = 20/28). Investigators and subjects not blinded, variance not reported. Sample size and confounding variables partially reported. Random allocation, and results/conclusion sufficiently reported.</td>
</tr>
<tr>
<td>Kasari 2015 USA</td>
<td>RCT (n = 75)</td>
<td>Children with high functioning ASD (n = 20) Typically developing peers (n = 45) 6-11y</td>
<td>Peer mediated group (n = 60) 12 sessions/wk for 6 wks Recess and lunch at school</td>
<td>No intervention Children with high functioning ASD (n = 15)</td>
<td><strong>Friendships</strong></td>
<td>↑ no. Friendships and social network (p = 0.02) Reciprocal friendships were nonsignificant ↓ isolation on the playground <strong>Social skills</strong></td>
<td>Good quality (score = 21/28). Blinding of subjects not reported, sample size and confounding variables partially reported. Investigators blinded, random allocation, and results/conclusion sufficiently reported.</td>
</tr>
<tr>
<td>Becker 2010 USA</td>
<td>Mixed methods (n = not stated)</td>
<td>Girl with Down syndrome (11y, mild cognitive impairment) Typically developing</td>
<td>Performing arts group 12 weekly sessions Community performing arts</td>
<td>-</td>
<td><strong>Quality of life</strong></td>
<td>-</td>
<td>Adequate quality (score = 9/14). Poorly described study. Study design and subject selection not clearly identified. Blinding, random allocation, analytical variance described.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Size</td>
<td>Population</td>
<td>Intervention</td>
<td>Assessments</td>
<td>Outcomes</td>
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<tr>
<td>Haring</td>
<td>Multiple baseline</td>
<td>1992 USA (n = 11)</td>
<td>Adolescent's with autism (n = 1) &amp; intellectual disability (n = 1)</td>
<td>Social network group Aims: facilitate social interaction and inclusion Weekly sessions 2 Groups: 1 (n = 5), 2 (n = 6) Recess, lunch and classroom (after-hours)</td>
<td>Parent report Social interaction/ friendships • Observations (assessor) • Qualitative – satisfaction, peer interaction/ relationship (child and peers)</td>
<td>Social skills • ↑ knowledge of social skills</td>
<td></td>
</tr>
<tr>
<td>Barry</td>
<td>One-group pretest-posttest</td>
<td>2009 USA (n = 11)</td>
<td>Children with high functioning autism (n = 4) Typically developing peers (n = 7) (only used for assessment period) 6-9y</td>
<td>Social skills group Aims: Social skills and friendships 8 weekly sessions</td>
<td>Friendship/Social Support • Social support scale (child) • Loneliness scale (child)</td>
<td>Social Skills • Significant ↑ Greeting skills (p = 0.03) &amp; conversation skills (p = 0.10) • ↑ Greeting skills outside clinic Friendship/Social Support • Significant ↑ in perceived social support from peers (p = 0.05), play (p = 0.03) • ↑ meaningful peer relationships between children with and without autism • ↓ perceived loneliness</td>
<td></td>
</tr>
<tr>
<td>Siperstein</td>
<td>One-way repeated measures</td>
<td>2009 USA (n = 67)</td>
<td>Children with mild intellectual disability (n = 29) Typically developing peers (n = 38) 8-13y</td>
<td>Summer recreational program Aims: participation in swimming, basketball, soccer, free play, arts &amp; crafts 5 sessions/wk for 4 wks 12 per group Leisure centre</td>
<td>Friendship • Peer hang-out-with and friendship inventory (child) Recreational participation • Adapted sports skills assessment (investigators)</td>
<td>Friendship • Children with ID made new friends and more accepted by peers Recreational participation • Significant ↑ in swimming and soccer skills for children with ID (p = 0.001) Strong relationship between sports skills and building relationships (p = 0.01)</td>
<td></td>
</tr>
<tr>
<td>Drysdale</td>
<td>RCT</td>
<td>2008 Ireland (n = 40)</td>
<td>Children with moderate intellectual disability (8 autism and 32 non-specified) 9-11y</td>
<td>Community skills group Aims: participation in games, learning shopping and telephone skills 2 sessions/wk for 8 wks 6 per group 2 groups: 1 - classroom and community training (n = 12), 2 - classroom training (n = 12) Classroom (after hours)</td>
<td>No intervention Community skills (shopping and telephone) • Observations • Task analysis</td>
<td>Community skills (shopping and telephone) • ↑ shopping skills for both intervention groups (p = 0.007), no change for control group No significant difference between intervention groups and control group in handling of money skills or telephone skills</td>
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</tr>
</tbody>
</table>

**Community participation for girls and women with Rett syndrome**

Adequate quality (score = 15/22). Sample size not identified. Confounding variables, variance and analytical methods partially described. Blinding and random allocation N/A.

Good quality (score = 18/24). Small sample size, confounding variables not considered, and study design not clearly identified. Investigators blinded, results/conclusion sufficiently reported, and analytical methods justified.

Good quality (score = 17/22). Blinding and random allocation N/A. Study design, confounding variable and variance not clearly identified. Large sample size and analytical methods described.

Strong quality (score = 24/28). Subjects not blinded. Confounding variables considered, large sample size, analytical methods described, random allocation, blinded investigators, study design evident, and results/conclusion sufficiently reported.
Community participation for girls and women with Rett syndrome

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Group Details</th>
<th>Activities</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fennick</td>
<td>Two-group pretest-posttest (n = 7)</td>
<td>Children with mild to severe autism (n = 5) Typically developing peers 6-13yo</td>
<td>Recreation group Aim: participation in swimming, gymnastics, develop friendships 2 groups: 1 - swimming (n = 3); 2 - gymnastics (n = 2) Leisure centre</td>
<td>Adequate quality (score = 11/20). Random allocation and blinding N/A. Analytical methods, results and conclusion partially described. Small sample size and confounding variables not considered</td>
</tr>
<tr>
<td>Schleien</td>
<td>Multiple baseline (n = 32)</td>
<td>Children with mild to severe autism (n = 7) Typically developing peers (n = 25) 7-11yo</td>
<td>Community art program Aim: develop friendships, learn art skills 7 monthly sessions Community museum</td>
<td>Strong quality (score = 18/22) Random allocation and blinding N/A. Sample size is large. Confounding variables and variance partially described</td>
</tr>
<tr>
<td>Schleien</td>
<td>One-group pretest-posttest (n = 69)</td>
<td>Children with severe autism (n = 2) Typically developing peers (n = 67) 7-12yo</td>
<td>Summer recreation program Aim: participation in badminton, basketball, volleyball, gymnastics, swimming, tennis, squash, free time 5 sessions/ wk for 3 wks 3 age groups: 7-8yo; 9-10yo; 11-12yo University campus (community)</td>
<td>Strong quality (score = 18/22) Random allocation and blinding N/A. Sample size, variance and confounding variables not mentioned. Analytical methods and results/conclusions sufficiently described</td>
</tr>
<tr>
<td>Carter</td>
<td>Two-group pretest-posttest (n = 10)</td>
<td>Children with Asperger’s syndrome 8-15yo</td>
<td>Friendship club Aim: develop friendships and skills 6 weekly sessions 2 age groups: 9-10yo (n = 6); 11-15yo (n = 4) Classroom (after hours) and community</td>
<td>Adequate quality (score = 13/22). Random allocation and blinding N/A. Study design, outcome measures, analytical methods and results not sufficiently described. Variance and confounding variables not described</td>
</tr>
</tbody>
</table>

