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## Agreement between participation ratings of children with intellectual disabilities and their primary caregivers

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### ABSTRACT

**Background:** Participation of children with ID it is argued must be understood in relation to the fit with the environment. Since caregivers are a vital factor within the close environment of a child with intellectual disability, their perceptions are unequivocally important.

**Aims:** The main aim of this study is to describe the self-reported participation of children with ID and the perceptions of their primary caregivers. Both frequency of attendance and perceived importance of activity was measured with self-reported and proxy-reports.

**Methods & Procedures:** A custom developed Picture my Participation (PmP) survey was utilised in an interview format with children with intellectual disability whilst their primary caregivers completed the survey independently.

**Results:** Overall, the perceptions of children with intellectual disabilities and of primary caregivers showed similarities regarding attendance and activities considered important. On group level, both children and primary caregivers perceived the child to have a high level of attendance of *Formal learning in school*, *Family mealttime*, *Interacting with family* and *Celebrations*. An overall poor agreement in perceived frequency of attendance was found. However, in child-primary caregiver-dyads poor agreement in perceived frequency of attendance was found.

**Conclusions:** While primary caregivers and children's ratings of attendance and selection of the most important activities appeared somewhat similar, there was a noted difference, in that primary caregivers' were uniform in their selection, whilst there was a diversity in the selection of activities amongst children.

### What this paper adds?

Participation, as reported from a child's perspective, is an imperative clinical and research agenda for children with ID. This study provided evidence by describing the self-reported participation of children with ID and the perceptions of their primary caregivers. Participation was measured as frequency of attending activities and prioritised involvement in activities rated as important. Our results showed that children with ID did not report attendance ('being there') or participation in the same way as their caregivers perceived. While primary caregivers and children's selection of the most important activities appeared somewhat similar, children reported greater diversity in their selection. The current study makes an important contribution to the argument for including the self-reported perceptions of children with ID in clinical practice and future research endeavours.

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## 1. Introduction

Participation in everyday activities is important for all children as it provides the context in which to develop new skills, social competence, emotional well-being and cultural awareness, and to pursue an enriched quality of life (Amaral, Drummond, de, Coster, & Mancini, 2014; Axelsson, Granlund, & Wilder, 2013; King, Shields, Imms, Black, & Arden, 2013; Lyngegård, Almqvist, Granlund, & Huus, 2018). Participation is especially important for children who are dependent on others, for example children with an intellectual disability, as they need to be afforded opportunities to develop a sense of belonging within their family. This helps them to build independence in their community life (Law et al., 2013).

Intellectual disability (ID) is a neurodevelopmental condition that originates before 18 years of age and is characterised by limitations in intellectual potential and adaptive behaviours (i.e., difficulties in performing everyday functions expressed in social, conceptual or practical skills) (Arvidsson, Granlund, Thyberg, & Thyberg, 2014). Successful participation of children with ID in various everyday activities is the ultimate health and educational goal (Willis et al., 2016).

Participation is defined by the International Classification of Functioning, Disability and Health (ICF) as one's 'involvement in everyday activities' (World Health Organisation, 2001). Axelsson et al. (2013) however argue that this definition is too broad and vague. To conceptualise participation as a multidimensional construct, Imms et al. (2016) presented a Family of Participation-Related Constructs (fPRC) framework in which participation is operationalised by two key constructs, i.e. attendance and involvement. Attendance is defined as 'being there', and is measured as the frequency and/or the range or diversity of activities in which one takes part. Involvement, on the other hand, refers to the subjective experience of participation while attending activities (Imms et al., 2016).

The fPRC framework extends participation to include participation-related intrinsic person-related concepts (e.g. activity competence, sense of self, preferences) and extrinsic factors (e.g. context and environment). Since involvement entails a group of intrinsic elements that include motivation, affect, persistence, and social connection (Imms et al., 2016), it can be argued that involvement is best measured directly from the responses of children. Eriksson and Granlund (2009, p. 206) mention that participation is "a feeling of belonging and engagement experienced by the individual in relation to being active in a certain context". This definition corresponds with studies that underscore the value of taking the experiences of children with disability into consideration when describing their participation (Arvidsson, 2013; King, Law, Hurley, Petrenchik, & Schwellnus, 2010).

Children with ID are often dependent on their caregivers to express themselves (Oosterhoorn & Kendrick, 2001). In previous studies, the observable aspects of activity attendance – which is easier to gauge – have been reported mainly via children's primary caregivers as proxies (Willis et al., 2016). Moreover, it cannot be inferred that the activities in which children with ID are attending, are those which they necessarily enjoy or perceive to be important (Imms et al., 2016). Accordingly, enjoyment and perceived importance of activities constitutes subjective experiences which may be difficult to be captured by means of family or caregivers' proxy ratings (Adair et al., 2018).

