# Test-Retest Reliability of the Picture My Participation Instrument

**by**

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# Abstract

**Introduction**: People who have disabilities are often deprived of opportunities to be involved in daily life situations. While research attempts to explore the participation patterns of individuals with disabilities, there is a paucity of studies that have obtained the personal opinions of participation from children with intellectual disabilities, and none that have obtained personal opinions (self-reports) from children living in low- to middle-income (LAMI) countries. Reasons for this are thought to be the lack of measures and methods available for obtaining self-reports from children with intellectual disabilities. The Picture my Participation (PMP) instrument has been developed for use in LAMI countries and when used with the Talking Mats$^{TM}$ framework, ensures that the views of children with intellectual disabilities can be obtained. This study aimed to assess the test-retest reliability of the PMP instrument.

**Methods:** Sixteen children aged 12 to 17 years with intellectual disabilities and their primary caregivers took part in this study. Each participant pair was required to complete the Picture My Participation survey twice in a space of two weeks. Cronbach's alpha coefficient and Spearman's rank order were used to measure internal consistency and test-retest reliability.

**Results and conclusions:** While the questionnaire yielded high alpha values, indicating high internal consistency, the values for test-retest reliability were incomparable due to a small sample size and limited data. Further study is required with a larger and more diverse data sample.



**Keywords:** children with intellectual disability, measures of participation, participation, test-retest reliability, internal consistency

# List of Abbreviations/Acronyms

| | |
|---|---|
| A-PACS | Arabic PACS (Preschool Activity Card Sort) |
| APCP | Assessment of Children's Participation |
| CAMP | Caregiver Assessment of Movement Participation |
| CAPE | Children's Assessment of Participation and Enjoyment |
| CASP | Child and Adolescent Scale of Participation |
| CHIEF | Craig Hospital Inventory of Environmental Factors |
| COSMIN | COnsensus-based Standards for the selection of health status Measurement INstrument |
| CP | Cerebral Palsy |
| CPQ | Children Participation Questionnaire |
| DCD | Developmental Coordination Disorder |
| ICC | Interclass Correlation Coefficient |
| ICF | International Classification of Functioning, Disability and Health |
| ICF-CY | International Classification of Functioning, Disability and Health child and youth version |
| KBIT-2 | Kaufman Brief Intelligence Test - Second Edition |
| KPEM-CY | Korean PEM-CY (Psychometric Evaluation of the Participation and Environment) |
| LAMI | low- and middle-income |
| LEAP | Lunchtime Enjoyment of Activity and Play |

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| LeSTE | Learner Screening Tool by Educators |
| LoLT | Language of Learning and Teaching |
| LSEN | Learners with Special Education Needs |
| PAC | Preferences for Activities of Children |
| PACS | Preschool Activity Card Sort |
| PEM-CY | Participation and Environment Measure for Children and Youth |
| PICO-Q | Participation in Childhood Occupation Questionnaire |
| PMP | Picture My Participation |
| TQQ | Ten Questions Questionnaire |
| VABS | Vineland Adaptive Behavior Scale |
| WHO | World Health Organization |
| YC-PEM | Young Children's Participation and Environment Measure |

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# CHAPTER 1: Problem Statement and Literature Review

The International Classification of Functioning, Disability and Health (ICF) defines participation as "involvement in life situations" (World Health Organization (WHO), 2001, p. 14), with the child and youth version (ICF-CY) expanding this definition to include participation in childhood activities (WHO, 2007). Referring to the activities and participation component, the ICF-CY considers participation together with activity, defined as an individual's execution of a task or action (WHO, 2001, 2007). Within the activity and participation component of the ICF, nine domains of activities and participation covering a wide range of life situations are distinguished, namely: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas (including education, work and employment, and economic life); and community, social and civic life (WHO, 2007).

Participation is emphasised as a human right and recognised as a component of general health and well-being and is often the aspired outcome of healthcare interventions including rehabilitation for children and adolescents with disabilities (Eriksson & Granlund, 2004). Children with disabilities, however, continue to lack opportunities to participate in day-to-day interactions and activities (Lilienfeld & Alant, 2005). This includes not being able to take part in leisure activities and relating socially with other people and peers (Arvidsson, Granlund, Thyberg, & Thyberg, 2014).

Very few studies exist in which children with intellectual disabilities are asked to provide their personal opinion (self-ratings) (Arvidsson, Granlund, & Thyberg, 2008), with researchers relying predominantly on proxy ratings obtained from caregivers (Huus, Granlund, Bornman, & Lygnegård, 2015). Research shows that the focus in participation studies is on high-income countries (Hammel et al., 2008; Rainey, Van Nispen, Van der Zee, & Van Rens, 2014). This lack may be attributed in part to the paucity of strategies available to obtain the views of children with intellectual disabilities. In the Huus et al. (2015) study, however, a Talking Mats™ framework was used successfully in obtaining children with intellectual disabilities' perceptions of their human rights. The authors suggested that this framework can be used as a strategy to ensure that

the views of children with intellectual disabilities in low- and middle-income (LAMI) countries can be obtained.

In a systematic review that appraised 61 measures of participation in children with disability, researchers (Rainey et al., 2014) excluded 53 measures which were not considered comprehensive in their evaluation of participation. The remaining eight were assessed using the COnsensus-based Standards for the selection of health status Measurement INstrument (COSMIN) checklist which includes an appraisal of reliability (internal consistency, reliability and measurement error), validity (content validity and construct validity), responsiveness and interpretability (Rainey et al., 2014). Approximately 50% of the measurement properties were either not assessed or were assessed as having poor quality (Rainey et al., 2014). It is evident also that there is currently no agreed upon measure of participation, and measures which do exist are often not comprehensive in their evaluation of participation (Amado, Stancliffe, McCarron, & McCallion, 2013; Rainey et al., 2014). This displays a clear indication for the development of valid and reliable instrumentation dedicated to the evaluation of participation, and further indicates the necessity for the focus on studies in LAMI countries.

The Picture My Participation (PMP) instrument has been developed for use in LAMI countries (Elliot et al., 2015). The instrument uses pictures and conversation to identify 1) frequency of and involvement in activities, 2) level of involvement, and 3) barriers to and facilitators of a child's participation in home, school and community activities (Elliot et al., 2015). Using PMP in conjunction with the Talking Mats$^{TM}$ framework can ensure that the views of children with intellectual disabilities in LAMI countries can be obtained.

Laher (2016) suggested that in validating an instrument, reliability should be examined and reported, as without it, it is not possible to draw conclusions based on the instrument. According to the COSMIN manual, in validation of a health-related patient-reported outcome measure (PROM), a variety of measurement properties are relevant, which include reliability, validity and responsiveness (Terwee et al., 2017). The COSMIN manual details reliability as containing the measurement properties internal consistency, reliability and measurement error, which include test-retest, inter-rater and intra-rater reliability (Terwee et al., 2017). Reliability is critical in health-related quality of life instruments, and refers to the consistency of scores obtained by the same person when re-examined with the same test on different occasions or alternatively with different

sets of equivalent items (Marx, Menezes, Horovitz, Jones, & Warren, 2003). Reliability consists of both absolute consistency (consistency of individuals' scores) and relative consistency (scores relative to others in a group) (Weir, 2005).

There are a variety of procedures which have been applied to determine reliability of instruments, including the widely used Cronbach's alpha, the Pearson *r*, and the Limits of Agreement (LoA) (Spiliotopoulou, 2009; Weir, 2005). An instrument's reliability can be examined by using tests of internal consistency, such as the test-retest procedure (i.e. multiple administrations of the same instrument to the same group of participants) (Hendrickson, Massey, Cronan, & Hendrickson, 1993). When dealing with a heterogeneous construct such as participation, establishing test-retest reliability becomes increasingly relevant (Marx et al., 2003). Test-retest reliability can be effectively calculated using the Interclass Correlation Coefficient (ICC) (Bult et al., 2013; Weir, 2005).

Content validity was done for the PMP instrument (Arvidsson et al., in preparation). Test re-test needs to be done, which is another aspect of improving the psychometric properties of the PMP, aspects of the suggestion made by COSMIN have been conducted with the PMP in South Africa (Arvidsson, et al., in preparation). The current study sought to contribute towards the validation of the PMP to be used for children with intellectual disabilities in South Africa, a LAMI country.

## 1.1 Studies Focussing on Validation of Participation Measures

A search of the literature was conducted to determine the current research base for participation measures and the methods of validation applied with each instrument. A Boolean search was conducted using the key terms 'participation or involvement" AND 'measures' OR 'validation studies or validation scales' OR 'test-retest reliability'. Only one database, Ebscohost, was searched using the key words. According to Grant and Booth (2009) and Schlosser, Wendt, and Sigafoos (2007), this is a limited search as the search terms were limited and the number of databases were less than the recommended number of five.

An initial 120 articles were located, all limited to scholarly, peer-reviewed journals and published in English. After perusing the titles and abstracts of the articles, it was found that 18

included children or youth and were thus included in this study. The studies were summarised and are presented in Table 1 below.