*N.B. – Scoring for methodological quality = total sum ('yes'x2 + 'partial'x2) / total possible score (28 – number of N/A x 2)*
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Journal of Intellectual & Developmental Disability, Special Education Centre, University of Newcastle, Callaghan,
Community participation for girls and women living with Rett syndrome.

Research Report

Community participation for girls and women living with Rett syndrome.

Jaimi Andrews
Abstract

Purpose: To describe the relationship between impairment, personal and environmental factors, and community participation for Australian girls and women with Rett syndrome.

Methods: Data was collected from the 2009 follow-up questionnaire completed by families participating in the Australian Rett Syndrome Database (n = 214). Univariate and multivariate logistic regression were used to analyse relationships between impairment, personal and environmental factors and participation.

Results: In 2009, the mean age was 17.6 years (SD = 7.95, range three to 34 years) with 114 (53.3%) girls still at school and 100 (46.7%) women post school. Frequency of activities was influenced by levels of walking, community support and maternal education. For girls living at home, participation in activities was associated with greater functional independence, higher levels of maternal education and better family income. Participation in recreational (90.1%), physical/skill-based (67.6%) and/or social (70.3%) activities were commonly reported by families, whilst self-improvement (17.6%) activities were less reported. Younger girls participated in activities mainly with family members and older girls more frequently participated with carers.

Conclusion: Participation for girls and women with Rett syndrome could be enhanced by stronger community supports. Future studies should use both qualitative and quantitative methodologies to determine the level of satisfaction and enjoyment experienced by girls and women in community activities.

Key words: Rett syndrome · disability · community participation · International Classification of Functioning, Disability and Health
Introduction

Rett syndrome is a severe and rare neurodevelopmental disorder which predominantly affects females, with a prevalence of one in 8,600 Australian females aged five to 18 years [1,2]. In most cases, it is associated with an X-linked dominant mutation of the MECP2 gene [3]. It is characterised by a period of apparently normal physical and intellectual development up until six to 18 months of life at which point the child begins to display signs of stagnation or regression in development [4]; however, some parents have reported that subtle signs of delayed development may appear even earlier [5]. Clinical presentations includes loss of acquired fine and gross motor skills, development of stereotypical hand movements (mouthing, clasping, complex finger movements, hand wringing and tapping) and absence or loss of communication skills. Common comorbidities in Rett syndrome include epilepsy, scoliosis, gastro-intestinal dysfunction, feeding and nutritional problems, and breathing abnormalities [6].

Community participation can be defined as one’s ability to interact and engage with others in social or recreational activities outside the home [7]. It is important for individuals with an intellectual disability to have the opportunity to participate in community activities as it can enhance overall physical and psychological wellbeing as well as contribute to their self-worth, self-esteem and quality of life [8-11]. Current research suggests that people living with an intellectual and physical disability participate in fewer recreational activities than their peers [12,13]. This may be the case for those with Rett syndrome because of the complex nature of the disorder.

A range of underlying factors contribute towards a person’s ability to participate within the community, especially those with severe intellectual and physical disability. The International
Classification of Functioning, Disability and Health (ICF) is a holistic, theoretical framework which provides a universal classification system to describe health and health-related states of all people [14]. It is used to explore the relationships between body functions and structures (impairment factors), contextual factors (personal and environmental) and activities and participation. The ICF is therefore a useful framework in the investigation of factors influencing the community participation of girls and women with Rett syndrome.

Historically research on children with a disability has focused on impairment factors, and only recently contextual factors have begun to be identified as possible factors affecting community participation [15]. Research involving those with a mild and moderate disability has highlighted how community participation is influenced by impairment, personal and environmental factors [16]. However little is known about the factors that might promote successful community participation for girls and women with Rett syndrome.

Previous research on impairment factors for young people with a mild to moderate intellectual disability suggests that the more severe the intellectual disability, the less the likelihood of participating in community activities [17,18]. Furthermore it has been reported that children with cerebral palsy with poorer gross motor functioning experienced greater restrictions in community participation [19].

Personal factors including functional independence and age have been recognised as influencing community participation. Children with Down syndrome with poorer functional ability were less likely to be part of friendships, sports and hobbies [20]. Mixed findings have been found in relation to age and community participation with some studies suggesting that as children with an intellectual and physical disability grow older, they participate in less
recreational activities and more social activities [12,17]. In contrast, another study found that as younger children with complex communication needs grow, they participate in less recreational, social and self-improvement activities [21].

Research suggests that environmental factors are the most important factors to consider when participating in the community. Families of children with a physical and intellectual disability who have poorer community support and live in a non-metropolitan area experienced increased difficulty in accessing community activities [12,23]. Additionally, children with an intellectual disability were less likely to participate in social and leisure activities if their parents had a lower income or education level, poorer physical and mental health and less available time [20,23].

The purpose of this study was to describe the relationships between impairment and contextual factors and community participation for girls and women with Rett syndrome. The main hypothesis for this study was: Impairment factors (mobility and behaviour), personal factors (age and functional independence) and environmental factors (parent health status, parent socio-economic status, parent available time, community support, place of residence) would influence the community participation for girls and women with Rett syndrome.

Methods

Study design

A cross-sectional design was used to examine the relationship between impairment, personal and environmental factors and community participation.
Participants

Participants for this study were participating in the Australian Rett Syndrome Database (ARSD) which is a population-based study collecting longitudinal data since 1993 [24]. To be included in the database, the girl or woman must have a confirmed diagnosis of Rett syndrome which requires them to have a pathogenic MECP2 mutation or meet the current diagnostic criteria [25]. Cases can be referred from clinicians and families as well as the Australian Paediatric Surveillance Unit and the Rett Syndrome Association of Australia [1]. At enrolment in the database, clinicians and families receive an initial questionnaire and since 2000, follow-up questionnaires have been distributed to families every two to three years. For this study, data from the 2009 follow-up questionnaire which collected information regarding the individual's current health status and functioning, and current community activities was used. To be included in this study, individuals had to be female, have a confirmed Rett syndrome diagnosis and the ‘activities in the community’ question had to have been completed in the 2009 follow-up questionnaire.