Several researchers concur that understanding participation from a child's perspective through their direct self-reports will provide deeper insight into their own participation and what activities they consider to be important (Arvidsson, 2013; Arvidsson, Granlund, & Thyberg, 2007; Coster & Khetani, 2008; Granlund, 2013; King, 2013; Perenboom & Chorus, 2003; Nilsson et al., 2013). This paradigm of thought is congruent with a child-rights perspective articulated through the United Nations' Convention on the Rights of the Child (CRC), which foregrounds children's right to express themselves in matters that affect their lives (United Nations General Assembly, 1989).

But, as King et al. (2007) posited, participation of children with ID must be understood in relation to the 'person-environment fit'. Since caregivers are a vital factor within the close environment of a child with ID, their perceptions are unequivocally important. Clinically, caregivers' perceptions are imperative since they are not only the principal decision makers of their child with ID, but their perceptions are also more likely to inform the content of interventions designed to promote their child's participation (Bedell, Cohn, & Dumas, 2005; Eriksson & Granlund, 2004; McGarty & Melville, 2018; Milićević & Nedović, 2018). To sum up, participation can be measured from what is observed and rated by others (e.g. proxy reports of caregivers), or from self-reports of children with ID (Falkmer, Parsons, & Granlund, 2012).

There is an emerging trend in research to grasp the unique perceptions of children with disabilities, since they may offer different insights than adult perceptions (Harding et al., 2009; Huus, Granlund, Bornman, & Lyngegård, 2015; Nelson, Masulani-Mwale, Richards, Theobald, & Gladstone, 2017). In a study comparing the perceptions of needs of children and caregivers, Huus et al. (2015) found that children agreed with their caregivers on the more basic needs, e.g. food to eat. However, children's self-reports did not correspond with their caregivers' proxy reports for more complex needs, e.g. friends to play with. The difference in perceptions may also be seen in participation-oriented goal setting, with children reporting social interaction and joy in meaningful activities as goals for intervention, in contrast to caregivers reporting goals related to school task performance (Costa, Brauchle, & Kennedy-Behr, 2016). While the perceptions of children with ID and primary caregivers are equally valid, integrating both perceptions may provide a clearer picture of children's participation (Nilsson et al., 2013).

Despite being an emerging trend, there is still a paucity of research studies that have included the opinions of children with ID. This may be partly due to a lack of participation measures based on the self-ratings of children with ID (Arvidsson et al., 2019). The impetus for the current study is significant as the findings may contribute to the salience of including the voice of children with ID in research and to design interventions that address their participation needs.

The principal aim of this study was to describe the self-reported participation of children with ID and the perceptions of their primary caregivers. We measured self-reported and proxy-reported participation as frequency of attendance and perceived importance.

In order to achieve this aim, the following specific research questions were investigated:

- What is the frequency of attendance of everyday activities as perceived by children with ID and their primary caregivers?
- What do children with ID and their primary caregivers select as the three most important activities they are involved in?

Based on previous literature (Costa et al., 2016; Harding et al., 2009; Huus et al., 2015; Nelson et al., 2017), we hypothesised that (a) there would be a discrepancy in the perceptions of attendance of everyday activities between the child with ID and their caregiver; (b) everyday activities that children with ID considered important would differ from the perceptions of their caregivers in that children would consider activities related to playing and social interaction as most important, while primary caregivers would consider activities related to skills most important.

## 2. Methods

This study formed part of a larger study that uses the Picture my Participation (PmP) instrument to measure children's participation in home, school and community activities. The PmP is an instrument specifically intended to measure participation in children with disability.

### 2.1. Participants

Children with ID and their primary caregivers were invited to participate in the study. Participants were recruited via convenience sampling due to the accessibility of children at a school that caters for children with ID in South Africa and Sweden. Child participants with a chronological age of 7–18 years were selected if they had a diagnosis of mild or moderate ID, and if they were able to speak and understand English or Swedish. Primary caregivers agreed to participate in the study by providing written informed consent for their own and their child's participation in the study, and by completing and returning the PmP instrument through the teacher at their child's school. Written informed parental consent and child assent were received prior to test administration.

### 2.2. Measures used

#### 2.2.1. Demographic information

A demographic questionnaire was used to obtain information about the child's gender and age, as well as the primary caregiver's age, educational level, employment and relationship to the child.

#### 2.2.2. Ten questions screen (TQS)

The Ten Questions Screen (TQS) is a screening tool developed to detect childhood disabilities (Durkin et al., 1995; Mung'ala-Odera et al., 2004). The TQS includes 10 closed questions that screen the child for cognitive, motor and seizure disabilities (Durkin et al., 1995) and has shown good test-retest reliability and interrater agreement (Mung'ala-Odera et al., 2004). In the present study, the TQS was completed by the primary caregiver to describe the level and nature of the child's disabilities.