**Table 1: Summary of studies relating to psychometric properties of participation measures**

| Author(s) | Title | Aim(s) | Design | Participation Measure | Participants | Procedures | Findings |
|---|---|---|---|---|---|---|---|
| C. Lim, M. Law, M. Khetani, P. Rosenbaum and N. Pollock (2018) | Psychometric Evaluation of the young children's participation and environment measure (YC-PEM) for use in Singapore. | To evaluate the internal consistency, test-retest reliability, and construct validity of the culturally adapted YC-PEM (Singapore). | Quantitative (Cross-sectional study) | YC-PEM (Singapore) | One hundred and fifty-one (151) caregivers of Singaporean children aged 0-7 years, with (n = 83) and without (n = 68) developmental disabilities. Ninety (90) were male and 61 were female. | Convenience sampling was used to recruit caregivers from a government hospital in Singapore. Caregivers completed the YC-PEM (Singapore) questionnaire. Parents who signed the consent form were requested to complete the same questionnaire 2-3 weeks later. | Internal consistency estimates varied from 0.59 to 0.92 for the participation scales and 0.73 to 0.79 for the environment scale. Test-retest reliability estimates from the YC-PEM conducted on two occasions, 2-3 weeks apart, varied from 0.39 to 0.89 for the participation scales and from 0.65 to 0.80 for the environment scale. Moderate to large differences were found in participation and perceived environmental support between children with and without a disability. |
| Y. Jeong, M. Law, P. Stratford, C. DeMatteo, and H. Kim (2016) | Cross-cultural validation and psychometric evaluation of the Participation and Environment (PEM) Measure for Children and Youth in Korea. | To cross-culturally translate the PEM-CY to Korean based on a strict and rigorous guideline and to establish the internal consistency, test–retest reliability and construct validity (i.e. known group validity) of the Korean PEM-CY (KPEM-CY). | Quantitative | KPEM-CY | Eighty (80) parents of children with disabilities aged 5-13 years were recruited in Daejeon, South Korea. | Convenience sampling was used to recruit children in special-education schools. The PEM-CY was cross-culturally translated into Korean using a specific guideline: pre-review of participation items, forward/backward translation, expert committee review, pre-test of the KPEM-CY and final review. Parents were requested to complete the PEM-CY. After two weeks, they were asked to complete the questionnaire again. | Across the home, school and community settings, 76% of participation items and 29% of environment items were revised to improve their fit with Korean culture. Internal consistency was moderate to excellent (0.67–0.92) for different summary scores. Test–retest reliability was excellent (>0.75) in the summary scores of participation frequency and extent of involvement across the three settings and moderate to excellent (0.53–0.95) in all summary scores at home. |
| S.H. Malkawi, S.M.N. Abu-Dahab, A.F. Amro and | The Psychometric Properties of the Arabic Preschool Activity Card Sort (PACS). | To examine the psychometric properties of the Arabic PACS | Quantitative | A-PACS | One hundred and fifty-one (151) parents of typically developing children aged 3-6 years, from different | Parents representing different geographical areas completed the A-PACS. Parents completed the A-PACS and the Vineland | The A-PACS was able to differentiate between the participation level of young and old children in the domains of education, community mobility, |

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| N.A. Almasri (2017) | | (A-PACS) for children aged 3-6 years old. | | | geographical areas of Jordan. | Adaptive Behavior Scale (VABS) as 1:1 interviews. Two trained occupational therapy researchers conducted interviews. The time to complete the two measures varied from 40 to 60 minutes. To assess test-retest reliability, a randomly selected subsample of 30 parents, ten from each age group (3-3;11, 4-4;11, 5-6 years), completed the A-PACS twice in a two-week interval. | and low-demand leisure of the A-PACS, giving evidence to its construct validity and it significantly correlated with some aspects of the VABS, giving evidence to its concurrent validity. The A-PACS showed excellent overall internal consistency ($\alpha$=0.859) for all domains and good test-retest reliability (r=0.976, p<0.001). |
| Y. Jeong, M. Law, P. Stratford, C. DeMatteo, and C. Missiuna (2017) | Measuring Participation of Children and Environmental Factors at Home, School, and in Community: Construct Validation of the Korean PEM-CY. | To determine construct validity of the KPEM-CY in South Korean children with and without disabilities | Quantitative | KPEM-CY | One hundred and eighty-four (184) parents of children aged 5-13 years: 80 with disabilities and 104 without disabilities. | Parents completed the KPEM-CY. Construct validity was analysed by assessing differences in the participation and environment scores for children with and without disabilities across age and gender. | Validity of the KPEM-CY was supported by significant differences in participation and environmental factors for subgroups (p<0.05). Children with disabilities participated less in activities and had more environmental barriers than those without disabilities across all settings. Parents of children with disabilities reported a higher level of desire to change their children's participation patterns. Similar participation patterns and environmental factors, which were influenced by interaction effects between disability and age, were confirmed at home and in the community. |
| C. Tuffrey, B.J. Bateman and A.C. Clover (2013) | The Questionnaire of Young People's Participation (QYPP): a new measure of participation frequency | To develop a measure of participation frequency, covering all major domains, for young | Qualitative | QYPP | Seventeen (17) experts for review; 12 young people and 12 carers for cognitive interviews; field-testing with 107 | A pool of 88 items was developed using the published literature, existing measures and qualitative data from young people. The | Known-groups validity was demonstrated by correlation with impairment severity. Test-retest |

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| | for disabled young people. | people with cerebral palsy (CP). | | | young people with CP aged 13-21 years, and 540 young people from the general population. | item pool was revised following expert review, wording changed following cognitive interviews and items were decreased to 45 following field testing. | reliability was satisfactory for all domains.<br><br>Internal consistency varied between domains. |
| F.M. Åström, M. Khetani and A.K. Axelsson (2018) | Young Children's Participation and Environment Measure: Swedish Cultural Adaptation. | To establish the initial psychometric properties of a culturally adapted Young Children's Participation and Environment Measure (YC-PEM) for use by caregivers of Swedish children with and without disabilities. | Quantitative | Swedish YC-PEM | Thirty-three (33) caregivers of children aged 2–5 years in Sweden: 11 with disabilities and 22 without disabilities. | Thirteen (13) cognitive interviews and two focus groups were conducted with caregivers of children with and without disabilities to evaluate the cultural relevance of YC-PEM content for use in Sweden. A revised version of the Swedish YC-PEM was created per participant feedback and pilot-tested with caregivers of children with disabilities (n = 11) and children with typical development (n = 22). User feedback informed content revisions to 7% of items. | Internal consistency estimates of the Swedish YC-PEM pilot version were acceptable and ranged from 0.70 to 0.92 for all but two of the YC-PEM scales. Mean percentage agreement between raters ranged from 47% to 93% across YC-PEM scales for inter-rater, and 44% to 86% for test-retest. One of 12 YC-PEM scales revealed significant group differences between young children with and without disabilities. |
| C. Chien, S. Rodger and J. Copley (2015) | Development and Psychometric Evaluation of a New Measure for Children's Participation in Hand-Use Life Situations. | To describe the development of the Children's Assessment of Participation with Hands, a parent-report questionnaire that assesses children's participation in life situations requiring hand use specifically, and to investigate its construct validity (using Rasch analysis and known-group comparison) and reliability (test-retest | Quantitative (Cross-sectional study) | Children's Assessment of Participation with Hands | Two hundred and two (202) parents/caregivers with children aged 2-12 years: 97 with disabilities and 105 without disabilities. | The Children's Assessment of Participation with Hands was developed based on a content review of existing children's participation measures and literature, expert review, and pilot testing. Parents/caregivers (n = 202) reported on their children with and without disabilities. | Evidence for construct validity of the Children's Assessment of Participation with Hands domains was established through Rasch analysis (after removing two non-fitting items from the recreational domain and one from the domestic life and community domain). Differences in summary scores of each domain between children with and without disabilities were also significant ($p < 0.01$). Test-retest reliability of the Children's Assessment of Participation with Hands was moderate to high |

| Author(s) | Title | Aim(s) | Design | Participation Measure | Participants | Procedures | Findings |
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| | | reliability and internal consistency). | | | | | (intraclass correlation coefficients; 0.69-0.96), except for the desire for change dimension scale of the recreational domain (0.40). Internal consistency was varied across the dimensions/domains. |
| M.A. Khetani, J.E. Graham, P.L. Davies, M.C. Law and R.J. Simeonsson (2015) | Psychometric Properties of the Young Children's Participation and Environment Measure. | To evaluate the psychometric properties of the newly developed YC-PEM. | Quantitative (Cross-sectional study) | YC-PEM | Three hundred and ninety-five (395) caregivers of children aged 0-5 years living in North America: 93 with developmental disabilities and delays; 300 without. | Caregivers completed the YC-PEM questionnaire with three participation scales (frequency, involvement, and change desired) and one environment scale for three settings (home, childcare/preschool, and community). After 2-4 weeks, caregivers completed the questionnaire again. | Internal consistency ranged from 0.68 to 0.96 and 0.92 to 0.96 for the participation and environment scales, respectively. Test-retest reliability ranged from 0.31 to 0.93 for participation scales and from 0.91 to 0.94 for the environment scale. One of the three participation scales and the environment scale demonstrated significant group differences by disability status across all three settings, and all four scales discriminated between disability groups for the day care/preschool setting. The participation scales exhibited small to moderate positive associations with functional performance scores. |
| J. McDougall, G. Bedell and V. Wright (2013) | The youth report version of the Child and Adolescent Scale of Participation (CASP): assessment of psychometric properties and comparison with parent report. | To assess the psychometric properties of a CASP youth self-report version, to further validate the parent report, and to compare parent and youth reports of youths' activity and participation. | Quantitative (Longitud-inal study) | CASP | Four hundred and nine (409) youths aged 11-17 years with various conditions/disabilities. | Baseline data from a longitudinal study were used examining predictors of changes in quality of life for youth with chronic conditions/disabilities. CASP data were collected on 409 youth using youth and parent reports. Internal consistency and factor structure were examined for both versions, using Cronbach's alpha and exploratory factor analyses. | Strong internal consistency and internal structure validity were demonstrated for the CASP youth and parent report. The youth report factor structure was similar to the parent report in this study. Youth reported their activity/participation to be significantly higher than did their parents. Significant differences in CASP scores were found among condition/disability groups. |