Ethical considerations

Ethics approval was obtained from Princess Margaret Hospital for Children Ethics Committee (reg. no. 447/EP) and Edith Cowan University, Western Australia. All data is stored at Telethon Institute for Child Health Research according to the approved privacy policy.

Data collection instruments

Identified factors were grouped into impairment factors, personal factors and environmental factors according to the ICF [14]. Impairment factors included mobility and behaviour problems. Behaviour problems were measured by the general mood and fear/anxiety
subscales of the Rett Syndrome Behaviour Questionnaire (RSBQ), with a higher score indicating greater behavioural problems [26]. Personal factors included child age at the time the questionnaire was returned and level of functional independence as measured by the Functional Independence Measure for Children (WeeFIM) [27]. A higher score on the WeeFIM indicated a higher level of functional ability. Environmental factors included community support (measured by the Family Support Scale (FSS)) [28], parent availability of time (measured by the Family Resource Scale (FRS)) [29], accessibility (determined by using the Accessibility/Remoteness Index of Australia (ARIA)) [30], and parental physical and mental health (Short Form Health Survey (SF-12)) [31]. Additionally socio-economic status (determined by maternal education, parental occupation measured by the Australian and New Zealand Standard Classification of Occupations (ANZSCO) [32], and the families ability to save money) was included. Higher scores indicated better community support, more available time, and increased health and wellbeing.

Data coding and analysis

Community participation outcomes included the overall participation in community activities, the variety of activities, the frequency of activities, and who accompanied the girl or woman in the activity. The overall participation of activities was grouped into two categories: those who participated in an activity and those who reported no activity participation. Only girls and women living at home were included in this outcome as it was expected that girls living in a group home would participate in at least one activity. The variety of community activities was coded into four categories according to the Children’s Assessment of Participation and Enjoyment (CAPE) model [33]: recreational activities (e.g., visiting the zoo, going ten pin bowling, leisure groups), physical/skill based activities (e.g. swimming, horse riding, dancing), social activities (e.g. shopping, going to the movies, a concert or restaurant) or self-
improvement activities (e.g. church, holidays, library). Variety was further described as low participation if the young women participated in one to three activities and high participation if they participated in four or more activities. Frequency of community activities was scored on a continuous scale based on how many times the young women attended a particular activity per year. An overall frequency was then calculated for each participant by summing the frequencies for all activities. With whom the girl or women participated in the activities was coded into two outcomes: with or without a carer and/or with or without a family member.

Participations were divided into four age groups for analysis: early childhood (< 8 years), primary school (8 ≤ 13), adolescence (13 ≤ still at school) and post school. Post school was further classified according to living in the family home or elsewhere (e.g. group home). For the purpose of this study, the ARIA [30] categories: very remote, remote and outer regional areas were combined due to small numbers. Additionally, some maternal education and ANZSCO categories [32] were combined due to small numbers. Mean substitution was used if there was 25% or less missing items in the scale.

Relevant data was cleaned and coded in FileMaker Pro 11 then exported into STATA 11 for statistical analysis. Chi-square tests, one-way analysis of variance (ANOVA) and t-tests were used to describe the relationships between community participation outcomes and categorical (age, mobility, ARIA and SES) and continuous (subscales of the RSBQ, the WeeFIM, the SF-12, parent availability of time, and community support) factor variables. Univariate and multivariate logistic regression was used for analysis of binary community participation outcomes and poisson linear regression was used to examine factors impacting frequency of
community participation. For all environmental factors, with exception of the ARIA, the analysis was restricted to daughters living at home.

Results

Sample characteristics

In 2009, 260 follow-up questionnaires were distributed of which 226 were returned (87% response fraction). Data on the community activities question was provided by 214 families (94.7%) with most families ($n = 182$, 85.0%) reporting that their daughter participated in community activities. Participants had a mean age of 17.6 years (SD = 7.95, range 3 to 34 years) with 114 (53.3%) girls still at school and 100 (46.7%) women attending post school options. For girls who were still at school, 26 (12.2%) were <8 years, 42 (19.6%) were 8-13 years, and 46 (21.5%) were >13 years. Of women who were post school, 38 (38.0%) lived in a group home and 62 (62.0%) lived with their parents. With regards to mobility, 82 families (38.3%) reported that their daughter had mildly restricted levels of walking, 40 (18.7%) had severely restricted levels of walking, and 92 (43.0%) were either able to support their weight briefly during transfer or required full assistance.

The majority (68.7%) of families lived in major cities, 44 (20.6%) lived in inner regional areas, and 23 (10.8%) in outer regional/remote/very remote areas. Forty nine (27.5%) mothers had completed some high school, 42 (23.6%) completed year 12, 46 (25.8%) had a vocational qualification (Tafe or Advanced dip.), and 41 (23.0%) had a university degree. The majority of mothers reported their occupation as homemakers (45.5%) whilst most fathers reported that they were in a manger/professional occupation (41.3%) or clerk/trade occupation (43.2%). Most (78.5%) families provided information about their financial situation with 88 (52.4%) families reporting that they could save some money, eight (4.8%)
reporting that they had some money left over but they just spend it, and 72 (42.9%) reported that they could not save money.

Overall participation in activities

Of the girls and women living at home (n = 175), 145 (82.9%) reported participating in an activity and 30 (17.1%) reported participating in no activities. The univariate relationships between the ICF predictor factors and the outcome participation in an activity, are presented in Table I. Girls and women had greater odds of participating in an activity if they had a higher functional independence (OR = 1.05, 95% CI 1.00-1.09, p = 0.05), if their mother had a university degree compared to mothers with some high school education (OR = 4.87, 95% CI 1.00-23.71, p = 0.05) and if their families were able to save money compared to those who could not save (OR = 4.87, 95% CI 1.00-23.71, p = 0.07). The relationship between community participation, and maternal education (OR = 5.23, 95% CI 1.06-25.79, p = 0.05) and functional independence (OR = 1.04, 95% CI 1.00-1.09, p = 0.06) persisted, even after adjusting for age group. However, the effect of saving money on participation in activities was no longer present after adjusting for the father’s occupation (OR = 1.61, 95% CI 0.59-4.36, p = 0.35). The girls and women’s age, mobility, and behaviour, family factors such as place of residence, level of community support, parent mental and physical health, parent available time, parental occupations and maternal education did not appear to influence activity participation.

