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Title Investigating the participation of children with autism across home and community: A longitudinal study.

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Abstract

Background

The World Health Organisation recognises that meaningful participation in one's community empowers individuals. Children and adolescents on the autism spectrum consistently report lower participation than their typical peers in activities and this appears to continue into adulthood. The aim of this study was to investigate the participation of children on the autism spectrum over a 3-year period across home, school, and community.

Method

Caregivers of 84 participants aged 9 – 10 years at Year 1 completed the Participation and Environment Measure for Children and Youth (PEM-CY) at three annual data collection points. The PEM-CY is a 25-question measure of the child's level of involvement in home, school, and community activities. Distribution frequencies were calculated for each time point.

Results

Although participation in the majority of items across home, school and community remained stable, the longitudinal data suggests that children change the types of socialising activities across time. Over the 3 years there was a decline in physical activity (both organised and unstructured) and in participation in school activities.

Conclusion

This decline in participation as children move into adolescence is concerning. Further, reduced participation at this phase of development may potentially limit future participation

opportunities throughout adolescence and into adulthood. Further exploration of the participation trajectories of children on the autism spectrum is needed.

Key messages

- Participation in activities is related to a person's health and well being
- Investigation of participation patterns in children on the autism spectrum report changes across time
- Over a three-year period, there was a decrease in the frequency of participation in physical activities and a shift in participation in types of socialising activities
- Reduced participation over time may limit opportunities to contribute to decisions affecting personal well-being.

Introduction

Participation in life activities is viewed as important for a person's long-term health and well-being (World Health Organization, 2007). Participation is viewed as a multidimensional construct with attendance and involvement identified as the key elements (Imms et al., 2016; Imms et al., 2017). Comparative research exploring the participation patterns in children who do and do not have a diagnosis on the autism spectrum repeatedly report lower participation patterns in children and youth on the autism spectrum and this appears consistent across time (Askari et al., 2014; Egilson, Jakobsdóttir, & Ólafsdóttir, 2017a; Taheri, Perry, & Minnes, 2016). Emerging findings suggest participation in life activities may not only be quantitatively but also qualitatively different for children on the autism spectrum.

Comparative studies have identified qualitative differences in participation patterns of children on the autism spectrum and their non-autistic peers. For example, children are more involved in computer and video games than their peers (Egilson, Jakobsdóttir, and Ólafsdóttir (2017b) but participate less in social media or socially interactive video games (Mazurek & Wenstrup, 2013). Differences in participation patterns have also been reported in school activities, with children on the autism spectrum as involved as their peers in activities with less social demands although they frequented these activities more often (Falkmer, Oehlers, Granlund, & Falkmer, 2015). These differences may be associated with the characteristic differences in social communication, and restricted and repetitive patterns of behaviours and interests in autism (American Psychiatric Association, 2013) interacting with the environment to create differences or challenges in desire or ability to participate in activities. In general, research has suggested that more frequent participation in a more diverse range of activities is a better or a more desirable outcome. However, research is needed to determine whether this is also the case for children on the autism spectrum. Research into the specific nature of participation for children on the autism spectrum and how this may change over time could offer useful insights.

Cross-sectional studies with children on the autism spectrum at multiple ages have provided some insight into potential developmental trajectories of participation. Simpson,

Keen, Adams, Alston-Knox, and Roberts (2018) identified specific differences in participation patterns in two age cohorts (5, and 9 – 10 years). Parents reported higher frequency and involvement trends in indoor play activities in younger children, and in socialising using technology in older children. Older children more frequently participated in jobs/chore activities and organised skill activities. In a large population study, Ratcliff, Hong, and Hilton (2018) investigated leisure participation trajectories in children on the autism spectrum ($n = 823$) and children who did not have a diagnosis on the autism spectrum ($n = 34,457$) in five age cohorts (6 – 17 years). There was a shift in participation levels around 11 years of age with adolescents on the autism spectrum (11-17 years) reporting significantly lower levels of participation compared to their non-autistic peers in physical activities, jobs and chores, and skill activities, but no significant difference in participation levels on recreational activities. Interestingly, participation in social activities remained stable in children aged 6 – 15 years with a significant decrease only reported in 16 – 17-year-olds on the autism spectrum. This increased disparity in leisure participation in children and youth on the autism spectrum as they age appears to continue into adulthood (Myers, Davis, Stobbe, & Bjornson, 2015).