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| | | | | | | Inter-rater agreement and magnitude of differences between youth and parent report were evaluated using ICC and paired t-tests, respectively. | |
| E. Longo, M. Badia, B. Orgaz and M.A. Verdugo (2014) | Cross-cultural validation of the Children's Assessment of Participation and Enjoyment (CAPE) in Spain. | To validate a Spanish version of the Children's Assessment of Participation and Enjoyment (CAPE). | Mixed (Exploratory and sequential) | CAPE | Three hundred and ninety-eight (398) children from seven regions of Spain, aged 8-18 years: 199 children and adolescents with CP and 199 without CP. | Adaptation of the original version of CAPE was carried out through translation and backward translation, and the validity of the instrument was analysed. Construct validity was assessed through the correlation of the diverse CAPE domains and the quality of life domains (KIDSCREEN questionnaire). Discriminant validity was established by comparing children and adolescents with CP with typically developing children and adolescents. For test-retest reliability, the children and adolescents completed the CAPE questionnaire twice within four weeks. | The correlations found between the CAPE domains and the quality of life domains show that the CAPE presents construct validity. The CAPE distinguished children and adolescents with CP from those without any disability in the results of participation. According to most CAPE domains, typically developing children and adolescents engage in a greater number of activities than children and adolescents with CP. Test-retest reliability for the Spanish version of CAPE was adequate. |
| A. Fink, B. Gebhard, S. Erdwiens, L. Haddenhorst and S. Nowak (2016) | Reliability of the German version of the Children's Assessment of participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC). | To present a German version of the CAPE and PAC. | Mixed (Exploratory and sequential) | CAPE and PAC | One hundred and fifty-two (152) youths with and without disabilities participated in the study, with a mean age of 15;2 years. | The CAPE and PAC questionnaire was translated into German, a cultural adaptation process was designed, and a reliability study was conducted. The participants completed CAPE and PAC twice within four weeks. Reliability was examined by ICC, standard error of measurement, | The absolute values of participation differ between the typically developed youth group and those with impairments; the reliability of the CAPE and PAC is comparable in both groups. ICC ranged from 0.43 to 0.74 for the CAPE and from 0.71 to 0.83 for the PAC for all participants. The alpha values for internal consistency ranged from 0.42 to 0.82 for the |

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| | | | | | | smallest detectable change and Cronbach's alpha. | CAPE and from 0.65 to 0.92 for the PAC. |
| M.K. Bult, O. Verschuren, M.K. Kertoy, E. Lindeman, M.J. Jongmans and M. Ketelaar (2013) | Psychometric Evaluation of the Dutch Version of the Assessment of Preschool Children's Participation (APCP): Construct Validity and Test-Retest Reliability. | To examine construct validity, internal consistency, and test-retest reliability of the Dutch translation of the Assessment of Preschool Children's Participation (APCP), a participation measure for children aged 2-5 years with and without physical disabilities. | Quantitative | APCP | Parents of 126 preschool children aged 2-5 years participated: 67 of the children had no physical disabilities and 59 children had physical disabilities. | Validity was tested using three hypotheses regarding having a physical disability, as well as gender and age differences. | Children with a physical disability participated in fewer activities and with lower intensity than children without physical disabilities ($p < 0.001$). Boys and girls participated in an equally wide variety of activities and with similar intensity, except for skills development. Four to five-year-old children in general participated in more activities than two to three-year-old children and had a higher intensity score ($p < 0.001$). For activity types, differences were found between age groups for skills development ($p < 0.001$) and social activities ($p < 0.001$). Internal consistency was sufficient for four out of ten activity types. Intra-class correlations for test-retest reliability ranged from 0.63 to 0.91. |
| D. McCauley, J.W. Gorter, D.J. Russell, P. Rosenbaum, M. Law and M. Kertoy (2012) | Assessment of environmental factors in disabled children 2-15 years: development and reliability of the Craig Hospital Inventory of Environmental Factors (CHIEF) for Children-Parent Version. | To conduct secondary data analysis to determine which items are suitable for use as a parent-completed proxy measure for disabled children and to collect data to determine reliability and utility of the CHIEF for Children–Parent Version. | Quantitative | CHIEF | Six hundred and eight (608) parents of physically disabled school-aged children (aged 2-15 years): 427 were children aged 6-15 years, and 181 were aged 2-5 years. | The adaptation process consisted of four steps, using data from previous research conducted at CanChild: (1) analysis of item-total correlations from all items on the CHIEF; (2) frequency of endorsement; (3) determination of the representativeness of the questions; and (4) correlations on selected items. Once the items were selected, a test-retest | The internal consistencies (α) for the Time 1 and Time 2 administrations were 0.76 and 0.78, respectively. Test-retest reliability of the questionnaire was acceptable (ICC = 0.73) for the total product score. |

| Author(s) | Title | Aim(s) | Design | Participation Measure | Participants | Procedures | Findings |
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| | | | | | | reliability study was conducted. | |
| L.A. Chiarello, R.J. Palisano, S.W. McCoy, D.J. Bartlett, A. Wood, H. Chang, L. Kang and L. Avery (2014) | Child engagement in daily life: a measure of participation for young children with cerebral palsy. | To determine the: (1) internal consistency and test-retest reliability of the Child Engagement in Daily Life measure; (2) construct validity of the measure (known groups methods), that is, the ability of the measure to discriminate participation in family and recreational activities and self-care among young children of varying age and motor ability and between children with and without CP; and (3) stability and hierarchical ordering of the items for young children with CP to devise an interval-level scoring system. | Qualitative (Multi-site prospective cohort) | Child Engagement in Daily Life. | Five hundred and thirty-nine (539) children and their parents participated: 429 children with CP and their parents and 110 children without CP and their parents. | Parents completed the Child Engagement in Daily Life measure and therapists assessed the children's gross-motor function. Rasch analysis was used to create an interval-level measure. | Children's frequency and enjoyment of participation in family and recreational activities and self-care varied by age and gross-motor ability. Internal consistency of the domains of the measure was high, Cronbach alpha values ranging from 0.86 to 0.91; test-retest for participation in family and recreational activities was acceptable (ICC = 0.70) and in self-care was high (ICC = 0.96). The items in the measure had a good fit and a logical hierarchical ordering. |
| T. Bar-Shalita, A. Yochman, T. Shapiro-Rihtman, J. Vatine and S. Parush (2009) | The Participation in Childhood Occupation Questionnaire (PICO-Q): a pilot study. | To examine content validity and reliability of the PICO-Q with parents of children with sensory modulation disorder (SMD). | Quantitative | PICO-Q | Mothers of 41 children aged 6-10 years (24 children with SMD and 17 children without SMD). | Phase 1 included test construction and establishment of content validity for the domain of childhood participation. In phase 2, internal consistency, test–retest reliability, and construct validity were examined. | Cronbach's alpha varied from 0.86 to 0.89, indicating internal consistency of items. Test-retest reliability varied from 0.69 to 0.86, indicating that the instrument provides a stable measurement over time. |
| K.L. Tsang, K. Stagnitti and S.K. Lo (2010) | Screening children with developmental coordination disorder: the development of the | To develop a valid caregiver-proxy measuring instrument to assess movement | Quantitative | CAMP | Three hundred and twelve (312) children aged 5-8 years: 19 with developmental | A pool of 76 daily-living tasks was identified that children with DCD have difficulty in performing at | All of the CAMP items had a point–measure correlation ranging from 0.37 to 0.60, indicating all item scores were correlated with expected total scores. The CAMP |

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| | Caregiver Assessment of Movement participation. | participation for children aged 5-8 years, and to investigate the psychometric properties of the Caregiver Assessment of Movement Participation (CAMP), which was developed to measure and identify children with movement participation problems in home contexts. | | | coordination disorder (DCD) and 293 without. | home. In expert review, experts rated the degree of item relevancy on a 6-point scale. Focus-group discussions were conducted, each with four participants from a parents' support group, whose members were concerned for their children's movement participation difficulties at home. The CAMP was revised into a 35-item version.<br><br>Test–retest reliability was conducted on 76 caregivers (11 in the DCD group and 65 in the typically developing (TD) group), who completed the CAMP twice, 2-3 weeks apart. | yielded excellent test–retest reliability scores and the ICC (1,1) was 0.94. The Pearson correlation coefficient for all the participants (n = 149) was moderately and significantly correlated (r = 0.56; 95% confidence interval [CI] = 0.44–0.66). Additional correlation analyses were carried out on subgroups stratified by age; the scores were all significantly correlated and ranged between 0.42 and 0.69. The CAMP scores were also mildly correlated with the Movement Assessment Battery for Children (MABC) Test (r = 0.31; 95% CI = 0.21–0.41). Children with DCD had significantly higher total CAMP scores, indicating poorer performance (57.80 ˙ 49.40) when compared with their TD counterparts (31.80 ˙ 27.70; $p < 0.05$) |
| L. Rosenberg, T. Jarus and O. Bart (2010) | Development and initial validation of the Children Participation Questionnaire (CPQ). | To develop and test the psychometric properties of a parent-reported questionnaire (Children Participation questionnaire [CPQ]) measuring participation of preschool children aged 4–6 years in their everyday activities. | Quantitative (Survey) | CPQ | Four hundred and eighty (480) children participated in the study: 231 children with mild to moderate developmental disabilities (mean age 5.16 years old) were compared to 249 children without disabilities (mean age 5.13 years old). | Reliability was tested by Cronbach's α and by test–retest. Construct validity was computed by known group differences analysis. Convergent and divergent validities were calculated by correlation with the Vineland Adaptive Behaviour Scale (VABS). | The CPQ has good internal reliability. Cronbach's α for the participation measures ranged between 0.79 and 0.90, indicating good homogeneity. The temporal stability of the CPQ was supported with intra-class correlations ranging from 0.71 to 1.00. Significant differences were found between children with disabilities and children without disabilities in all the CPQ measures. The CPQ could also differentiate between age groups and groups of varying socioeconomic statuses. Convergent and divergent validity were supported. |

| Author(s) | Title | Aim(s) | Design | Participation Measure | Participants | Procedures | Findings |
|---|---|---|---|---|---|---|---|
| B. Hyndman, A. Telford, C. Finch, S. Ullah and A.C. Benson (2013) | The Development of the Lunchtime Enjoyment of Activity and Play Questionnaire. | To develop and assess the reliability of the Lunchtime Enjoyment of Activity and Play (LEAP) questionnaire. | Quantitative | LEAP | One hundred and seventy-six (176) children aged 8-12 years attending a government elementary school in regional Victoria, Australia. | Questionnaire items were categorised employing a social-ecological framework including intrapersonal, interpersonal and environment/policy components to identify the broader influences on children's enjoyment. The LEAP questionnaire was administered on two separate occasions, ten days apart. | Test-retest reliability confirmed that 35 of 39 LEAP questionnaire items had at least moderate kappa agreement ranging from 0.44 to 0.78. Although four individual kappa values were low, median kappa scores for each aggregated social-ecological component reached at least moderate agreement (0.44-0.60). |

Based on the studies outlined in Table 1, various trends were identified, including the context in which the studies were conducted, the age of the participants and the inclusion of self-reports. Consideration was made of elements, including the measures used in the various studies, the domains of participation covered, the methods of validation applied in each study and the findings made regarding the validity of each instrument. These trends and elements are detailed below.