Variety of activities

One hundred and sixty four (90.1%) individuals were reported to participate in recreational activities, 123 (67.6%) in physical/skill-based activities, 128 (70.3%) in social activities and
32 (17.6%) in self-improvement activities. The majority of the girls and women participated in four or more recreational (61.0%), physical/skill-based (69.3%), social (73.4%) and self-improvement (93.8%) activities. Engagement in all four types of activities was similar across all age groups. The univariate relationships between variety of activities and the ICF factors; impairment, personal and environmental, are presented in Table II. Girls and women who had more mood related behaviours had less odds (OR = 0.64, 95% CI 0.39-1.06, p = 0.08) of participating in self-improvement activities but the effect was reduced after adjustment for age group (OR = 0.71, 95% CI 0.42-1.19, p = 0.19). Daughter's whose mothers who had completed year 12 had greater odds (OR = 3.33, 95% CI 1.16-9.61, p = 0.03) of participating in recreational activities whilst those whose mothers who had completed a university degree had increased odds (OR = 2.96, 95% CI 0.88-9.95, p = 0.08) of participating in social activities when compared to those whose mothers who had completed some high school. After adjusting for age group, the relationship between maternal education and recreational activities had a greater likelihood (OR = 3.48, 95% CI 1.19-10.19, p = 0.02) whilst the relationship between maternal education and social activities had a smaller likelihood (OR = 2.79, 95% CI 0.82-9.46, p = 0.10). Girls and women whose mothers had a clerk/trade qualification had increased likelihood (OR = 2.26, 95% CI 0.97-5.24, p = 0.06) of participating in recreational activities compared to mothers who were homemakers. This relationship was still present after adjusting for age group (OR = 2.21, 95% CI 0.94-5.18, p = 0.07). There were few strong relationships for personal characteristics such as age, mobility, functional independence and fear anxiety behaviour and environmental characteristics such as place of residence, community support, financial situation, father occupation, parent mental and physical health and parental availability of time.
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Frequency of activities

The average frequency of activity per year was 217.55 (SD = 218.91) which equates to approximately 4.2 times per week. The univariate relationships between frequency of activities and impairment, personal and environmental factors can be seen in Table I. Compared to those who were younger than eight years old, girls who were still at school and aged 8≤13 (IRR = 0.42, 95% CI 0.26-0.67, p = 0.00) and >13 (IRR = 0.52, 95% CI 0.33-0.83, p = 0.01) engaged in activities less frequent, and this relationship persisted after separately adjusting for mobility (8≤13: IRR = 0.42, 95% CI 0.26-0.68, p = 0.000; >13: IRR = 0.52, 95% CI 0.33-0.82, p = 0.005), general mood behaviour (8≤13: IRR = 0.38, 95% CI 0.24-0.62, p = 0.000; >13: IRR = 0.48, 95% CI 0.30-0.76, p = 0.002), fear anxiety behaviour (8≤13: IRR = 0.39, 95% CI 0.25-0.63, p = 0.000; >13: IRR = 0.48, 95% CI 0.31-0.76, p = 0.002) and functional independence (8≤13: IRR = 0.39, 95% CI 0.24-0.63, p = 0.000; >13: IRR = 0.48, 95% CI 0.30-0.78, p = 0.003). For women who had left school, no difference was found in the frequency of activities between those living at home and those living in a group home. On the other hand, girls and women who had severely restricted levels of walking were more likely (IRR = 1.41, 95% CI 0.99-2.02, p = 0.06) to frequently participate in activities compared to those who required full assistance when walking. Daughter’s whose mothers had a higher education qualification (IRR = 1.75, 95% CI 1.15-2.66, p = 0.01) or whose family had greater community support (IRR = 1.22, 95% CI 1.03-1.44, p = 0.02) had increased frequency of activities. Even after adjusting separately for age group, mobility (IRR = 1.37, 95% CI 0.96-1.96, p = 0.08), maternal education (IRR = 1.69, 95% CI 1.13-2.53, p = 0.01) and community support (IRR = 1.19, 95% CI 1.01-1.41, p = 0.04) continued to have an effect on how often the girls and women participated. The relationship between community support and the frequency of activities also remained significant after the adjustment of mobility (IRR = 1.22, 95% CI 1.03-1.44, p = 0.02). The girls and women's behaviour and functional
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independence, as well as environmental factors including place of residence, financial situation, parent occupation, parent mental and physical health and parental availability of time did not have a significant effect on the frequency of activities.

**Involvement of family/carer**

Overall, 123 (41.8%) cases participated in activities with a carer, 111 (37.76%) participated with family, three (1.0%) with friends, 42 (14.3%) with a carer and family, five (1.7%) with a carer and friends, eight (2.7%) with family and friends and two (0.7%) with family, friends and a carer. Additionally, 136 (54.6%) individuals reported participating with a carer only and 113 (45.4%) reported participating without a carer, whilst 149 (51.4%) individuals participated with family only and 141 (48.6%) participated without family. The univariate relationships between predictor factors of impairment, personal and environmental factors and who the girls and with were accompanied with can be seen in Table III. For all girls and women, it was found that as they aged, they were more likely to participate with a carer \((p<0.000)\) and less likely to participate with family members \((p<0.002)\). Women who had left school and were living in a group home were 3.6 times more likely to participate with a carer in activities than those living at home \((OR = 3.62, 95\% CI 1.43-9.19, p = 0.01)\) and less likely to participate with family compared to those living at home \((OR = 0.32, 95\% CI 0.15-0.7, p = 0.004)\). This relationship persisted even after separately adjusting for mobility (with carer: \(OR = 3.60, 95\% CI 1.41-9.16, p = 0.007\); with family \(OR = 0.32, 95\% CI 0.15-0.70, p = 0.004\)), general mood behaviours (with carer: \(OR = 3.27, 95\% CI 1.26-8.50, p = 0.02\); with family \(OR = 0.33, 95\% CI 0.15-0.73, p = 0.006\)), fear anxiety behaviours (with carer: \(OR = 3.62, 95\% CI 1.41-9.31, p = 0.008\); with family \(OR = 0.33, 95\% CI 0.15-0.72, p = 0.005\)) and functional independence (with carer: \(OR = 3.68, 95\% CI 1.44-9.40, p = 0.007\); with family \(OR = 0.31, 95\% CI 0.14-0.69, p = 0.004\)). Child characteristics such as general mood...
Community participation for girls and women with Rett syndrome

behaviour, fear anxiety behaviour, and functional independence and family characteristics such as maternal education, parent mental and physical health, financial situation and place of residence did not predict who was accompanying the girls and women.