To date, research findings from cross-sectional studies have indicated disparity in participation for individuals on the autism spectrum compared to their peers. Little is known about the trajectory of participation across time and settings and what is known is drawn from studies comparing multiple age groups at a single point in time. This is a significant limitation, as participation is influenced by personal and external factors, both of which are very sensitive to cohort effects inherent in cross-sectional studies. Exploring longitudinal participation trajectories in individuals controls for some of these issues. The study reported here investigates the participation (measured by frequency and involvement) in activities of children on the autism spectrum over a 3-year period (Y1, Y2, Y3) across home, school, and community. The specific research question that was posed was:

1. Does the participation of children on the autism spectrum fluctuate in the home, school, and/or community across a 3-year period?

Method

Data used in this study were drawn from <removed for blind review>, a cross-sequential cohort study focusing on child participation and educational outcomes for children on the autism spectrum. The full recruitment procedure for the larger study is described in <removed for blind review>. Briefly, parents or caregivers of children on the autism spectrum aged 4 – 5 or 9 – 10 years were recruited through clinics and social media advertisements. Once enrolled, they were invited to complete an annual questionnaire pack. Data from Y1 have been reported <removed for blind review>; however, this study reports on a smaller subsample of children from the older cohort only, who have participation data across the first 3 years of the sequential study. Ethical approval for this study was obtained from participating universities and health authorities.

Participants

Participants were selected for this study from the older cohort of the larger cross-sequential sample if they met the following two criteria: (a) a confirmed community diagnosis of autism or a score above the cut-off of ≥ 15 on the Lifetime Social Communication Questionnaire (SCQ; Rutter, Bailey, Berument, Lord, & Pickles, 2003); and (b) completed at least 75% of the PEM-CY questions (see measures) at all three data collection points. This resulted in 84 participants; demographics of both children and their caregivers from initial data collection point (Y1) are shown in Table 1. There were no significant differences between participants included in this sample and those who did not meet the inclusion criteria on child gender ($\chi^2(1, n = 133) = .02, p = .89, \phi = -.012$), medical condition ($\chi^2(1, n = 130) = .001, p = .98, \phi = .002$), caregiver age ($U = 1960, p = .61$), caregiver education ($U = 1861, p = .41$), and family income ($U = 1704, p = .14$).

<Table 1. *Child and Caregiver Characteristics at Y1* goes about here>

Age range and mean for the children at each data collection point was Y1 (*M*age 119.17 months, *SD* 7.62 months), Y2 (*M*age 132.92 months, *SD* 6.58 months), and Y3 (*M*age 144.65 months, *SD* 7.75 months).

The child ratio of males to females was 3.7:1, which reflects a slightly higher proportion of males than that expected, given recently published rates of approximately 3.3:1 (Loomes, Hull, & Mandy, 2017). In addition, more than 50% of children had another medical condition or disability, including attention deficit hyperactivity disorder ($n = 23$, 27.4%), anxiety ($n = 7$, 8%), asthma and allergies ($n = 4$, 4.7%), and epilepsy ($n = 2$, 2.4%). The questionnaires were completed predominantly by mothers. The majority of caregivers had a tertiary education, and more than half reported a family income above \$80,000. For reference, the 2016 Australian Census reported the median Australian annual family income to be AUD \$90,168.