#### 2.2.3. Picture my participation (PmP)

Picture my Participation (PmP) is a 20-activity item measure of participation in activities at home, school and in the community, developed to measure the subjective perceptions of children between 5 and 21 years of age. Both the Picture My Participation instrument and its manual were developed in English, translated into Swedish and then back-translated into English before being used in this study. It has been found to be valid for children with ID in South Africa and Sweden (Arvidsson et al., 2019). The test-retest reliability of the PmP total scale and at component level has been explored showing a moderate agreement (ICC = 0.5–0.75) in children with ID (Balton, Arvidsson, Granlund, Huus, & Dada, submitted).

The PmP is administered to a child as a picture-supported interview. The interview was supported with pictures for each item and for each scale, and it took approximately 10–20 min to complete with a child. The PmP has four components categorised as (a) organised activities, (b) social activities, (c) family activities, and (d) personal activities (Arvidsson et al., 2019). The PmP also comprises four measurement sections:

- (1) Frequency of attendance for each item, rated on a four-point Likert scale (Never; Not really; Sometimes; Always).
- (2) Selection of the three most important activities according to the child.
- (3) Perceived involvement in these three activities, rated on a three-point Likert scale (Not involved; Somewhat involved; Very involved). In this section, the child is also asked if there is any other activity, besides the provided 20, that they would select as important.
- (4) Evaluation of perceived barriers to and facilitators of participation in relation to the activities that are most important to the child.

For the purposes of the present study, only data from Sections 1 and 2 were used as it was felt that agreement may be more difficult to achieve for ratings on parents and children due to its subjective/internal nature. The barriers and facilitators will be described qualitatively in a separate manuscript in the future. One item – *Employed or unemployed work* – was excluded from the

analysis due to not being relevant to the age ( $M = 12.45$  years) of the participant children; thus, in our study the PmP included in total 19 items. Both child and primary caregiver participants answered the same set of 19 questions; however, the primary caregivers conducted a paper-based, self-administered version of the PmP that provided proxy ratings of their children's participation. Both self-reported and proxy-reported participation was measured as frequency of attendance. Cronbach's alpha for children's self-reports and for the primary caregivers' proxy reports was reported as  $\alpha = .87$  and  $\alpha = .78$  respectively.

### 2.3. Procedure

Ethical approval for the study was obtained from the relevant ethical review boards in South Africa and Sweden (Dnr 2016/544-31). Additionally, permission was obtained from the relevant local departments of education and school principals.

The researchers in the respective countries met with the principals of the schools involved. A survey pack was sent to the children's primary caregivers in a sealed envelope via the classroom teachers. The survey pack comprised the following: (a) letters of consent for the primary caregivers for their own participation in the study as well as for that of their child; (b) the demographic questionnaire; (c) the TQS; and (d) the PmP. The primary caregivers who consented to participate in the study were asked to complete the forms in the survey pack and return them to the school in a sealed envelope.

On the pre-arranged time, the researchers in the respective countries met the children with ID whose primary caregivers had consented to their participation. The researchers comprised the authors and postgraduate student who were trained in conducting the PmP with children with intellectual disabilities. Child participants were interviewed at school or at the after-school facility. The information letter was read to the child again, after which the latter provided confirmation of understanding the information and gave assent to participate. The children used graphic symbols from Picture Communication Symbols (PCS<sup>1</sup>) as a visual support – both during the child assent procedure and as part of the PmP interview. A specific structured interview approach, namely the Talking Mats™ (Murphy & Cameron, 2006), was used together with the PCS. The Talking Mats™ framework is a strategy to facilitate conversations with persons with disabilities, in this instance with children with ID.

The PmP interviews were introduced with three trial items created to facilitate and ensure the children's understanding of the instructions. The children were reassured that there was no right or wrong answer and that their participation in the study was voluntary. For frequency of attendance (Section 1), the children were asked "How often do you participate in daily routines?", while being shown the PCS™ symbol of the specific routine. The child had to place the PCS™ symbol on the mat in the column to indicate which item that they felt best represented their frequency of participation. Because of the difficulties children with ID can have with relating experiences of frequency of attending to specific time period in days, weeks or months (Janeslätt, Granlund, & Kottorp, 2010) the questions was stated as above without specifying a time period. As a consequence the rating must be seen as a measure of the subjective experience of how frequently the child attend an activity. This was made possible by having ratings linked to a more general scale of time: Never; Not really; Sometimes; Always than to a specified time period. The researcher recorded the response on a separate score sheet and then moved on to the next question until all 20 items were completed. Non-contingent feedback was provided.

Thereafter the children were asked to select three activities (from the 19 PmP items) that they considered the most important. Upon selection they were asked to rank these activities from most to least important for themselves. At the end of the interview the children were thanked for their participation and in South Africa the participants were provided with a small token of appreciation.