Discussion

This study found that age and mobility influenced how often girls and women with Rett syndrome participated in community activities as did the level of maternal education and community support. For girls and women who lived with their parents, greater participation in activities were related to greater functional independence, as well as higher levels of maternal education and better family income. Common activities included social, recreational and/or physical/skill-based activities. Age was related to who the girls participated with for activities, with younger girls participating with family members and older girls participating with carers.

This study found that for girls still at school, younger girls participated more frequently in activities compared to older girls. At a younger age, children are more likely be involved in family activities as families play a vital role in supporting and facilitating community participation. As children grow older, they usually become more aware of their own participation needs [21,34]. However, possibly due to the medical effects of epilepsy [35] and scoliosis [36] during the school years and the physical demands placed on the family, their participation in activities became less frequent. There was also a trend towards women who were post school engaging in more frequent activities most likely due to post school options including structured activity programs.
Our findings on relationships between functional abilities and overall participation in activities were consistent with previous studies of children with intellectual disabilities who were less likely to participate in activities in the presence of greater functional limitations [16, 37]. Interestingly, girls and women with more severely restricted levels of walking were more likely to frequently participate in activities compared to those with mildly restricted levels of walking. This may be linked to the use of wheelchairs for mobility during outings [38], and the possibility that girls with less restricted levels were less likely to use wheelchairs and therefore less likely to engage in community outings. As for girls who require full assistance for mobility, those with severely restricted levels of walking may have had access to more supported participation opportunities to meet their needs.

In this study higher levels of community support for families was associated with their daughter's participating in activities more frequently. In general, children and adults with an intellectual disability still remain the most socially excluded people in Australia and continue to experience negative and discriminatory attitudes within their community [39]. However, there is limited literature on the effectiveness of strategies to support families in achieving optimal participation levels for their daughter with Rett syndrome, but strategies might relate to social networks, infrastructure, and community awareness. Organisations including disability services may therefore need to advocate for supportive and accessible environments for positive community participation experiences [39, 40].

Daughter's whose mothers had a higher educational qualification were more likely to participate in an activity and frequently participate in activities. The importance of maternal education has been indicated in several studies finding that for children with an intellectual disability, their health and development as well as access to health facilities is predicted by
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their mother's education [41]. Additionally, maternal education has been found to have the most powerful influence over their child's health and well-being when compared to other socio-economic predictors such as the father's education and parent's occupation [42]. Collectively these findings highlight the important role that maternal education can have on the development of children with an intellectual disability as well as a mother's empowerment in supporting a more comprehensive program of activities for their child with a disability.

Another important finding was that girls and women whose families who were able to save money were more likely to participate in activities. This finding is consistent with previous studies of young adolescents with developmental disabilities suggesting that participation in social and recreational activities is predicted by the family's financial status [43]. These results of this study may suggest that a higher proportion of income is spent on meeting the medical and equipment needs of the child leaving less money to expend on discretionary community activities [43-45]. Therefore further planning and resourcing of cost-effective community activities and programs is needed for families and people with intellectual disabilities.

In this study, girls and women with Rett syndrome participated in a variety of activities. Recreational, physical/skill-based and social activities were often reported by families, whilst self-improvement activities were less frequently reported although some could argue that physical/skill-based (e.g. hydrotherapy) and social (e.g. shopping) activities may be regarded as self-improvement activities. It was expected that participation in recreational and social activities would be more common as they can accommodate for wheelchair use and increased severity of Rett syndrome [38,46]. For example, walking (recreational) was frequently
Community participation for girls and women with Rett syndrome reported by majority of families as this activity could be undertaken with all levels of mobility. Physical/skill-based activities such as horse riding and swimming were also frequently reported as common activities in which the girls and women participated as they may help to build their skills as well as provide enjoyment. This study also found that there was no differences in that variety of activities between girls who were still at school and those who were post school, consistent with previous studies on children and adolescents with profound disabilities [13,25]. We can therefore conclude that many of the girls and women participated in a range of activities but challenges still remain in identifying the environment factors which further support accessible, affordable and meaningful participation in a more comprehensive range of activities.

Younger girls were more likely to participate in activities with a family member whilst older girls were more likely to participate with a carer. This is likely related to the higher proportion of older women living in a group home, increasing independence from the family and poorer physical health of parents as they age [47,48]. It is clear that care workers have a critical role in ensuring favourable quality of life for women with Rett syndrome. Several studies of adults with an intellectual disability have suggested that care workers influence the level of community participation for those for whom they care and are often unaware that their role includes facilitating activity participation [49]. This indicates the need for the resourcing of education and training programs for caring staff to enable a greater understanding of their role in facilitating participation in social and recreational activities as well as building strong and positive relationships for those they care for [50].

Families of children with severe disabilities are often faced with a difficult decision as to whether they should continue to care for their child, or place them in a community home [48].
When families do make the decision for their child to live out of home, they may experience a sense of guilt associated with no longer caring for their child [47]. However, living independently is an expected phase of transition [21]. For families who choose to care for their daughter with Rett syndrome at home, greater levels of support may be needed due to the complexity and severity of the disability [25,47]. For these families, supports such as respite services are important in alleviating stress [51].

The major strengths of this study were the population-based nature of the sample, the high response fraction and large sample size. The ICF framework [14] proved to be a valuable framework in identifying the factors affecting community participation whilst the CAPE model [33] provided a clear understanding on the variety of activities. This study was limited by our inability to describe the level of enjoyment and satisfaction experienced in activity for the girls. Parent proxy reporting may have contributed to parents over reporting or under reporting their daughter’s participation in activities and there may have also been some degree of recall error with parents providing incorrect information. Lastly, our study was cross sectional and the results only reflect the 2009 sample. Longitudinal data is available in the database for future analysis.

Several other factors should be considered for future studies. Firstly, it would be important to gain further understanding of how the individual’s current living situation affects their community participation. This could include if they live in a single parent family and levels of sibling involvement in activities. Secondly, qualitative research is needed to obtain further insight into the barriers and enablers of community participation.
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Conclusion

In summary, Rett syndrome is a complex disability which can restrict community participation. The findings from this study have provided an insight into how impairment, personal and environmental factors can influence community participation for girls and women with Rett syndrome. By identifying the barriers to community participation, families, disability services and health professionals including occupational therapists can advocate and encourage the successful inclusion of not only girls and women with Rett syndrome, but also for all people with severe disabilities.

Key messages

- The majority of girls and women with Rett syndrome participated in recreational, physical/skill-based and social activities in the community.
- Frequency of participation was influenced by levels of mobility, community support and maternal education.
- As the girls grew older, they were more likely to participate with a carer and less likely to participate with family members.
- Further understanding of impairment, personal and environmental factors to provide meaningful, accessible and affordable community activities.
Community participation for girls and women with Rett syndrome

References

Community participation for girls and women with Rett syndrome


Table I. Univariate relationships between impairment; personal and environmental factors and overall participation and frequency of activity participation.