## 1.2 Context

Not one of the studies reviewed were conducted in Africa. Five were conducted in Europe, including one in North East England (Tuffrey, Bateman, & Colver, 2013), one in Germany (Fink, Gebhard, Erdwiens, Haddenhorst, & Nowak, 2016), another in Spain (Longo, Badia, Orgaz, & Verdugo, 2012), one in Netherlands (Bult et al., 2013), and one in Sweden (Åström, Khetani, & Axelsson, 2018). Six studies were conducted in Asia, including South Korea (Jeong, Law, Stratford, DeMatteo, & Kim, 2016; Jeong, Law, Stratford, DeMatteo, & Missiuna, 2017), Jordan (Malkawi, Abu-Dahab, Amro, & Almasri, 2017), Israel (Bar-Shalita, Yochman, Shapiro-Rihtman, Vatine, & Parush, 2009; Rosenberg, Jarus, & Bart, 2010), and Singapore (Lim, Law, Khetani, Rosenbaum, & Pollock, 2018). Another four studies were conducted in North America, including various regions of the United States (Chiarello et al., 2014; Khetani, Graham, Davies, Law, & Simeonsson, 2015), and several provinces of Canada (Chiarello et al., 2014; McCauley et al., 2012; McDougall, Bedell, & Wright, 2013). The remaining three studies were conducted in Australia (Chien, Rodger, & Copley, 2015; Hyndman, Telford, Finch, Ullah, & Benson, 2013; Tsang et al., 2010).

None of the studies completed were conducted in South Africa and although they represent a diverse sample, none can be generalised to the South African context. This, in part, is because participation as a construct is context specific and influenced by an individual's interaction with their environment (Hammel et al., 2008; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009).

## 1.3 Ages of Participants

The studies reviewed were focused on the youth, which encompassed children aged 0 to 12 years and adolescents aged 13 to 18 years. Twelve of the studies investigated the participation of children ranging in age from 0 to 6 years (Åström et al., 2018; Bult et al., 2013; Chiarello et al., 2014; Chien et al., 2015; Jeong et al., 2016, 2017; Khetani et al., 2015; Lim et al., 2018; Malkawi et al., 2017; McCauley et al., 2012; Rosenberg et al., 2010; Tsang et al., 2010). Eleven studies investigated participation of children ranging from 7 to 12 years (Bar-Shalita et al., 2009; Chien et al., 2015; Fink et al., 2016; Hyndman et al., 2013; Jeong et al., 2016, 2017; Lim et al., 2018; Longo et al., 2012; McCauley et al., 2012; McDougall et al., 2013; Tsang et al., 2010). Six studies explored participation in adolescents aged 13 years to 18 years (Fink et al., 2016; Jeong et al., 2016, 2017; Longo et al., 2012; McDougall et al., 2013; Tuffrey et al., 2013). One study expanded to include individuals up to the age of 21 (Tuffrey et al., 2013).

## 1.4 Self-Ratings and Proxy Ratings

Of the reviewed studies, 13 were compiled using proxy reports, where significant others completed questionnaires or underwent interviews regarding their children's participation (Åström et al., 2018; Bar-Shalita et al., 2009; Bult et al., 2013; Chiarello et al., 2014; Chien et al., 2015; Jeong et al., 2016, 2017; Khetani et al., 2015; Lim et al., 2018; Malkawi et al., 2017; McCauley et al., 2012; Rosenberg et al., 2010; Tsang et al., 2010). Three studies were compiled using self-reports of participation (Hyndman et al., 2013; Longo et al., 2012; Tuffrey et al., 2013). Only one study reported using both self- and proxy ratings for comparison (McDougall et al., 2013). These findings are consistent with the previously mentioned lack of studies in which children with disabilities are asked to provide self-ratings, with researchers relying predominantly on proxy ratings from caregivers due to the paucity of strategies to obtain children's own views (Arvidsson et al., 2008).

## 1.5 Measures of Participation

In the reviewed studies, 15 measures of participation were used as primary measures. These included the Young Children's Participation and Environment Measure (YC-PEM) (Åström et al.,

2018; Khetani et al., 2015; Lim et al., 2018), the Participation and Environment Measure for Children and Youth (PEM-CY) (Jeong et al., 2016, 2017), the Preschool Activity Card Sort (PACS) (Malkawi et al., 2017), Questionnaire of Young People's Participation (QYPP) (Tuffrey et al., 2013), Assessment of Preschool Children's Participation (APCP) (Bult et al., 2013), Child and Adolescent Scale of Participation (CASP) (McDougall et al., 2013), the Children's Assessment of Participation and Enjoyment (CAPE) (Fink et al., 2016; Longo et al., 2012), the Caregiver Assessment of Movement Participation (CAMP) (Tsang et al., 2010), Craig Hospital Inventory of Environmental Factors for Children - Parent Version (CHIEF-PR) (Hyndman et al., 2013), the Children Participation Questionnaire (CPQ) (Rosenberg et al., 2010), the Lunchtime Enjoyment of Activity and Play (LEAP) questionnaire (Hyndman et al., 2013), the Children's Assessment of Participation with Hands (Chien et al., 2015), Preferences for Activities of Children (PAC) (Fink et al., 2016), Child Engagement in Daily Life measure (Chiarello et al., 2014), and the Participation in Childhood Occupation Questionnaire (PICO-Q) (Bar-Shalita et al., 2009). Two additional measures, the Vineland Adaptive Behaviour Scale (VABS) (Malkawi et al., 2017; Rosenberg et al., 2010) and the KIDSCREEN (Longo et al., 2012), were used in the studies, secondary to the PACS and the CAPE, respectively, with the purpose of correlation of the instruments.

Six of the abovementioned instruments were newly developed and required validation in their respective environments (Bar-Shalita et al., 2009; Hyndman et al., 2013; Khetani et al., 2015; Rosenberg et al., 2010; Tsang et al., 2010; Tuffrey et al., 2013). Furthermore, in nine of the studies, instruments were culturally adapted in order to be applicable to the various contexts in which they were being administered. Included in the instruments which were adapted were the YC-PEM, which was adapted for use in Singapore (Lim et al., 2018) and Sweden (Åström et al., 2018); the PEM-CY, adapted for use in South Korea (Jeong et al., 2016, 2017); the PACS, adapted for use in Jordan (Malkawi et al., 2017); the CAPE, adapted for use in Spain (Longo et al., 2012) and Germany (Fink et al., 2016; Longo et al., 2012); the PAC, for use in Germany (Fink et al., 2016); and the APCP, for use in the Netherlands (Bult et al., 2013).

One form of adaptation applied included the translation of the following six instruments: the YC-PEM into Swedish (Åström et al., 2018), the PEM-CY into Korean (Jeong et al., 2016, 2017), the PACS into Arabic (Malkawi et al., 2017), the CAPE into Spanish and German (Fink et al., 2016; Longo et al., 2012), the PAC into German (Fink et al., 2016), and the APCP into Dutch

(Bult et al., 2013). A second form of adaptation included revising items to be culturally relevant to the respective settings. This adaptation was made to all nine instruments applied cross-culturally (Åström et al., 2018; Bult et al., 2013; Fink et al., 2016; Jeong et al., 2016, 2017; Lim et al., 2018; Longo et al., 2012; Malkawi et al., 2017).

## 1.6 Domains of Participation

In closer review of the studies reviewed and included in Table 1, the domains of activities and participation as detailed in the ICF-CY model (WHO, 2007) could be applied comparatively. The majority of the studies addressed the five domains of participation, namely: self-care; domestic life; interpersonal interactions and relationships; major life areas; and community, social and civic life (Åström et al., 2018; Bar-Shalita et al., 2009; Fink et al., 2016; Jeong et al., 2016, 2017; Khetani et al., 2015; Lim et al., 2018; Longo et al., 2012; Malkawi et al., 2017; Rosenberg et al., 2010; Tsang et al., 2010; Tuffrey et al., 2013).

One of the studies reviewed addressed the complete nine domains of participation (McDougall et al., 2013). This study by McDougall et al. (2013) was considered to have been the more comprehensive, also being the only one which examined both self- and proxy reports. A major contributor to this scarcity of comprehensiveness is that consensus has not been reached on the definition of participation, and on what should be measured when measuring participation (Amado et al., 2013). Consequently, the comparison of instruments is complicated (Rainey et al., 2014).