### 2.4. Statistical analyses

Descriptive statistics were used to summarise the demographic characteristics of the participants and to calculate the frequencies, mean and standard deviation of attendance of the item activities. The proportions of agreements and disagreements in perceived attendance were calculated in 'child primary caregiver' dyads for the four-point scale. Weighted kappa values (K) in frequencies of attendance between the children and the primary caregivers were calculated for the four-point scale. Kappa coefficients of 0.01 indicates "poor" agreement, 0.01 to 0.20 indicate "slight" agreement, 0.21 to 0.40 indicate "fair" agreement, 0.41 to 0.60 indicate "moderate" agreement, 0.61 to 0.80 indicate "substantial" agreement, and 0.81–1.00 indicate "almost perfect" agreement (Landis & Kock, 1977). Frequencies of attendance are presented in percentages. For the two subgroups, children and primary caregivers, the rank order of the 19 items was calculated based on frequencies of the items being rated as one of the three most important to participate in. The relationship in the rank order of important items between the subgroups was calculated by using Spearman's rank order correlations.

## 3. Results

### 3.1. Participants

Altogether 93 children with ID ( $n = 79$  from South Africa,  $n = 20$  from Sweden) and their primary caregivers participated in the study. The response rate was 36 % (South Africa 49 %, Sweden 18 %). The participants were 52 boys and 42 girls, and the children ranged from 7–18 years in age ( $M = 12.45$  years,  $SD = 2.09$ ). On the TQS, the primary caregivers reported their perceptions of their child's learning difficulties to be mild ( $n = 36$ , 36.4 %), moderate ( $n = 33$ , 33.3 %), and severe ( $n = 8$ , 8.1 %). Most children were perceived to understand spoken language and to speak with understandable words. Although two thirds of the children were perceived to be age appropriate in learning, about one half of the children were perceived by their caregivers as cognitively slow

**Table 1**  
Sociodemographic data for children (N = 93) and primary caregivers (N = 86).

|   |   |                   |      |
|---|---|-------------------|------|
| Gender (n = 88)                             | Boys (%)  | 58                |      |
| Age (n = 88)                                | Md (SD)   | 12.53 (2.08)      |      |
|   | Range (Y)   | 7-18              |      |
|   | South Africa/Sweden (n)                             | 73 / 20           |      |
| Country                                     | Mild (%)  | 36.6              |      |
|   | Moderate (%)  | 35.5              |      |
|   | Severe (%)  | 8.6               |      |
| Ten Question Questionnaire (n = 93)         | Delays in sitting, standing, walking                | 34.4              |      |
|   | Vision problems                                     | 11.8              |      |
|   | Hearing difficulties                                | 5.4               |      |
|   | Understanding of spoken language                    | 72.0              |      |
|   | Problems in motor functions                         | 20.4              |      |
|   | Having fits, becoming rigid or losing consciousness | 15.1              |      |
|   | Age-appropriate learning                            | 62.4              |      |
|   | Speaking with understandable words                  | 77.4              |      |
|   | Able to name an object                              | 34.3              |      |
|   | Cognitively slow                                    | 57.0              |      |
|   | Primary caregivers (n = 83)                         | Father            | 12.9 |
|   |   | Mother            | 65.6 |
|   |   | Grandmother       | 1.1  |
|   |   | Mother and father | 2.2  |
| Other                                       |   | 6.5               |      |
| Missing (n)                                 |   | 10                |      |
| Highest educational level<br>Woman (n = 71) | Grade 10 or lower                                   | 23.7              |      |
|   | Grade 12  | 17.2              |      |
|   | Diploma   | 19.4              |      |
|   | Bachelor's degree                                   | 8.6               |      |
|   | Postgraduate degree                                 | 7.5               |      |
| Man (n = 24)                                | Grade 10 or lower                                   | 4.3               |      |
|   | Grade 12  | 7.5               |      |
|   | Diploma   | 7.5               |      |
|   | Bachelor's degree                                   | 5.4               |      |
|   | Postgraduate degree                                 | 1.1               |      |
| Work status (n = 82)                        | Full time   | 43.0              |      |
|   | Part time   | 18.3              |      |
|   | Unemployed  | 24.7              |      |
|   | Studying  | 1.1               |      |
|   | Other   | 1.1               |      |

Note: The TSQ is presented as the primary caregivers' proportion (%) of positive answers to question.

(n = 50, 54.5 %). The primary caregivers' survey was answered by mothers (n = 63), fathers (n = 13), mother and father (n = 2), grandmother (n = 1) or other (n = 6), and their age ranged from 31 to 61 years (M = 43.9 years, SD = 7.58). About one half of the mothers had an educational level of 12 years or more. Most primary caregivers (59 %) worked full time or part time, while about 20 % were unemployed. Nine primary caregivers had missing data in all items of the PmP and were therefore excluded from further analysis. [Table 1](#) illustrates the demographic information of the participants.

### 3.2. PmP

#### 3.2.1. What is the frequency of attendance of everyday activities as perceived by children with intellectual disability and their primary caregivers?

The agreement between children and primary caregivers in South Africa and Sweden respectively was compared showing a difference only in the item Spiritual activities. In South Africa 24.1 % of the child-primary caregiver dyads agreed on the item while in Sweden 50 % of the dyads agreed. The weighted kappa value for South Africa was  $K = 0.04$  ( $p = 0.63$ ) while the level of agreement for Sweden showed a fair agreement ( $K = 0.22$ ,  $p = 0.003$ ).