<table>
<thead>
<tr>
<th>Categorical predictors</th>
<th>Overall participation a (n = 175)</th>
<th>Frequency of activities b (n = 214)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Activities / No activities)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (%) OR CI p-value</td>
<td>n IRR CI p-value</td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependent/Weight bear</td>
<td>76 (43.4%) Ref.</td>
<td>92 (43.0%) Ref.</td>
</tr>
<tr>
<td>Severely restricted</td>
<td>32 (18.3%) 3.69 0.79-17.18 0.10</td>
<td>40 (18.7%) 1.41 0.99-2.02 0.06</td>
</tr>
<tr>
<td>Mildly restricted</td>
<td>67 (38.3%) 1.02 0.44-2.34 0.96</td>
<td>80 (38.2%) 1.21 0.89-1.64 0.22</td>
</tr>
<tr>
<td>Age (still at school)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 8</td>
<td>26 (14.9%) Ref.</td>
<td>26 (23.0%) Ref.</td>
</tr>
<tr>
<td>8 &lt; 13</td>
<td>41 (23.4) 1.07 0.33-3.45 0.91</td>
<td>42 (36.3%) 0.42 0.26-0.67 0.00</td>
</tr>
<tr>
<td>13 &lt; still at school</td>
<td>46 (26.3%) 1.67 0.50-5.64 0.41</td>
<td>46 (40.7%) 0.52 0.33-0.83 0.01</td>
</tr>
<tr>
<td>Age (post school)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent home</td>
<td>62 (35.4%) 2.03 0.62-6.57 0.24</td>
<td>62 (62.0%) Ref.</td>
</tr>
<tr>
<td>Group home</td>
<td></td>
<td>38 (38.0%) 0.99 0.69-1.43 0.97</td>
</tr>
<tr>
<td>Mother ANZSCO c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaker/Unemployed/Retired</td>
<td>77 (45.8%) Ref.</td>
<td>77 (45.8%) Ref.</td>
</tr>
<tr>
<td>Clerk/Trades</td>
<td>55 (32.7%) 1.54 0.61-3.91 0.36</td>
<td>55 (32.7%) 1.05 0.73-1.50 0.81</td>
</tr>
<tr>
<td>Manager/professional</td>
<td>36 (21.4%) 2.10 0.65-6.80 0.22</td>
<td>36 (21.4%) 1.17 0.80-1.72 0.41</td>
</tr>
<tr>
<td>Father ANZSCO c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaker/Unemployed/Retired</td>
<td>22 (15.2%) Ref.</td>
<td>22 (15.2%) Ref.</td>
</tr>
<tr>
<td>Clerk/Trades</td>
<td>61 (42.1%) 0.34 0.07-1.62 0.17</td>
<td>61 (42.1%) 1 0.75-1.81 0.49</td>
</tr>
<tr>
<td>Manager/professional</td>
<td>62 (42.8%) 0.79 0.15-4.10 0.78</td>
<td>62 (42.8%) 1 0.92-1.90 0.13</td>
</tr>
<tr>
<td>Maternal education c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primacy or Some high school</td>
<td>49 (28.7%) Ref.</td>
<td>49 (28.7%) Ref.</td>
</tr>
<tr>
<td>High school year 12</td>
<td>39 (22.8%) 0.85 0.31-2.37 0.76</td>
<td>39 (22.8%) 1.30 0.80-2.13 0.29</td>
</tr>
<tr>
<td>Vocational qualification</td>
<td>43 (25.2%) 1.12 0.40-3.16 0.83</td>
<td>43 (25.2%) 1.41 0.94-2.12 0.10</td>
</tr>
<tr>
<td>University degree</td>
<td>40 (23.4%) 4.87 1.00-23.71 0.05</td>
<td>40 (23.4%) 1.75 1.15-2.66 0.01</td>
</tr>
<tr>
<td>ARIA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major cities</td>
<td>122 (69.7%) Ref.</td>
<td>147 (68.7%) Ref.</td>
</tr>
<tr>
<td>Inner regional</td>
<td>34 (19.4%) 0.97 0.36-2.64 0.95</td>
<td>44 (20.0%) 1.06 0.76-1.47 0.73</td>
</tr>
<tr>
<td>Very remote/Remote/Outer</td>
<td>19 (10.9%) 1.11 0.30-4.15 0.88</td>
<td>23 (10.8%) 1.17 0.82-1.67 0.38</td>
</tr>
<tr>
<td>Family spending c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We cannot save</td>
<td>70 (42.9%) Ref.</td>
<td>70 (42.9%) Ref.</td>
</tr>
<tr>
<td>Some left over each week but we spend it</td>
<td>8 (4.8%) 2.07 0.24-18.13 0.51</td>
<td>8 (4.8%) 0.81 0.48-1.39 0.45</td>
</tr>
<tr>
<td>We can save</td>
<td>85 (52.2%) 2.22 0.94-5.27 0.07</td>
<td>85 (52.2%) 1.27 0.91-1.77 0.15</td>
</tr>
</tbody>
</table>
Table I. (continued)

<table>
<thead>
<tr>
<th>Continuous Predictors</th>
<th>Overall participation (^a) (n = 175)</th>
<th>Frequency of activities (^b) (n = 214)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Activities / No activities)</td>
<td>(Activities / No activities)</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>OR</td>
</tr>
<tr>
<td>General Mood behaviours</td>
<td>7.7 (4.4)</td>
<td>1.03</td>
</tr>
<tr>
<td>Fear and Anxiety behaviours</td>
<td>4.0 (2.1)</td>
<td>1.09</td>
</tr>
<tr>
<td>Functional Independence</td>
<td>29.4 (14.4)</td>
<td>1.05</td>
</tr>
<tr>
<td>Parent Mental Health (^c)</td>
<td>39.3 (10.3)</td>
<td>1.03</td>
</tr>
<tr>
<td>Parent Physical Health (^c)</td>
<td>49.3 (8.8)</td>
<td>0.97</td>
</tr>
<tr>
<td>Community support (^c)</td>
<td>2.6 (0.8)</td>
<td>1.59</td>
</tr>
<tr>
<td>Parent available time (^c)</td>
<td>1.5 (0.5)</td>
<td>1.72</td>
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</tbody>
</table>

\(^a\) For overall participation, only girls and women living with parents were included in analysis; \(^b\) For frequency of activities, all girls and women were included unless otherwise specified in the factors; \(^c\) Only girls and women living with parents were included in analysis.
Table II. Univariate relationships between impairment, personal and environmental factors and variety of activities.