Participation measure

Caregivers completed the PEM-CY (Coster et al., 2011) at three annual data collection time points. The PEM-CY is a caregiver-report measure of participation and environment of children and youth and includes 25 questions about participation in activities across home (10 items), school (5 items), and community (10 items). Caregivers rate the frequency of participation on an 8-point scale (from *never* = 0 to *daily* = 7), and level of involvement on a 5-point scale (*minimally involved* = 1 to *very involved* = 5). If caregivers rated a 0 (*never*) for frequency, they did not provide a rating on the involvement scale. Questions on caregivers' desire for change and environment were not considered for this study. Test-retest reliability is reported to be moderate for the school setting (0.58), and good for home and community (0.84 and 0.79 respectively) (Coster et al., 2011). In the current study the Cronbach alpha coefficient for attending was reported across time (Y1, Y2, Y3) for home (.70, .66, .69), school (.42, .38, .28), and community (.61, .60, .65).

Data analysis

Data were explored using R Statistical Software. The skew or kurtosis did not reflect a normal distribution. To explore the data over time, median and quartile graphs were used to illustrate the distribution of scores across each item.

Results

Distribution frequencies for each PEM-CY item, at each time point, are presented for home (Figure 1), school (Figure 2), and community (Figure 3). The median score for each item is illustrated with a dot. This value represents the score which has 50% of the data both above and below it. The solid line represents the middle 20% of the data (quantiles 40% and 60%). On occasion, the median may coincide with one or both quantiles. In such a case, the line will be non-symmetrical about the median or obscured completely. These situations represent data that are heavily distributed around a particular score. The dashed lines represent the interquartile range, which is the middle 50% of the data (quantiles 25% and 75%). As with the previous solid segment, it can be obscured by the median or middle 20% quartile range in cases of high data distribution around a particular score. The fine dotted line represents the 95% range over which all scores are distributed.

<Figure1 goes about here>

<Figure2 goes about here>

<Figure3 goes about here>

Home participation (Figure 1)

All home items across Y1, Y2, Y3 were completed 96% of the participants. Across time, there was a relatively stable pattern of frequency for home activities with slight differences in median values between time periods. In Y2 there was an increase in median value on “Indoor play and games” to daily ($Mdn = 7$), and a decrease in median value on “school preparation”

to a few times a week ($Mdn = 6$). In Y3, “getting together with other people” decreased on median frequency ($Mdn = 6$), while “socialising using technology” increased on median frequency to at least once a week ($Mdn = 5$) when compared with a few times a month in both Y1 and Y2 ($Mdn = 4$). In Y3, median values for involvement increased for “personal care” ($Mdn = 4$) and “school preparation” ($Mdn = 3$) and there was less spread of involvement on “homework”. At each time period, children were reported to attend daily ($Mdn = 7$) and be very involved ($Mdn = 5$) in “computer and video games” and “watching TV, videos, and DVDs”.

School participation (Figure 2)

Between 75 – 80% of the participants completed all items within the school subscale across Y1 - Y3. Based on the median frequency, there was an overall tendency for children to “attend school” daily ($Mdn = 7$) and to be “somewhat involved” ($Mdn = 3$) and to never participate in “special roles at school” ($Mdn = 0$). The children who participated in “special roles at school” were most involved at Y2 ($Mdn = 4$). Fewer children frequented “school teams, clubs and organisations” at Y2 and Y3 ($Mdn = 0$); however, they were more involved at Y2 ($Mdn = 4$) compared with Y1 ($Mdn = 3$) and Y3 ($Mdn = 3$). This increased involvement at Y2 was also reported on “field trips and school events” ($Mdn = 4$). Y3 “get together with peers outside of class” decreased on median frequency ($Mdn = 6$) with children being more involved in this item at Y3 ($Mdn = 4$) compared with Y1 and Y2 (both $Mdn = 3$).

Community participation (Figure 3)

At least 90% of the participants completed all the community items across the three time periods. Across time, parents reported a low frequency score ($Mdn = 0$) on “classes and lessons”, “organisations, groups, clubs, and volunteer or leadership activities”, “religious or spiritual gatherings”, and “working for pay”. There was a change in the proportion of children involved in “classes and lessons” across Y1, Y2, and Y3 (31%, 28%, 41%), with at least 50% of children frequenting these activities being more than somewhat involved ($Mdn = 4$). Across time, children most often frequented ($Mdn = 5$) and were somewhat involved ($Mdn = 3$) in “neighbourhood outings”. In Y3, there was a decrease in children’s reported

participation in “unstructured physical activities” on both median frequency (*Mdn* = 4) and median involvement (*Mdn* = 4). Across Y1, Y2, and Y3 there was a change in the proportion of children attending “organised physical activities” (74%, 58%, 49% respectively); however, there was an increase in involvement with over 60% of children in Y3 being at least somewhat involved in the activity, compared with 50% at Y1.