Results about the perceptions of children with ID and their primary caregivers in terms of frequency of attendance of everyday activities are presented in [Table 2](#). The children's perceptions of attendance were distributed along all the points of the Lickert scale. Most children reported that they always participated in personal care activities (71 %,  $m = 3.62$ ,  $SD = 0.67$ ), school (61.3 %,  $m = 3.45$ ,  $SD = 0.84$ ), family mealtimes (49.5 %,  $m = 3.26$ ,  $SD = 0.91$ ), interactions with family (44.1 %,  $m = 3.19$ ,  $SD = 0.89$ ) and celebrations (44.1 %,  $m = 3.10$ ,  $SD = 0.99$ ). Regarding social activities in the community (11.1 %,  $m = 1.91$ ,  $SD = 1.08$ ), meal preparation (16.3 %,  $m = 2.14$ ,  $SD = 1.36$ ) and taking care of animals (28.0 %,  $m = 2.38$ ,  $SD = 1.23$ ), there was a high proportion of children who reported that they never attended these. More than half of the primary caregivers reported that their child always attended formal learning at school (65.7 %,  $m = 3.6$ ,  $SD = 0.82$ ), family mealtimes (64.6 %,  $m = 3.64$ ,  $SD = 0.72$ ), personal care activities (62.6 %,  $m = 3.62$ ,  $SD = 0.71$ ), interactions with family (59.6 %,  $m = 3.58$ ,  $SD = 0.74$ ) and celebrations (54.5 %,  $m = 3.51$ ,  $SD = 0.76$ ). One third of the primary

**Table 2**

The perceptions of children and primary caregivers regarding children's attendance in everyday activities.

|                                | Children (N = 93) |           |            |       |         | Primary caregivers (N = 86) |           |            |       |         |
|--------------------------------|-------------------|-----------|------------|-------|---------|-----------------------------|-----------|------------|-------|---------|
|                                | Always            | Sometimes | Not really | Never | Missing | Always                      | Sometimes | Not really | Never | Missing |
| Personal care                  | 71.0              | 22.6      | 4.3        | 2.2   | –       | 72.1                        | 19.8      | 5.8        | 2.3   | –       |
| Family mealtime                | 49.5              | 34.4      | 8.6        | 7.5   | –       | 74.4                        | 18.6      | 3.5        | 3.5   | –       |
| Own health                     | 25.8              | 18.3      | 28.0       | 28.0  | –       | 24.4                        | 25.6      | 15.1       | 34.9  | 11      |
| Daily necessity                | 29.3              | 27.2      | 12.0       | 31.5  | 1       | 33.7                        | 20.9      | 15.1       | 30.2  | –       |
| Meal preparation               | 16.3              | 22.8      | 19.6       | 41.3  | 1       | 14.0                        | 41.9      | 17.4       | 26.7  | –       |
| Cleaning                       | 25.0              | 34.8      | 20.7       | 19.6  | 1       | 24.4                        | 44.2      | 14.0       | 17.4  | –       |
| Care of family                 | 38.5              | 30.8      | 13.2       | 17.6  | 2       | 27.9                        | 22.1      | 22.1       | 27.9  | –       |
| Care of animals                | 28.0              | 17.2      | 19.4       | 35.5  | –       | 19.8                        | 20.9      | 18.6       | 40.7  | –       |
| Interaction with family        | 44.1              | 37.6      | 11.8       | 6.5   | –       | 68.6                        | 25.6      | 1.2        | 4.7   | –       |
| Celebrations                   | 44.1              | 31.2      | 15.1       | 9.7   | –       | 62.8                        | 30.2      | 2.3        | 4.7   | –       |
| Playing with others            | 32.3              | 36.6      | 12.9       | 18.3  | –       | 54.5                        | 31.2      | 7.8        | 6.5   | 9       |
| Organised leisure              | 33.3              | 28.0      | 17.2       | 21.5  | –       | 29.1                        | 34.9      | 16.3       | 19.8  | –       |
| Quiet leisure                  | 37.6              | 22.6      | 22.6       | 17.2  | –       | 42.4                        | 41.2      | 8.2        | 8.2   | 1       |
| Spiritual activities           | 31.2              | 25.8      | 25.8       | 17.2  | –       | 34.9                        | 37.2      | 10.5       | 17.4  | –       |
| Shopping                       | 28.3              | 30.4      | 22.8       | 18.5  | 1       | 26.7                        | 41.9      | 14.0       | 17.4  | –       |
| Social activities in community | 11.1              | 20.0      | 17.8       | 51.1  | 3       | 14.0                        | 41.9      | 22.1       | 22.1  | –       |
| Health centre                  | 22.6              | 39.8      | 21.5       | 16.1  | –       | 24.4                        | 61.6      | 9.3        | 4.7   | –       |
| Learning in school             | 61.3              | 29.0      | 3.2        | 6.5   | –       | 75.6                        | 15.1      | 3.5        | 5.8   | –       |
| Visits or trips                | 26.9              | 34.4      | 22.6       | 16.1  | –       | 10.5                        | 45.3      | 19.8       | 24.4  | –       |

Note: Frequencies are presented as proportions (%).

caregivers reported that their child never took care of their own health (30.3 %,  $m = 2.4$ ,  $SD 1.2$ ) or of animals (35.4 %,  $m = 2.2$ ,  $SD 1.18$ ).