<table>
<thead>
<tr>
<th>Categorical Predictors</th>
<th>Variety of activities (n = 182)</th>
<th>Physical/Skill-based</th>
<th>Social</th>
<th>Self-improvement</th>
<th>p-value</th>
<th>p-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Recreational (low 1-3 / high 4+)</td>
<td>(low 1-3 / high 4+)</td>
<td>(low 1-3 / high 4+)</td>
<td>Low %</td>
<td>High %</td>
<td>p-value</td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependent/Weight bear</td>
<td>77</td>
<td>Ref.</td>
<td>Ref.</td>
<td>Ref.</td>
<td>0.00</td>
<td>100.00</td>
<td></td>
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<tr>
<td>Severe: 38</td>
<td>1.24</td>
<td>0.54-2.85</td>
<td>0.62</td>
<td>2.42</td>
<td>0.78-7.46</td>
<td>0.13</td>
<td>2.46</td>
</tr>
<tr>
<td>Mildly: 67</td>
<td>1.13</td>
<td>0.55-2.29</td>
<td>0.74</td>
<td>1.57</td>
<td>0.67-3.65</td>
<td>0.30</td>
<td>1.33</td>
</tr>
<tr>
<td>Age (still at school)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;8</td>
<td>20</td>
<td>Ref.</td>
<td>Ref.</td>
<td>Ref.</td>
<td>50.00</td>
<td>50.00</td>
<td>0.31</td>
</tr>
<tr>
<td>8-13</td>
<td>32</td>
<td>1.53</td>
<td>0.46-5.04</td>
<td>0.48</td>
<td>1.46</td>
<td>0.39-5.40</td>
<td>0.57</td>
</tr>
<tr>
<td>13+ still at school</td>
<td>39</td>
<td>1.48</td>
<td>0.48-4.53</td>
<td>0.49</td>
<td>2.25</td>
<td>0.59-8.88</td>
<td>0.24</td>
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<tr>
<td>Age (post school)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent home</td>
<td>54</td>
<td>Ref.</td>
<td>Ref.</td>
<td>Ref.</td>
<td>14.29</td>
<td>85.71</td>
<td>0.35</td>
</tr>
<tr>
<td>Group home HOSTEL</td>
<td>37</td>
<td>1.52</td>
<td>0.59-3.89</td>
<td>0.38</td>
<td>1.32</td>
<td>0.41-4.28</td>
<td>0.65</td>
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<tr>
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<td>0.97-5.24</td>
<td>0.06</td>
<td>1.98</td>
<td>0.75-5.26</td>
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<td>32</td>
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<td>0.49-2.98</td>
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<td>2.29</td>
<td>0.74-7.08</td>
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<tr>
<td>Father ANZSC0</td>
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<tr>
<td>Primary or Some high school</td>
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<td>Ref.</td>
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<td>1.35</td>
<td>0.40-4.57</td>
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<td>0.79-5.65</td>
<td>0.14</td>
<td>2.02</td>
<td>0.60-6.83</td>
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<td>0.66-7.04</td>
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Table II. (continued)

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<th>Categorical Predictors</th>
<th>n (%)</th>
<th>OR</th>
<th>CI</th>
<th>p-value</th>
<th>OR</th>
<th>CI</th>
<th>p-value</th>
<th>OR</th>
<th>CI</th>
<th>p-value</th>
<th>Low %</th>
<th>High %</th>
<th>p-value</th>
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<td></td>
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<td>Major cities</td>
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<td>Ref.</td>
<td>Ref.</td>
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<td>94.12</td>
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<td>Inner regional</td>
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<td>0.85</td>
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<td>0.49-3.43</td>
<td>0.60</td>
<td>8.33</td>
<td>91.67</td>
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<td>0.64</td>
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<td>5.00</td>
<td>100.00</td>
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<tr>
<td>Family spending</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>We cannot save</td>
<td>54</td>
<td>Ref.</td>
<td>Ref.</td>
<td>Ref.</td>
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<td></td>
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<td></td>
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<td></td>
<td>12.50</td>
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</tr>
<tr>
<td>Some left over each week but we spend it</td>
<td>7</td>
<td>1.77</td>
<td>0.30-10.57</td>
<td>0.53</td>
<td>1.63</td>
<td>0.19-17.24</td>
<td>0.69</td>
<td>b</td>
<td></td>
<td>0.00</td>
<td>100.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We can save</td>
<td>75</td>
<td>1.73</td>
<td>0.82-3.65</td>
<td>0.15</td>
<td>1.39</td>
<td>0.56-8.48</td>
<td>0.48</td>
<td>1.76</td>
<td>0.69-5.1</td>
<td>0.24</td>
<td>0.00</td>
<td>100.00</td>
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<tr>
<td>Continuous Predictors</td>
<td>Mean (SD)</td>
<td>OR</td>
<td>CI</td>
<td>p-value</td>
<td>OR</td>
<td>CI</td>
<td>p-value</td>
<td>OR</td>
<td>CI</td>
<td>p-value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Mood behaviours</td>
<td>8.0 (4.5)</td>
<td>0.95</td>
<td>0.81-1.02</td>
<td>0.19</td>
<td>0.97</td>
<td>0.80-1.06</td>
<td>0.46</td>
<td>1.02</td>
<td>0.93-1.13</td>
<td>0.67</td>
<td>0.64</td>
<td>0.39-1.06</td>
<td>0.08</td>
</tr>
<tr>
<td>Fear and Anxiety behaviours</td>
<td>4.0 (2.1)</td>
<td>0.98</td>
<td>0.85-1.14</td>
<td>0.80</td>
<td>0.99</td>
<td>0.84-1.18</td>
<td>0.95</td>
<td>1.09</td>
<td>0.89-1.33</td>
<td>0.39</td>
<td>0.64</td>
<td>0.28-1.50</td>
<td>0.31</td>
</tr>
<tr>
<td>Functional independence</td>
<td>29.6 (14.6)</td>
<td>1.00</td>
<td>0.98-1.02</td>
<td>0.91</td>
<td>1.01</td>
<td>0.98-1.04</td>
<td>0.60</td>
<td>1.00</td>
<td>0.97-1.04</td>
<td>0.84</td>
<td>1.01</td>
<td>0.89-1.14</td>
<td>0.94</td>
</tr>
<tr>
<td>Parent Mental Health</td>
<td>39.8 (10.1)</td>
<td>1.00</td>
<td>0.97-1.04</td>
<td>0.98</td>
<td>1.03</td>
<td>0.98-1.08</td>
<td>0.23</td>
<td>0.99</td>
<td>0.94-1.03</td>
<td>0.62</td>
<td>1.00</td>
<td>0.81-1.24</td>
<td>0.57</td>
</tr>
<tr>
<td>Parent Official Physical Health</td>
<td>40.0 (9.1)</td>
<td>1.00</td>
<td>0.97-1.04</td>
<td>0.91</td>
<td>0.99</td>
<td>0.94-1.04</td>
<td>0.83</td>
<td>1.00</td>
<td>0.95-1.06</td>
<td>0.87</td>
<td>1.20</td>
<td>0.89-1.62</td>
<td>0.23</td>
</tr>
<tr>
<td>Community support</td>
<td>2.6 (0.8)</td>
<td>1.20</td>
<td>0.76-1.88</td>
<td>0.44</td>
<td>0.86</td>
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<td>0.76-2.35</td>
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<td>1.80</td>
<td>0.98-4.08</td>
<td>0.71</td>
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<tr>
<td>Parent available time</td>
<td>1.5 (0.5)</td>
<td>1.17</td>
<td>0.55-2.49</td>
<td>0.69</td>
<td>0.91</td>
<td>0.35-2.38</td>
<td>0.84</td>
<td>1.07</td>
<td>0.39-2.95</td>
<td>0.89</td>
<td>1.03</td>
<td>0.98-3.87</td>
<td>0.99</td>
</tr>
</tbody>
</table>