## 1.7 Psychometric Properties of the Instruments

The reliability (internal consistency and test-retest reliability) of each of the instruments utilised in the reviewed studies was also reported in the respective studies. In order to measure internal consistency, Cronbach's alpha coefficient was used in 14 of the studies (Åström et al., 2018; Bar-Shalita et al., 2009; Bult et al., 2013; Chiarello et al., 2014; Fink et al., 2016; Hyndman et al., 2013; Jeong et al., 2016; Khetani et al., 2015; Lim et al., 2018; Malkawi et al., 2017; McCauley et al., 2012; McDougall et al., 2013; Rosenberg et al., 2010; Tuffrey et al., 2013). Two studies used the Rasch model to determine person-item reliability (Chien et al., 2015; Tsang et al.,

2010). Internal consistency was reported to range from moderate to excellent in 14 of the instruments used (Åström et al., 2018; Bar-Shalita et al., 2009; Chiarello et al., 2014; Chien et al., 2015; Hyndman et al., 2013; Jeong et al., 2016; Khetani et al., 2015; Lim et al., 2018; Longo et al., 2012; Malkawi et al., 2017; McCauley et al., 2012; McDougall et al., 2013; Rosenberg et al., 2010; Tsang et al., 2010). Furthermore, three studies reported that internal consistency varied from adequate to inadequate within the domains of the respective instruments (Bult et al., 2013; Fink et al., 2016; Tuffrey et al., 2013).

In order to measure test-retest reliability, intra-class coefficients (ICC) were used in 16 studies (Åström et al., 2018; Bar-Shalita et al., 2009; Bult et al., 2013; Chiarello et al., 2014; Chien et al., 2015; Fink et al., 2016; Jeong et al., 2016; Khetani et al., 2015; Lim et al., 2018; Longo et al., 2012; Malkawi et al., 2017; McCauley et al., 2012; McDougall et al., 2013; Rosenberg et al., 2010; Tsang et al., 2010; Tuffrey et al., 2013). One study made use of the Weighted Kappa ($Kw^2$) statistic to obtain Kappa values (Hyndman et al., 2013). Fourteen studies reported that test-retest reliability was good for the instruments used (Bar-Shalita et al., 2009; Chiarello et al., 2014; Chien et al., 2015; Hyndman et al., 2013; Jeong et al., 2016; Khetani et al., 2015; Lim et al., 2018; Longo et al., 2012; Malkawi et al., 2017; McCauley et al., 2012; McDougall et al., 2013; Rosenberg et al., 2010; Tsang et al., 2010; Tuffrey et al., 2013). Åström et al. (2018) and Fink et al. (2016) reported variances in test-retest values obtained.

The international studies reviewed reported acceptable reliability results for the instruments discussed. This is consistent to the view expressed by Brown and Bourke-Taylor (2014), who found that internal consistency and test-retest reliability are two of the most commonly used types of reliability estimates. This was evident in the studies reviewed. It can thus be agreed that when testing participation, test-retest is relevant (Marx et al., 2003).

## 1.8 Summary

From Table 1 it is evident that none of the participation studies reviewed above were conducted in South Africa, and although they represent a diverse sample and show mainly adequate levels of reliability, none can be generalised to the South African context because participation is context specific and influenced by individuals' interaction with their environment (Hammel et al., 2008; Verdonschot et al., 2009). It is also evident that there is a lack of studies in

which children with disabilities provide self-ratings (Arvidsson et al., 2008), as well as a need for the development of valid and reliable self-rating instruments (Brown & Bourke-Taylor, 2014). The PMP instrument has been developed for the evaluation of participation, focusing on LAMI countries. The current study aimed to determine the test-retest reliability of the PMP instrument for use with children who have intellectual disabilities.

# CHAPTER 2: Methodology

## 2.1 Main Aim of the Study

The current study forms part of a larger international study that focuses on participation in both high-income as well as LAMI countries. The main aim of the current study was to determine the test-retest reliability of the PMP instrument in measuring the perceptions of children with mild to moderate intellectual disabilities and their primary caregivers regarding the children's participation in activities occurring within their home and community.

## 2.2 Secondary Aim of the Study

The secondary aim of the study was to establish the test-retest reliability of the PMP instrument by comparing the responses of the primary caregivers and, independently, that of their children with intellectual disabilities on Test 1 (T1) and, again, two weeks later, on Test 2 (T2) in terms of:

1. the frequency of attendance,
2. the level of involvement,
3. the ranking of the most important activities, and
4. barriers to and facilitators of participation.

## 2.3 Research Design and Phases

The study was conducted using a quantitative, non-experimental comparative survey (McMillan & Schumacher, 2014). By making use of a quantitative design, participants' perceptions of participation could be determined and described using a set structure, while a comparative design allowed for investigation of the differences between participant responses provided on two separate occasions (McMillan & Schumacher, 2014). The benefit of using a non-experimental design was that the research could be conducted within a short period of time as no variables required manipulation (McMillan & Schumacher, 2014). Survey designs are routinely used to describe opinions, beliefs and attitudes in educational research (McMillan & Schumacher,

2014). In the current study, the use of a survey design offered numerous benefits both in the distribution of caregiver questionnaires to be completed at home and in conducting the interviews with the child participants. Caregiver questionnaires completed at home were both time efficient and allowed the researcher to save on travel expenses; it also provided the caregivers with the assurance that their responses were confidential (Leedy & Ormrod, 2005). Interviews with the child participants provided surety of their identity and allowed the researcher to facilitate understanding of the questions in the use of the adapted questionnaire incorporating the use of Talking Mats™ (Murphy & Cameron, 2008). Disadvantages to using a survey included increased costs incurred through photocopying expenses and significant amounts of time spent conducting interviews with the child participants (Leedy & Ormrod, 2005). In addition, sending the questionnaires home for completion did not provide surety of who completed the survey and what their state of mind was at the time (Leedy & Ormrod, 2005).

In order to achieve test-retest reliability, each participant was required to complete the survey on two different occasions, referred to as Test 1 (T1) and Test 2 (T2), scheduled two weeks apart (Marx et al., 2003; McMillan & Schumacher, 2014). The research comprised two phases, as outlined in Figure 1 below. These included: Phase 1 - the preparation phase and Phase 2 - the main study.

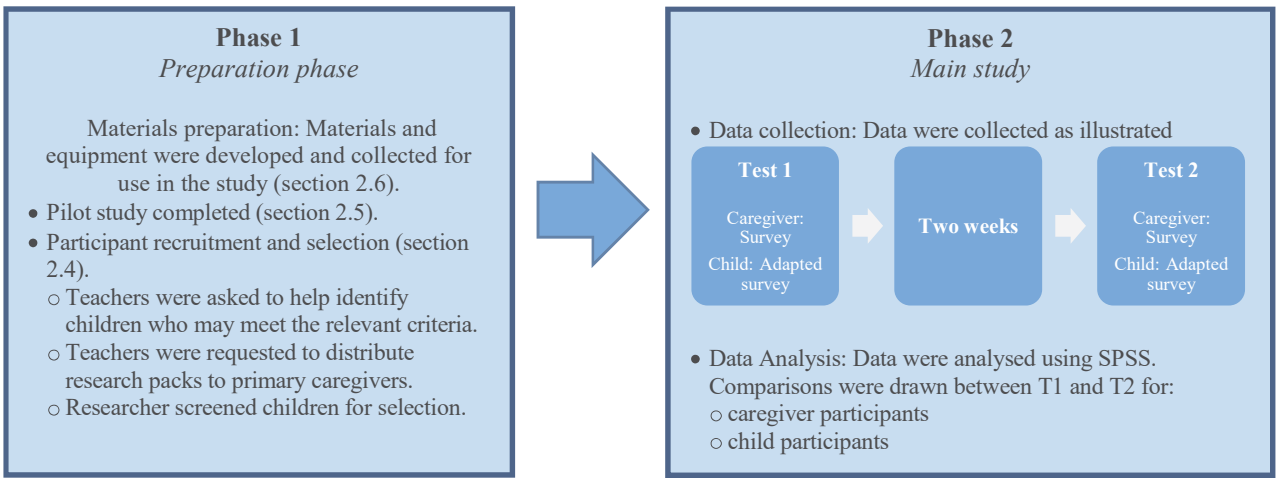



**Figure 1: Phases of the study**

## 2.4 Recruitment and Sampling

Two schools situated within the Gauteng province were approached to participate in the study and are represented as School A and School B. At the time of study, both were public schools located in an urban area and accepting children from their respective feeding areas in and around Tshwane, as prescribed by the Department of Education. The children enrolled in both schools were aged 12 to 18 years and diagnosed with intellectual disability ranging from mild to moderate. While learner assessments and enrolment were ongoing, both schools maintained an average of 640 learners enrolled at the time of the study. Both schools made use of both the adapted CAPS (Curriculum Assessment Policy Statement) and the TOC (Technical Occupational Curriculum), and offered tuition in English or Afrikaans. For the purpose of this study, only children enrolled in the English programmes offered at either school were considered for participation.

At School A, 25 research packages were distributed to caregivers, of which 17 returned; 14 caregivers provided consent to participate and three declined. Three others were excluded due to consent not being provided by a parent but by another family member and one was excluded due to the child not meeting the selection criteria. Data collection thus began with ten caregiver participants. Nine child participants underwent the assent procedure, provided assent and met the criteria following completion of the Kaufman Brief Intelligence Test - Second Edition (KBIT-2) screening. Only seven of these children completed the child data collection requirements for T1 and T2; however, a further two were excluded as they did not fulfil all data collection requirements, with primary caregiver information missing. Therefore, only five children from School A participated in the study.

At School B, 20 research packages were distributed to caregivers, of which 16 returned; 13 caregivers provided consent to participate and three declined. One was excluded due to the child not meeting the selection criteria. Eleven children underwent the assent procedure, provided assent and met the criteria following completion of the KBIT-2 screening. Therefore, 11 children from School B participated in the study.