For the 19 items, the proportion of agreement between the children and their primary caregivers ranged from 18.2 to 51.5 % and for disagreement from 38.4 to 64.6 %. The weighted kappa values showed overall poor agreement in perceived frequency of attendance. In the item *Spiritual activities*, the level of agreement was  $K = 0.26$  ( $p = 0.003$ ), indicating a significant but fair agreement (Landis & Kock, 1977). (See Table 3.)

### 3.2.2. What do children with ID and their primary caregivers select as the three most important activities they are involved in?

Results show that, for the children with ID, the activities selected as most important were distributed across all items in the PmP. The items *Organised leisure activities*, *Family time*, *Personal care*, *School* and *Quiet leisure* were most often selected as one of the three most important items by the children. The primary caregivers' rank order of most important activities was in line with the children's rank order. In the child group, *Organised leisure activities* was ranked as one of the three most important activities in 27 (9 %) cases.

**Table 3**

Proportion of agreement and disagreement in the perceptions of children and primary caregivers regarding children's attendance of everyday activities.

| PmP item            | Agree (%) | Disagree (%) | Missing (n) | Weighted kappa | 95 % CI     | <i>p</i> |
|---------------------|-----------|--------------|-------------|----------------|-------------|----------|
| Personal care       | 51.5      | 32.3         | 16          | .10            | -.06 to .26 | .24      |
| Family mealtime     | 36.4      | 47.5         | 16          | .04            | -.10 to .17 | .60      |
| Own health          | 19.2      | 64.6         | 15          | -.05           | -.21 to .12 | .57      |
| Gathering supplies  | 25.3      | 58.6         | 16          | .10            | -.07 to .26 | .26      |
| Meal preparation    | 18.2      | 64.2         | 17          | -.02           | -.16 to .12 | .79      |
| Cleaning at home    | 20.2      | 63.6         | 16          | .08            | -.07 to .23 | .29      |
| Caring for family   | 29.3      | 54.5         | 16          | .11            | -.05 to .27 | .14      |
| Caring for animals  | 25.3      | 58.6         | 16          | .14            | -.01 to .30 | .08      |
| Family time         | 35.4      | 48.5         | 16          | -.04           | -.16 to .08 | .57      |
| Celebrations        | 36.4      | 47.5         | 16          | .05            | -.07 to .17 | .47      |
| Playing with others | 23.2      | 51.5         | 25          | .04            | -.12 to .20 | .60      |
| Organised leisure   | 21.2      | 62.6         | 16          | .01            | -.13 to .16 | .86      |
| Quiet leisure       | 24.2      | 58.6         | 17          | .004           | -.14 to .15 | .96      |
| Spirituals          | 29.3      | 54.5         | 16          | .26            | .07 to .38  | .003     |
| Shopping            | 27.3      | 56.6         | 16          | .04            | -.12 to .20 | .60      |
| Social activities   | 19.2      | 62.6         | 18          | .07            | -.07 to .22 | .31      |
| Health centre       | 26.3      | 57.6         | 16          | .02            | -.11 to .14 | .76      |
| School              | 45.5      | 38.4         | 16          | .02            | -.14 to .18 | .81      |
| Trips and visits    | 23.2      | 60.6         | 16          | .07            | -.07 to .21 | .34      |

Note: Level of agreement is analysed for the four-option scale. The level of agreement and disagreement are presented in proportions, and the number of missing cases in numbers. In cases of a missing participant in the child-primary caregiver dyads, the dyad was excluded from the analysis. Level of significance was set to  $p \leq .05$ .

**Table 4**

Rank order of activities of importance and those rated with low frequency of attendance as selected by children and primary caregivers.