Discussion

This is the first study, to our knowledge, to document the longitudinal participation patterns of children (9 – 12 years) on the autism spectrum across home, school, and community using the PEM-CY. Longitudinal methodology, such as that employed within this study, reduces the potential personal and social cohort biases that can easily influence patterns of participation. The participation profiles of children on the autism spectrum over the 3-year period changes in specific items across contexts, particularly socialising and physical activity related items.

Socialising

Children at Y3 reported to get together with other people across contexts less frequently than reported at Y1 and Y2. This decline with increasing age in overall social participation is in contrast with the findings from Ratcliff et al. (2018) who reported a generally stable pattern of social activities participation between ages 6 – 15 years. Ratcliff et al.’s findings were based on a composite score and as such may not have reflected participation changes within types of social activities as reported in this study. They did, however, conduct further analysis on the social item “clubs/organisations after school” and, when controlling for personal and environmental factors, found participation levels only dropped significantly in 16 – 17-year-olds on the spectrum. In contrast, findings from this study identified low levels of participation (<20%) on this item across the three time periods, with the majority of children never attending this activity. These results highlight that, even at a young age, some children on the autism spectrum do not participate in organised social activities, which may be influenced by personal or environmental factors.

There were two social activities where participation appeared to increase with age. There was an increase in attending “overnight visits or trips” (Community: Y2, Y3), possibly due to older children having more opportunities to participate in these activities, and an increased frequency and involvement on “socialising using technology” (Home: Y3). The increase in socialising using technology is not surprising, as this appears to be consistent with teen behaviour (Mazurek & Wenstrup, 2013). Whilst some research has suggested that socialising using technology may reduce the anxiety of face-to-face interactions, emerging research has highlighted that socialising using technologies may create unique anxieties related to their online experience (van Schalkwyk et al., 2017). This highlights the importance of exploring activities in terms of their unique barriers and facilitators to fully understand the experience of participation for individuals on the autism spectrum.

Physical activities

The decline in participation in physical activities (organised and unstructured) with age is consistent with previous research on children on the autism spectrum (Jones et al., 2017; Ratcliff et al., 2018) and their typically developing peers (Dumith, Gigante, Domingues, & Kohl, 2011). There was a decrease in the number of children involved in organised physical activities from Y1 ($n = 51$; 60.7%) to Y3 ($n = 39$; 46.4%). The nature and culture of group and team programs has been identified as a restricting influence on the involvement of children on the autism spectrum in organised activities (see review by Askari et al., 2014). By Y3 the median frequency for attending organised physical activities had decreased to *never* and unstructured physical activities decreased to *a few times a month*. The decrease in participation is more commonly reported in older children (Dumith et al., 2011; Jones et al., 2017) and raises concerns for the long-term physical activity and health of children on the spectrum.

School participation

Across Y1-Y3, children were reported to be only *somewhat involved* in classroom activities. This appears to be consistent with involvement levels of younger children (5 years) on the

autism spectrum (Simpson et al., 2018), but lower than involvement levels reported for children with disabilities and children who are developing typically (Coster et al., 2013). Furthermore, the decrease in internal consistency on the school subscale would suggest a disparity in the school experiences for children on the autism spectrum as they develop. This may be influenced not only by the heterogeneity of the child population but also by the availability of opportunities to attend activities in the school context. The results also need considering in relation to school trajectories; in Y2 there was an increase in reported involvement in “special roles at school”, “school teams, clubs and organisations”, and “field trips and school events”, which for many children, would have coincided with their last year of primary school where involvement in special roles and school activities is promoted.