An initial number of 45 research packages were distributed to caregivers and 33 were returned, a return rate of 73%. Ultimately, only 16 primary caregivers and 16 children participated in the study.

### 2.4.1 Participant selection

Non-probability purposeful sampling (McMillan & Schumacher, 2014) was utilised to select 16 primary caregivers of children with mild to moderate intellectual disabilities and their children. A limitation of non-probability sampling is that results cannot be generalised to the broader population regardless of whether the sample meets the description of the population (McMillan & Schumacher, 2014). Purposeful sampling is dependent on the judgment of the researcher in selecting the sample. It was therefore imperative to outline the selection criteria carefully, based on sound knowledge so as not to disadvantage the study.

The participant selection criteria for primary caregiver and child participants are presented in Tables 2 and 3, respectively.

**Table 2: Primary caregiver selection criteria**

| Criterion | Justification | Measure used |
|---|---|---|
| Primary caregiver of a child with mild to moderate intellectual disability enrolled in a school for learners with special education needs (LSEN). | The study seeks to investigate participation in activities from the caregivers' perspectives. | Reported in the biographical section of the caregiver questionnaire. |
| Primary caregiver who is literate in English. | Literacy in English will ensure that the participant is able to independently complete the questionnaire. | Reported in the caregiver questionnaire. |

**Table 3: Child selection criteria**

| Criterion | Justification | Measure used |
|---|---|---|
| Enrolled in an LSEN school. | Children who have intellectual disabilities are likely to be enrolled in schools with admission criteria of intellectual disability (Human Rights Watch, 2015). | Caregiver Questionnaire. |
| Children aged 12;0 to 17;11 [years;months] years. | The PMP instrument is developed for children aged 5 to 21 years. | Caregiver Questionnaire. |

| Criterion | Justification | Measure used |
|---|---|---|
| Children who speak English. | The survey will be administered in English. Children must be enrolled in an LSEN school with English as language of learning and teaching (LoLT). | Caregiver Questionnaire and the Learner Screening Tool by Educators (LeSTE). |
| Mild to moderate intellectual disability. | There is limited research that focuses on obtaining children with intellectual disabilities' perceptions of participation (Cameron & Murphy, 2007). | Kaufman Brief Intelligence Test - Second Edition (KBIT-2) (Kaufman & Kaufman, 2004). |
| Functional hearing, vision and motor skills. | Verbal instructions are provided in administration. Pictures are used in the assessment materials. Data collection requires the participant to point to pictures on the Talking Mats™. | Caregiver Questionnaire. |

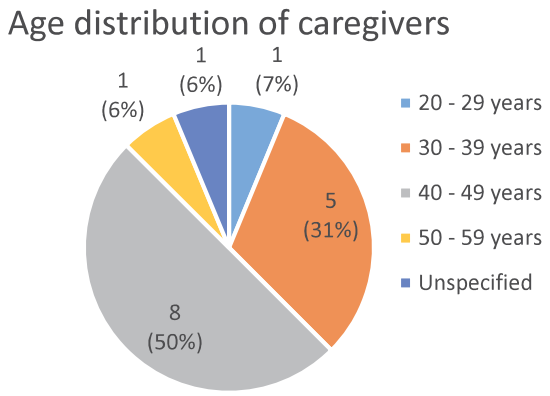
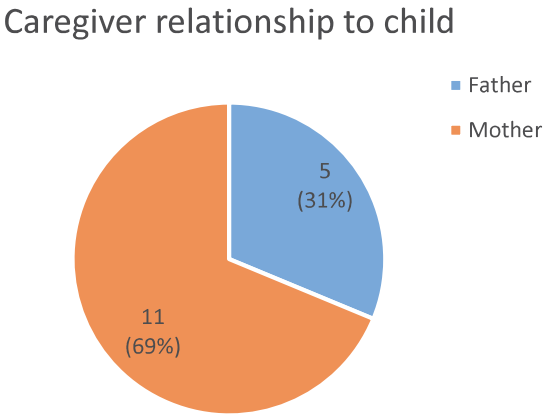
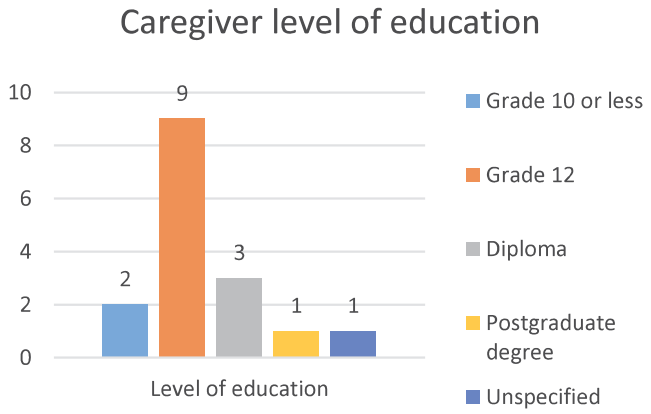
### 2.4.2 Participant Description

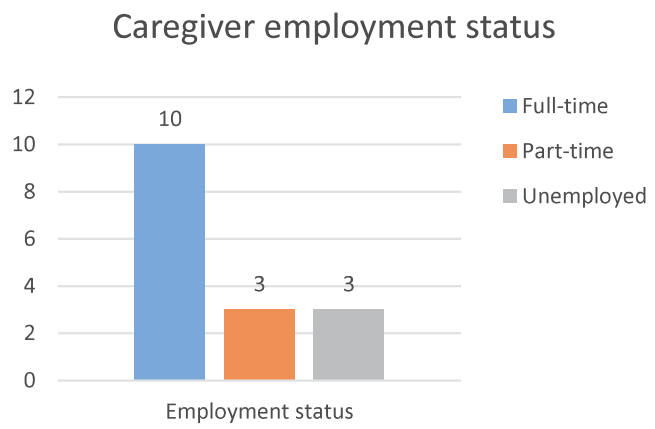
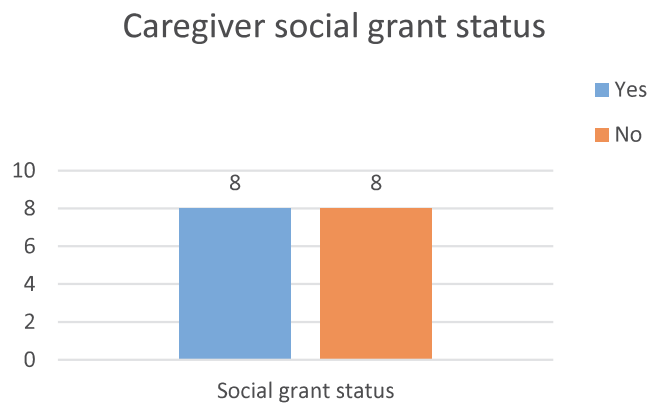
A description of the caregiver and child participants is provided below.

#### *2.4.2.1 Primary caregiver participants*

The sample of primary caregiver participants consisted of 16 parents who met the criteria detailed, who provided consent for themselves and their children to participate in the study, and who completed both sets of data collection procedures at T1 and T2 (two weeks apart). Primary caregiver participants are described in Table 4 below according to age, relationship to child as well as socio-economic status, including level of education, employment status and social grant status.

**Table 4: Description of caregiver participants**

| Descriptive Category | Graphic Representation |
|---|---|
| Age group<br><br>The mean age of primary caregiver participants was 39;4 (years;months). Fifty percent were aged 40-49 years (n = 8), 31% were aged 30-39 years (n = 5) and the remaining 19% (n = 3) indicated 20-29 years, 50-59 years and one did not specify their age. |  |
| Relationship to child<br><br>Sixty-nine percent (n = 11) of primary caregiver participants were mothers of the children; the rest were fathers (n = 5; 31%). |  |
| Level of education<br><br>Fifty-six percent (n = 9) of the primary caregivers who participated had completed grade 12, 19% (n = 3) had a diploma, 13% (n = 2) had a grade 10 or less, and 6% (n = 1) had a postgraduate degree. |  |

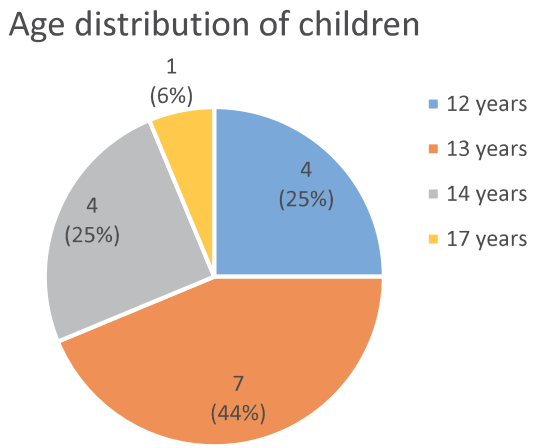
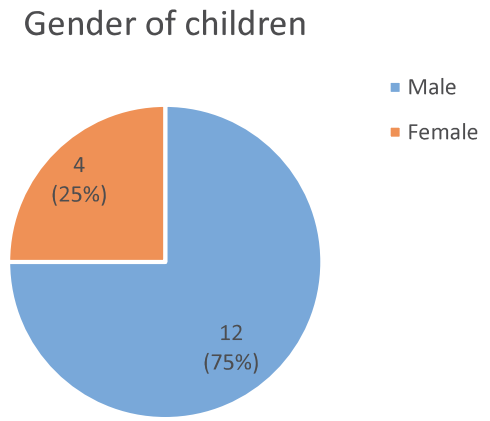
| Descriptive Category | Graphic Representation |
|---|---|
| Employment status<br><br>Sixty-two percent (n = 10) of the primary caregiver participants indicated that they were employed full-time, 19% (n = 3) were employed part-time, and 19% (n = 3) were unemployed. |  |
| Social grant status<br><br>Fifty percent (n = 8) of the caregiver participants indicated that they were receiving a social grant (disability grant for their child) and 50% (n = 8) indicated that they were not receiving a social grant. |  |