* Due to the small sample in self-improvement activities (n=32), a Fisher's exact test was used for the analysis instead of logistic regression; b Due to the small sample (n=7), unable to analyse this category with logistic regression; c Only girls and women living with parents were included in analysis.
Community participation for girls and women with Rett syndrome

Table III. Univariate relationships between impairment, personal and environmental factors and involvement with family and carer.

<table>
<thead>
<tr>
<th>Categorical predictor</th>
<th>Participates with in the activity (n=182)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>(Carer / No Carer)</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
</tr>
<tr>
<td>Mobility</td>
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</tr>
<tr>
<td>Dependent/Weight bear</td>
<td>77 (42.3%)</td>
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<tr>
<td>Severely restricted</td>
<td>38 (20.9%)</td>
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<tr>
<td>Mildly restricted</td>
<td>67 (36.8%)</td>
</tr>
<tr>
<td>Age (still at school)</td>
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</tr>
<tr>
<td>&lt; 8</td>
<td>20 (22.0%)</td>
</tr>
<tr>
<td>8 &lt; 13</td>
<td>32 (25.2%)</td>
</tr>
<tr>
<td>13 &lt; still at school</td>
<td>39 (42.9%)</td>
</tr>
<tr>
<td>Age (post school)</td>
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</tr>
<tr>
<td>Parent home</td>
<td>54 (59.3%)</td>
</tr>
<tr>
<td>Group home</td>
<td>37 (40.7%)</td>
</tr>
<tr>
<td>Mother ANZSCO *</td>
<td></td>
</tr>
<tr>
<td>Homemaker/Unemployed/Retired</td>
<td>61 (43.6%)</td>
</tr>
<tr>
<td>Clerk/Trades</td>
<td>47 (33.6%)</td>
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<tr>
<td>Manager/professional</td>
<td>32 (22.9%)</td>
</tr>
<tr>
<td>Father ANZSCO *</td>
<td></td>
</tr>
<tr>
<td>Homemaker/Unemployed/Retired</td>
<td>20 (16.4%)</td>
</tr>
<tr>
<td>Clerk/Trades</td>
<td>47 (38.5%)</td>
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<tr>
<td>Manager/professional</td>
<td>55 (45.1%)</td>
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<tr>
<td>Maternal education *</td>
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<tr>
<td>Primary or Some high school</td>
<td>30 (21.1%)</td>
</tr>
<tr>
<td>High school year 12</td>
<td>35 (24.7%)</td>
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<tr>
<td>University degree</td>
<td>38 (26.8%)</td>
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<tr>
<td>ARIA</td>
<td></td>
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<tr>
<td>Major cities</td>
<td>134 (68.1%)</td>
</tr>
<tr>
<td>Inner regional</td>
<td>38 (20.9%)</td>
</tr>
<tr>
<td>Very remote/Remote/Outer</td>
<td>20 (11.0%)</td>
</tr>
<tr>
<td>Family spending *</td>
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</tr>
<tr>
<td>We cannot save</td>
<td>54 (39.7%)</td>
</tr>
<tr>
<td>Some left over each week but we spend it</td>
<td>7 (5.2%)</td>
</tr>
<tr>
<td>We can save</td>
<td>75 (55.2%)</td>
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</table>
Community participation for girls and women with Rett syndrome 58

Table III. (continued)

<table>
<thead>
<tr>
<th>Continuous Predictors</th>
<th>(Carer / No Carer)</th>
<th>(Family / No family)</th>
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<tr>
<td></td>
<td>n (%) OR CI p-value</td>
<td>OR CI p-value</td>
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<tr>
<td>General Mood behaviors</td>
<td>8.0 (4.5) 1.01 0.95-1.07 0.71 0.99 0.94-1.04 0.70</td>
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<tr>
<td>Fear and Anxiety behaviours</td>
<td>4.0 (2.1) 0.93 0.83-1.05 0.24 1.06 0.95-1.18 0.31</td>
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<tr>
<td>Functional independence</td>
<td>29.6 (14.6) 1.01 0.99-1.02 0.58 0.99 0.98-1.01 0.54</td>
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</tr>
<tr>
<td>Parent Mental Health *</td>
<td>39.8 (10.1) 1.01 0.99-1.04 0.31 0.99 0.97-1.02 0.51</td>
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</tr>
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<td>Parental Physical Health *</td>
<td>40.0 (9.1) 0.99 0.96-1.03 0.70 1.00 0.97-1.03 0.87</td>
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</tr>
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<td>Community support *</td>
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</tr>
<tr>
<td>Parent available time *</td>
<td>1.5 (0.5) 0.93 0.50-1.73 0.82 1.08 0.60-1.95 0.79</td>
<td></td>
</tr>
</tbody>
</table>

* Only girls and women living with parents were included in analysis.
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For research report only

Journal of Disability and Rehabilitation
Journal guidelines

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Included below are examples. If you have any questions, please contact the Editor.

Example 1: Leprosy
• Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
• Reconstructive surgery is a technique available to this group.
• In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis
• Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
• People with MS have complex reasons for choosing to exercise or not.
• Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

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• Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
• CBR needs to be „owned” by those involved and subject to re-interpretation to be effective in other cultures.
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Method Describe the design, and methodological procedures adopted.
Results Present the main results.
Conclusions State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation.

The abstract should not exceed 200 words.

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