Limitations and future research

Participation is a multicomponent construct and although this study reported on attendance and involvement it did not address factors which may have influenced levels of participation. Furthermore, information was caregiver reported and involvement, a subjective experience, may not be easily observed. Exploring participation from the child’s perspective and investigating personal and external influences on participation would further add to the understanding of how to support meaningful participation.

The data were collected over three time points across a 3-year period. In at least one time point, more than 20% of participants did not provide data for the school component. The reason for this is not clear but parents may feel less able to report what happens at school than at home where they can directly observe their child. Regardless, given the difficulties that children on the spectrum often encounter at school (Roberts & Simpson, 2016), it is recommended that future studies consider ways of increasing parent reporting.

Conclusion

This is the first longitudinal study to explore the participation trajectories of children on the autism spectrum during the important developmental period of approaching and entering adolescence as well as moving from primary to secondary education. The item-level analysis contributes to the literature by revealing specific patterns of changes over time

across home, school, and community. Studying participation behaviours over a longer period would further understanding of participation trajectories of children on the autism spectrum and factors associated with participation patterns across time.

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Table 1*Child and Caregiver Characteristics at Y1*

Demographic variables	<i>N</i> = 84 <i>N</i> (%)
Child gender	
Male	66 (78.6)
Other Medical condition/disability (based on carer report)	48 (57.1)
English language spoken at home	84 (100)
Caregiver's relationship to the child	
Mother	71 (84.5)
Father	11 (13.1)
Missing	1 (1.2)
Caregiver's age	
31 – 40 years	37 (44.0)
41 – 50 years	44 (52.4)
>51 years	3 (3.6)
Caregiver's highest level of education	
No formal/Primary school	1 (1.2)
Secondary school	22 (26.2)
Tertiary education	60 (71.4)
Missing	1 (1.2)
Annual family income	
<\$18,200	2 (2.4)
\$18,201–\$37,000	5 (6.0)
\$37,001–\$80,000	18 (21.4)
\$80,001–\$180,000	42 (50.0)
>\$180,000	7 (8.3)
Do not wish to respond	10 (11.9)