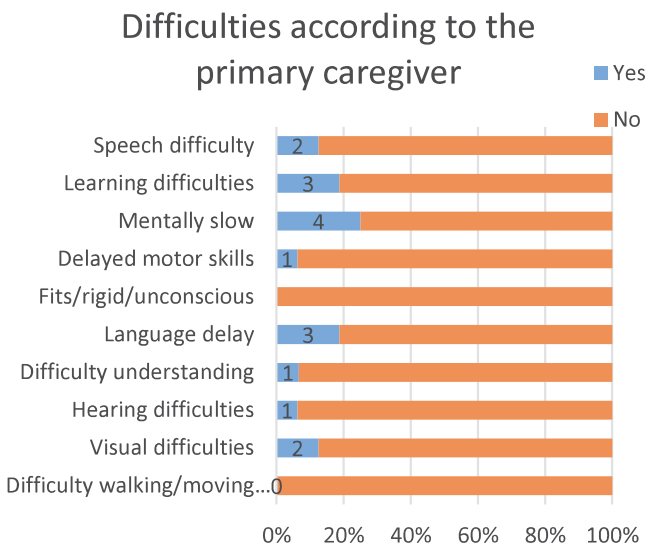
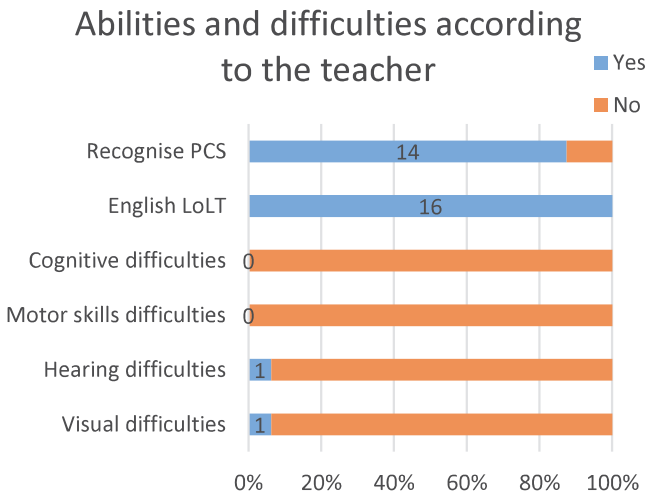
The majority of the caregivers who participated in this study were females who indicated that they were mothers to the children who participated in the study. The mean age of the participants was 39;4 years, with 50% indicating that they were aged 40-49 years. Descriptions of the caregiver sample show that 50% of the participants in the study were from low socio-economic (low-income) households, while 50% of the participants were from middle-income households. Factors suggesting this are the equal division observed in the reception of social grants, the high rate of full-time employment and the low level of tertiary education reported.

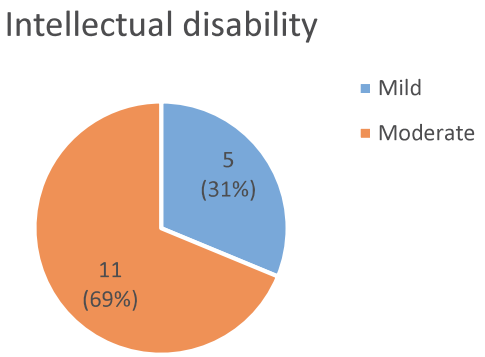
### *2.4.2.2 Description of child participants*

The sample of child participants comprised 16 participants who met the selection criteria for the study, provided assent to take part in the study, and completed both sets of data collection procedures. Child participants in the study are described in Table 5 below according to age, gender, ability to participate in the study (indicated by the LeSTE and the Ten Questions Questionnaire [TQQ]), and intellectual disability.

**Table 5: Description of child participants**

| Descriptive Category | Graphic Representation |
|---|---|
| Age<br><br>The mean age of the child participants was 13;3 (years;months). Forty-four percent (n = 7) were aged 13 years, 25% (n = 4) were aged 12 years, 25% (n = 4) were aged 14 years and 6% (n = 1) were aged 17 years. |  |
| Gender<br><br>Seventy-five percent (n = 12) of the children who participated were male, while 25% (n = 4) were female. |  |

| Descriptive Category | Graphic Representation |
|---|---|
| Caregiver rating on their child, using the TQQ<br><br>Four caregiver participants (25%) considered their child to be mentally slow. Three (19%) indicated that their child had difficulties with learning, three (19%) indicated language delay, while two (13%) indicated difficulties with speech and another two (13%) indicated difficulties with vision. One caregiver participant (6%) indicated delayed motor skills, another hearing difficulty and one other indicated difficulty understanding language. None of the caregiver participants indicated that their child had difficulties with seizures or with walking or moving arms. |  |
| Child abilities and difficulties according to the teacher, using the LeSTE<br><br>Fourteen (88%) of the child participants were considered able to likely recognise picture communication symbols (PCS). One (6%) was indicated as having hearing difficulties and another as having visual difficulties. All of the child participants were indicated as able to use English as LoLT. None were reported as having cognitive difficulties or motor difficulties, which could hinder their participation in the study. |  |

| Descriptive Category | Graphic Representation |
|---|---|
| Intellectual disability according to the KBIT-2<br><br>The mean IQ composite scored on the KBIT-2 was 68. Of the child participants, 69% (n = 11) presented with moderate intellectual disability, and 31% (n = 5) presented with mild intellectual disability. |  |

Seventy-five percent of the children who participated in the study were male and the mean age of child participants was 13;3 years. The majority of the child participants were not considered to have any significant limitations and all were considered to be able to participate in the study, as reported by the teachers and the caregivers. Thirty-one percent of the child participants presented with mild intellectual disability, while 69% presented with moderate intellectual disability. The mean IQ composite score for the child participants was 68. All the participants were able to communicate in English.

## 2.5 Pilot study

A pilot study was conducted in order to ensure that the strategies, procedures and materials proposed for the main study were appropriate for the study.

### 2.5.1 Participant

One child took part in the pilot study. The child selected passed the screening procedures for recruitment and for selection. He was a boy aged 8;9 years, with English as the LoLT at school. He scored an IQ composite of 73 on the KBIT-2, indicative of mild intellectual disability (Kaufman & Kaufman, 2004).

### 2.5.2 Aims, materials, procedures, results and recommendations

Table 6 below provides an overview of the pilot study aims, the materials and procedures used, the results and the subsequent recommendations.

**Table 6: Pilot study aims, materials, procedures, results and recommendations**

| Aim | Materials | Procedures | Results | Recommendations |
|---|---|---|---|---|
| To determine the appropriateness of the recruitment strategy to identify potential participants. | • LeSTE<br>• Biographical questionnaire | Questionnaire to be completed by teachers; however, for the pilot study, the researcher completed the questionnaire with assistance from the parent of the participant. | The participant was able to participate in the study in terms of vision, hearing, motor skills and cognition. | It was recommended that the same criteria be used in the main study, completed by the teachers. |
| To determine the appropriateness of the measures to identify potential child participants. | • Caregiver consent form and survey booklet<br>• KBIT-2 | Completed by the caregiver.<br>Screening instrument administered by researcher prior to data collection. | The participant passed the screening procedures. | It was recommended that the same criteria be used in the main study. |
| To determine the appropriateness of the PMP and Talking Mats™ for data collection with children who have intellectual disability. | • PMP instrument<br>• Talking Mats™ | Interview conducted with the participant and the PMP administered by the researcher using Talking Mats™. | The participant was able to understand and follow the instructions provided during the data collection procedures. | It was recommended that the same wording of the PMP and the same Talking Mats™ be used in the main study. Clearer markings were applied to the Talking Mats™ for the study, however, in order to enhance the clarity for the video recorder. |
| To determine the procedural integrity for data collection. | • Video recorder<br>• Procedural checklist | Interview conducted with the participant and the PMP administered by the researcher using Talking Mats™. | The researcher was able to complete the procedures. One limitation encountered was due to the interview being completed in the child's home environment; steps 1 to 3 (involving child collection | It was recommended that the same procedures be used in the main study. |

| Aim | Materials | Procedures | Results | Recommendations |
|---|---|---|---|---|
| | | | from and return to class) were excluded. | |
| To determine whether the strategy selected for recording and analysing data was appropriate for this study. | • Microsoft Excel<br>• SPSS | Data captured by the researcher using Microsoft Excel and transferred to SPSS for analysis. | It was noted that time efficiency was increased when data were captured directly using SPSS for analysis. Microsoft Excel was used for deeper analysis of barriers and facilitators with regards to priority activities. | Data were captured and analysed using SPSS. |

## 2.6 Materials and Equipment

A description of the letters, measures, equipment and tokens is provided below.

### 2.6.1 Letters

#### *2.6.1.1 Principal permission letter*

Permission to conduct research was requested from the principals of the two participating schools and obtained in the form of an informed permission letter. The letter contained information detailing the aims and data collection procedures of the study, and a reply form (Appendix C).

#### *2.6.1.2 Teacher consent letter*

Informed consent to assist with the research was obtained from the teachers at the participating schools in the form of a letter. The letter contained information detailing the aims and requirements of the study as well as what their involvement in the study would entail (Appendix D).

#### *2.6.1.3 Primary caregiver consent letter*

Consent to participate in the research was obtained from the primary caregivers in the form of a letter. The letter contained information detailing the aims and requirements of the study. Primary caregiver participants were required to consent for their own participation in the study as well as for their child with intellectual disability (Appendix E).

#### *2.6.1.4 Child assent form*

Assent to participate in the research study was requested from each child participant. The assent form included a child-appropriate information letter which outlined the relevant data collection procedures and a picture-based response regarding their assent (Appendix H).