| Children<br>(n = 93)                   |      | Primary caregivers<br>(n = 86)         |      |
|--|------|--|------|
| Rank order of activities of importance | (%)  | Rank order of activities of importance | (%)  |
| Organised leisure                      | 10.1 | Organised leisure                      | 21.9 |
| Family time                            | 9.7  | Personal care                          | 13.4 |
| Personal care                          | 8.6  | School                                 | 9.8  |
| School                                 | 8.2  | Family time                            | 8.9  |
| Quiet leisure                          | 7.8  | Quiet leisure                          | 8.5  |
| Spiritual activities                   | 6.7  | Playing with others                    | 8.0  |
| Celebrations                           | 5.6  | Cleaning at home                       | 4.0  |
| Caring for family                      | 5.6  | Spiritual                              | 3.1  |
| Caring for animals                     | 5.6  | Gathering supplies                     | 2.7  |
| Family mealtime                        | 4.5  | Celebrations                           | 2.7  |
| Meal preparation                       | 4.5  | Family mealtime                        | 2.2  |
| Trips and visits                       | 4.1  | Shopping                               | 2.2  |
| Playing with others                    | 3.4  | Social activities                      | 2.2  |
| My own health                          | 2.9  | Health centre                          | 2.2  |
| Health centre                          | 2.6  | Trips and visits                       | 1.8  |
| Shopping                               | 2.2  | Other                                  | 1.8  |
| Gathering supplies                     | 1.9  | Meal preparation                       | 1.3  |
| Cleaning at home                       | 1.9  | Caring for family                      | 1.3  |
| Social activities                      | 1.9  | Caring for animals                     | 0.9  |
| Other                                  | 0.3  | My own health                          | 0.4  |

The primary caregivers, however, more often ranked *Organised leisure activities* (n = 49, 19 %), as one of the three most important activities. The rank order correlation regarding the three most important activities showed fairly strong and positive significant correlations ( $r = 0.532$ , Sig. 2-tailed 0.019) between children with ID and their primary caregivers. The extent to which children with ID and their primary caregivers selected the same three most important activities is illustrated in [Table 4](#).

#### 4. Discussion

This study aimed to describe the self-reported participation of children with ID and their primary caregivers' perceptions of the children's participation. Participation was conceptualised as a multidimensional construct, recognising the perceptions of attendance and the perceived importance of activities to participate in. Overall, the descriptive results suggested that in both frequency of attendance and level of perceived importance, the perceptions of children with ID and of their primary caregivers generally showed similarities. On group level, both children and their primary caregivers perceived the child to have a high level of attendance of *Formal learning in school*, *Family mealtime*, *Interacting with family* and *Celebrations*. However, analysing the proportion of agreements and disagreements in the child-caregiver dyads, an overall poor agreement in perceived frequency of attendance was found relating to *Formal learning in school*, *Family mealtime*, *Interacting with family*, *Celebrations* and *Personal care*. The poor agreement was further noted in the Kappa analysis. Except for *Spiritual activities*, where a fair level of agreement ( $K = 0.26$ ) was noted, the Kappa values were not significant and did not exceed 0.11. The results may therefore confirm our first hypothesis by finding a noted difference in the perceptions of attendance of everyday activities when comparing the views of children with ID and their caregivers' ratings of participation.

Specifically, a higher proportion of disagreements was indicated in respect of social activities and family activities, while children with ID and primary caregivers were likely to agree on the *Personal care activities* component. Our results suggest that it may be difficult for children with ID and caregivers to agree on the experience significance of family activities (e.g. family mealtimes and family interaction) and social activities (e.g. social activities in the community and organised leisure activities) also for the frequency of attendance in activities. Since social activities involve doing things with others, the subjective experience for children with ID, in the frequency of attending an activity (too) often or (too) seldom comes to the fore. This can be linked to a child rights perspective and concurs with previous studies that highlight the importance of hearing the child's voice in participation research, especially concerning social activities (Huus et al., 2015; Longo, Badia, Orgaz, & Gómez-Vela, 2017). A higher proportion of disagreements in the children-caregiver dyads was also indicated with regard to activities connected to domestic chores such as *Meal preparation*, *Cleaning up at home*, *Gathering supplies* and *Shopping*. Although the frequency of attendance between these activities was inconsistent, the results indicate that subjective perceptions can be found for even seemingly simple and concrete activities – hence the importance of exploring the child's perspective.

The relatively low agreement in frequency of attending in child-primary caregiver-dyads may also partly be explained by that children with ID can have difficulties relating experiences of how frequent they attend activities to clock time or number of days/months. In the PmP no specification of time period to relate to is provided. This probably lead to that children as well as care providers base their rating on the subjective experience of whether the child attended: Never; Not really; Sometimes; or Always. It may however be that primary caregivers make this estimation (that will vary dependent on type of activity rated based on a more

conventional estimation of how frequently an activity take place). To conclude, PmP can only provide the subjective experience of frequency of attending. Thus, it is important to interpret the child's responses as a valid rating of the experience of participating without having primary caregivers as a interpretative frame when analysing children ratings.