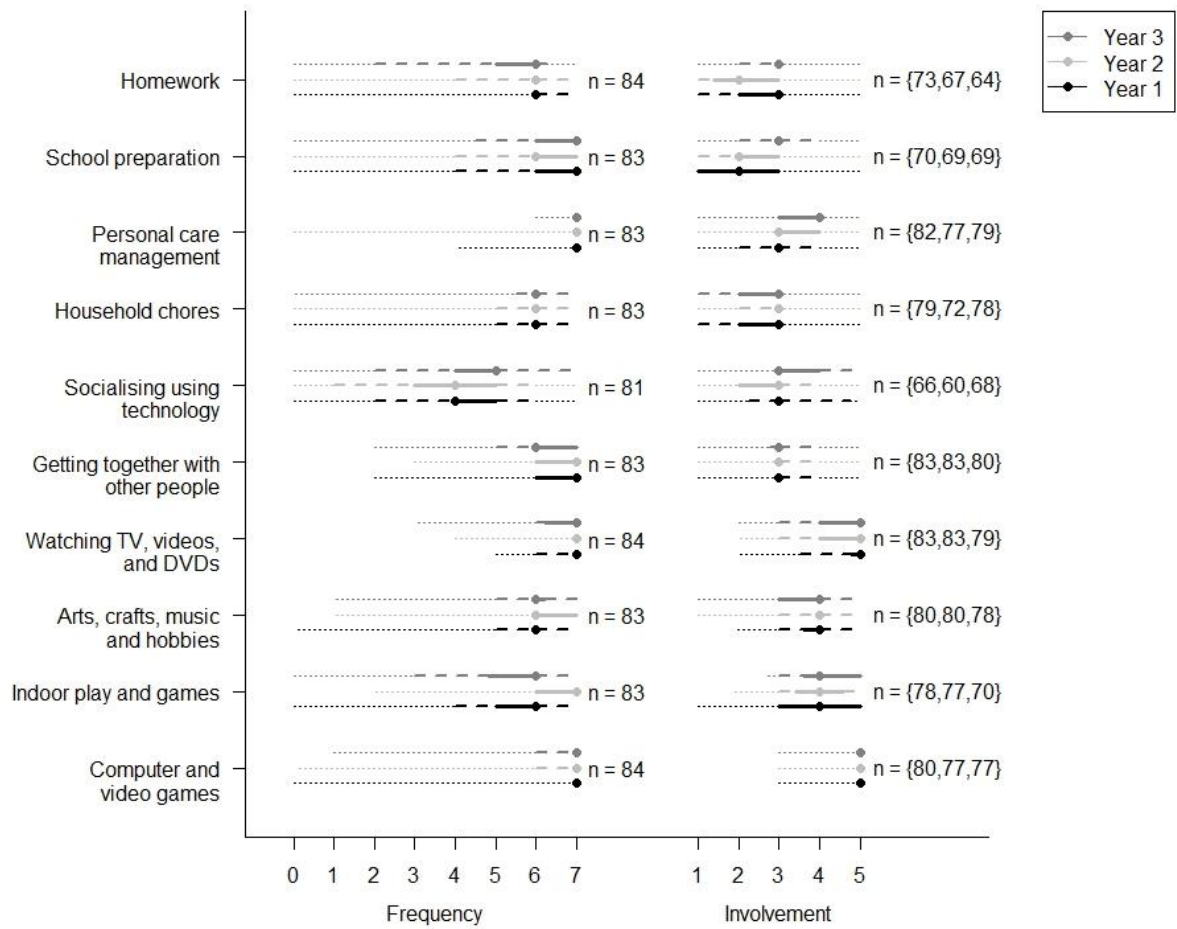


Figure 1. Home participation for Year (1,2,3). Frequency scale 0-7, Involvement scale 1-5

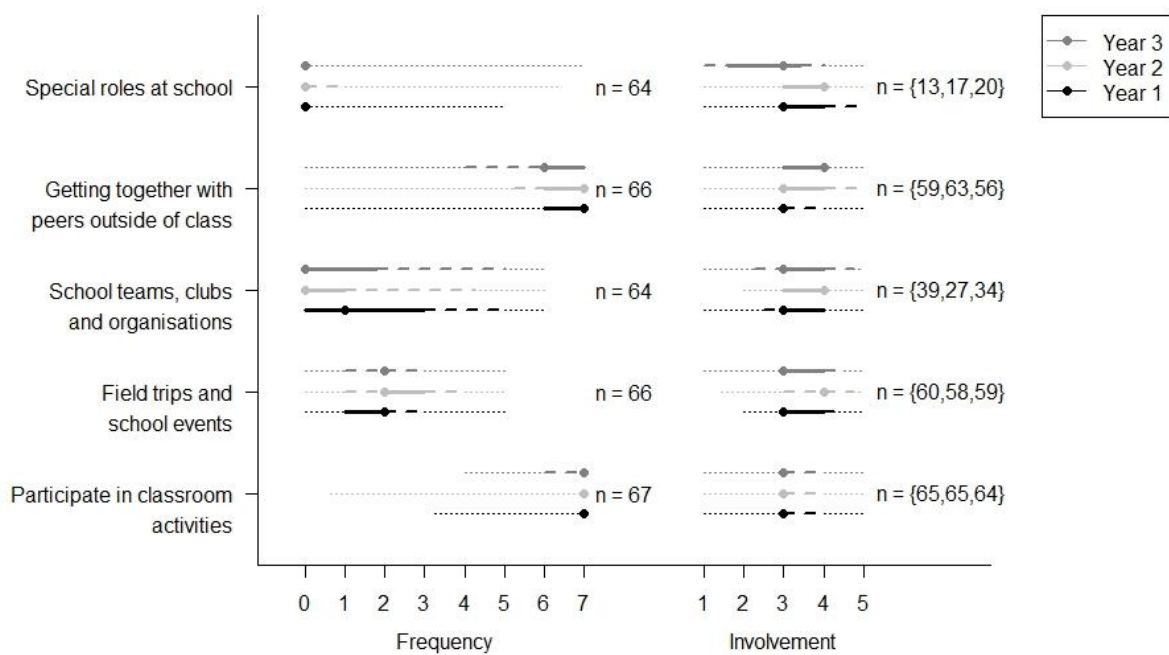


Figure 2. School participation for Year (1,2,3). Frequency scale 0-7, Involvement scale 1-5

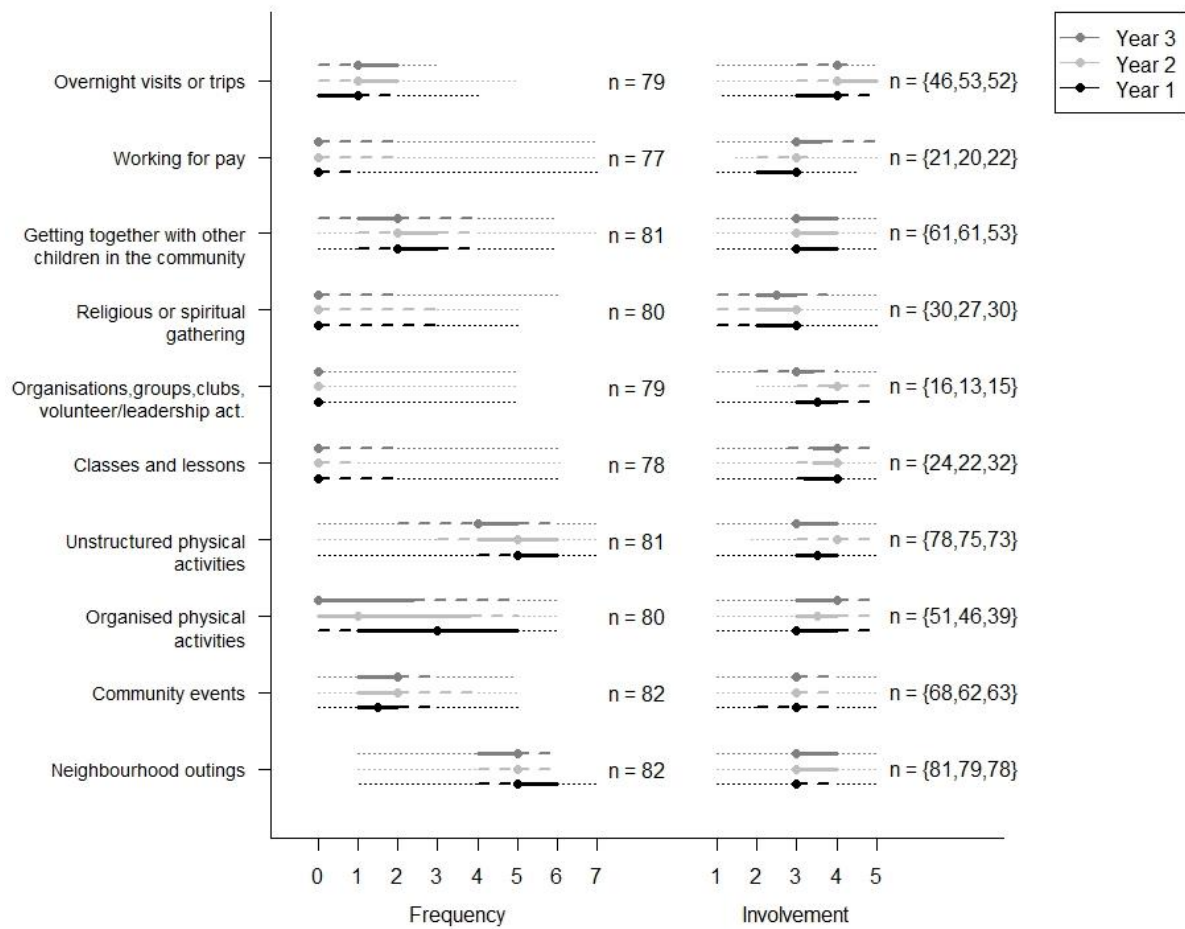


Figure 3. Community participation for Year (1,2,3). Frequency scale 0-7, Involvement scale 1-5