With regard to our second hypothesis, the children with ID overall shared the perceptions of their primary caregivers concerning the activities that were considered important. In terms of perceived importance, children and primary caregivers selected similar activities of organised leisure, family time, personal care, formal learning in school and quiet leisure as important. Organised leisure was most commonly selected as one of the three most important activities; one fifth of the primary caregivers, but less than a tenth of the children, selected the activity. It is notable that although both the children and the primary caregivers perceived organised leisure as being most important, about one third of the children never or seldom attended the activity, as indicated both by children and primary caregivers. This finding is similar to those of earlier studies that show a lower level of participation in leisure activities in children with ID, compared to children with typical development. Also, participation in leisure activities is more dependent on the school and the assistance given to allow participation (Chien, Rodger, & Copley, 2017). Spearman's rank order correlation analysis showed a substantial correlation ( $r = 0.532$ ) between the children's ranking of important activities and that of the primary caregivers. However, this correlation corresponds to 25 % shared variance, which in this case must be considered as a low level and even more strongly emphasises the significance of including the child's voice in research and in clinical practice. The children's selection of activities from all items on the PmP may suggest that they have a range of interests that they perceive as important. This correlates with previous research, which indicated that while caregivers may be valid proxies for their children, the perceptions of children with disability may offer different insights than are deduced from adult perceptions (Costa et al., 2016; Harding et al., 2009; Huus et al., 2015; Nelson et al., 2017). Adults fulfil a primary role as caregivers in guiding and protecting the child. Hence, they (adults) may give priority to the children's participation in activities deemed to be important for adult life. Eriksson and Granlund (2004) investigated different stakeholders' definitions of participation and reported that they are influenced by the role of the stakeholder, with parents and teachers perceiving school and a responsive environment as more important than children do.

The findings of this study highlight the significance of including the perspectives of children with ID and the activities that they deem as important when developing intervention goals (Willis et al., 2016). Recently, there have a variety of parent-reported participation measures, primarily focusing on frequency of attending, developed to be for children with severe or moderate disabilities who are unable to articulate their participation experience. These parent-reported participation measures may be useful for use with preschool-aged children and in population-based, public health studies when interventions made to increase the opportunities to participation are in focus. A strength of our study is that it adds to the few studies that describe and compare the self-reported and proxy-reported participation of children with ID and their primary caregivers. Children's ratings of frequency of attending may be based on the subjective experience of how frequently they attend. As such, these ratings provide important information about how children experience attending that can be used in intervention planning. This study indicate a research gap considering how children experience attending. Future studies need to investigate how experiences of frequency of attending are related to perceptions of importance. Previous studies (Liao, Hwang, & Liao, 2019) indicate that children tend to select activities they already perceive that they do frequently as important.

It also has to be admitted that there are several limitations to this study. The different data collection methods for obtaining information from caregivers and children with ID are acknowledged as a methodological limitation. However, studies have found even when different data collection methods parents and children can have similar ratings on perceptions of human rights (Huus et al., 2015). Due to the research design and selection criteria, there might have been sampling bias, as primary caregivers were literate enough to complete the self-administered questionnaire. The questions regarding each item were posed in a way to ensure that the child understood the question. However, the primary caregivers completed a self-administered questionnaire and there may have been discrepancies in their ability to understand and interpret the questions. Moreover, the primary caregivers' answers may have been a reflection of their perception of their child's capability in respect of the activity, i.e. whether the activity was performed independently or whether assistance was needed. Additionally, children with ID and primary caregivers were aware of their participation in data collection and may have deliberately provided socially favourable responses.

Furthermore, we had missing data that may be attributed to the nature of the children's difficulties, e.g. being unwell or absent from school, or children becoming fatigued during the test administration. One particular question relating to playing with friends was not answered by many of the caregivers due to a research administrative oversight.

Future studies could extend the measures of the present study to examine the perceived level of involvement of children with ID in the three important activities and how perception of involvement are related to subjective experiences of frequency of attending. It is also important to explore children's perceptions of factors facilitating or hindering participation in the activities and how such perceptions are related to experiences of frequency of attending and perceived importance. The measure could also be used in planning and goal setting in interventions and to determine changes in participation following an intervention to improve participation in activities.

## 5. Conclusion

Participation, as reported from a child's perspective, is an imperative clinical and research agenda for children with ID. This study provided evidence by describing the self-reported participation of children with ID and the perceptions of their primary caregivers. Participation was measured as frequency of attending activities and prioritised involvement in activities rated as important. Our results showed that children with ID did not report attendance ('being there') or participation in the same way as their caregivers perceived. While primary caregivers' and children's selection of the most important activities appeared somewhat similar, there was a



noted difference in that primary caregivers' were uniform in their selection, whilst there was a diversity in the selection of activities among children. The current study makes an important contribution to the argument for including the self-reported perceptions of children with ID in clinical practice and future research endeavours.

### CRediT authorship contribution statement

**Shakila Dada:** Conceptualization, Methodology, Funding acquisition, Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **Anna Karin Andersson:** Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **Adele May:** Formal analysis, Writing - original draft, Writing - review & editing. **Elisabeth Elgmark Andersson:** Formal analysis, Writing - review & editing. **Mats Granlund:** Conceptualization, Methodology, Funding acquisition, Formal analysis, Writing - review & editing. **Karina Huus:** Conceptualization, Methodology, Funding acquisition, Data curation, Formal analysis, Writing - original draft, Writing - review & editing.

### Declaration of Competing Interest

The authors declare no conflicts of interest.

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### Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.ridd.2020.103715>.

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