### 2.6.2 Materials

#### *2.6.2.1 Kaufman Brief Intelligence Test - Second Edition (KBIT-2)*

The KBIT-2 (Kaufman & Kaufman, 2004) is a standardised screening tool indicated for the identification of a child's intelligence quotient (IQ) (Kaufman & Kaufman, 2004). The KBIT-2 has been designed to measure verbal and nonverbal intelligence in individuals aged 4 to 90 years (Bain & Jaspers, 2010). It comprises three subtests: (1) verbal knowledge, (2) matrices and (3) riddles, of which two are verbal (requiring one-word responses) and one is non-verbal (Kaufman & Kaufman, 2004) (Appendix I).

The KBIT-2 was administered to each child participant prior to administration of the PMP instrument. Children scoring an IQ composite between 40 and 84, indicating mild to moderate intellectual disability, were included in the study.

#### *2.6.2.2 Picture My Participation (PMP) instrument*

The PMP instrument has been developed to identify the frequency of, involvement in as well as barriers to and facilitators of a child's participation in activities occurring at home, school and in the community (Elliot et al., 2015) (Appendix J). It contains three trial items followed by three sections aiming (1) to determine perceived attendance in various activities using a four-point Likert-type scale, and involvement in the same activities using a three-point Likert-type scale; (2) to prioritise activities considered to be most important to the child, and (3) to determine perceived barriers and facilitators to participation (Arvidsson, et al., in preparation). The PMP instrument comprises 20 activities and considers four domains of participation according to the ICF (WHO, 2007). Table 7 details the domains addressed by the PMP and groups the various activities discussed in the instrument according to domain.

**Table 7: Domains of participation and corresponding items and activities**

| Domain of Participation | PMP Item |
|---|---|
| Family activities | Meal preparation, Family time, Family mealtime |
| Organised activities | Overnight visits and trips, Organised leisure, Cleaning at home, Health centre, Gathering supplies, Shopping |
| Personal activities | School, Personal care, Own health |
| Social interactions | Playing with others, Caring for family, Spiritual activities, Celebrations, Caring for animals/pets, Social activities |

#### *2.6.2.3 Talking Mats™*

The Talking Mats™ framework is a low-tech, visual communication recourse that helps people with communication difficulties to express their thoughts (Cameron & Murphy, 2007). The Talking Mats™ framework utilises a mat and picture symbols to facilitate understanding and support expression (Bornman & Murphy, 2006; Germain, 2004; Murphy & Cameron, 2008). This framework has been used successfully in obtaining the views of children with intellectual disabilities in South Africa regarding their human rights (Donohue, Bornman, & Granlund, 2014; Huus et al., 2015) and is therefore considered likely to be effective in obtaining the views of children regarding participation as well.

The framework was used to complete the PMP instrument with children with intellectual disability and to elicit responses from child participants. Each child participant was required to complete two Talking Mats™ in accordance with the sections of the PMP instrument. The Talking Mats™ measured approximately 50 cm in length and 35 cm in width. Used with picture symbols (a set of colour and black-and-white drawings, as illustrated in Appendix J), child participants were required to place picture symbols on the relevant Talking Mats™ to indicate their responses. A sample of a completed Talking Mats™ has been included in Appendix K.

#### *2.6.2.4 Ten Questions Questionnaire (TQQ)*

The TQQ is a screening tool designed to gather information about the nature of the child's disabilities, including cognitive, motor and seizure (Mung'ala-Odera et al., 2004). Developed for use in developing countries, the TQQ is time and cost effective for children aged 2-9 years, comprising ten closed-ended questions (Singhi, Kumar, Malhi, & Kumar, 2007) (Item 12 of Appendix F). Primary caregivers were requested to complete this at the time of completing the

PMP instrument, in order to provide information regarding the abilities and possible limitations that the child may have.

#### *2.6.2.5 Survey booklet*

A survey booklet was used to collect data from the primary caregiver participants (see Appendix F). The booklet comprised three sections: Section A included demographic data about the caregivers and their children, as well as the TQQ (Mung'ala-Odera et al., 2004), Section B included the PMP instrument (attendance and involvement), Section C was on prioritisation and Section D on barriers and facilitators.

#### *2.6.2.6 Learner Screening Tool by Educators (LeSTE)*

The LeSTE (Naudé, 2014) is a questionnaire that was completed by teachers of the child participants for each child participant. It comprised 18 closed-ended questions intended to provide information on the learners' abilities pertaining to vision, hearing, motor skills, cognitive ability and LoLT (see Appendix G).

#### *2.6.2.7 Procedural script*

A procedural script was used to outline the various procedures to be followed in the data collection process for the child participants. It consisted of eight steps and 21 sub-steps to be completed as part of the data collection process (see Appendix L).

#### *2.6.2.8 Procedural checklist*

A procedural checklist was used for the child data collection, to guide adherence to procedures set out (see Appendix M). It consisted of 24 items comprising eight steps and 21 sub-steps to be followed in order. The 'yes' box had to be ticked after completing each step.

### 2.6.3 Equipment and tokens

#### *2.6.3.1 Videorecorder and camera*

A Samsung ES30 digital camera was used to video record the adapted survey conducted with child participants.

#### *2.6.3.2 Tokens of appreciation*

Each child participant was provided with a stationary combo, which included a ruler, a pen and a pencil, to thank them for participating in the study.

## 2.7 Procedures

### 2.7.1 Ethical procedures

Specific principles and guidelines were adhered to in order to uphold the ethical and legal responsibilities of conducting a research study using human participants (McMillan & Schumacher, 2014). A research proposal was submitted to the Ethics Committee at the University of Pretoria (UP) in order to obtain ethical clearance. Ethical clearance was granted for the purpose of conducting this study (see Appendix A). Permission to conduct research at schools in the Gauteng province was subsequently applied for at the Gauteng Department of Education. Permission was obtained (see Appendix B). In addition, permission to conduct research at the selected schools was requested and obtained from the respective school principals (see Appendix C).

Informed consent letters outlining the aims and procedures of the study were provided to the teachers assisting and to the primary caregivers (Appendices D and E, respectively). Assent was also obtained from child participants (Appendix H). All participants were informed that their participation is voluntary, that they have the right to withdraw from the study at any point, and that data will be stored at the University of Pretoria for 15 years.

Moreover, the confidentiality of participants was protected by provision and return of survey booklets in sealed envelopes. All data were treated confidentially and no identifying

information was provided on the booklets or response sheets. Participants were assigned participant numbers.

Teachers were consulted about an appropriate time to conduct the study to ensure that it did not interfere with academic time.

### 2.7.2 General procedures

The researcher contacted the schools telephonically and requested a meeting with the respective school principals. In each meeting, the purpose and the nature of the study were presented to and discussed with the principals. The principals provided written permission and facilitated introductions with the teachers. Informed consent letters were distributed to the teachers, who were required to provide written consent to assist the researcher in the study with the distribution and collection of the research packages to the primary caregivers, completion of the LeSTE for prospective child participants and assisting the researcher in locating the child participants during data collection.

### 2.7.3 Data collection procedures

#### *2.7.3.1 Caregiver data collection procedure*

Upon obtaining the relevant approvals and permissions, research packages were sent to the relevant primary caregivers. Primary caregivers were provided with a research package in a sealed envelope containing (1) an informed consent letter and reply slip (Appendix E), (2) a survey booklet (Appendix F), and (3) an unused sealable envelope. The informed consent letter and survey booklet were required to be completed at home and returned to the school in the sealed envelope provided. Paper-pencil surveys (Leedy & Ormrod, 2005) were utilised for caregiver participants. After two weeks of the initial package being sent, the same participants who had provided consent and whose children had provided assent were provided with a research package which included the same survey booklet and an unused sealable envelope contained in a sealed envelope and requested to complete the survey booklet once again.

#### *2.7.3.2 Child data collection procedure*

On the dates for data collection, as pre-arranged with the participating schools, assisting teachers and child participants one at a time were taken to a quiet room for the data collection procedures to be completed. Data were collected using the procedural script (Appendix L).

The assent procedure was administered for prospective child participants. For those participants who provided assent, the KBIT-2 (Kaufman & Kaufman, 2004) was administered to screen for intelligence. Child participants who met the criteria were asked questions and shown corresponding pictures using the PMP instrument, following a familiarisation of the process with trial items. Adapted surveys of the PMP instrument (Appendix J) were used for child participants. Each item was read aloud by the researcher, with a corresponding visual depiction of the item shown to the child, as is illustrated on the PMP instrument. The child participants completed the surveys individually with the researcher using the Talking Mats$^{TM}$ framework (Appendix K). Each participant was required to respond by placing the relevant symbols on the relevant section of the Talking Mats$^{TM}$ or by pointing to the appropriate choice indicating their selection. Two weeks after the initial administration of the PMP, the administration process of the PMP was repeated. Each child was provided with a small token of appreciation upon completion of the data collection process.

After the study was completed, feedback (Appendix N) was provided to the school principal and teachers through a presentation, as well as a one-page easy-to-read version of the study and its findings. A report on the findings of this study will be provided to the Gauteng Department of Education (GDE). A copy of this mini-dissertation will also be provided to the GDE after the examination process.

## 2.8 Validity and Reliability

### 2.8.1 Internal validity

In order to avoid the Hawthorne effect in which participants may give what they believe to be socially desirable answers (McMillan & Schumacher, 2014, p. 126), it was ensured that each

participant was informed that there was no wrong or right answer to the questions and that the study sought to explore their own opinions and perceptions.

### 2.8.2 Reliability

#### *2.8.2.1 Procedural reliability*

To ensure procedural integrity, a procedural checklist (Appendix M) was used. Inter-rater reliability was used to ensure procedural reliability (McMillan & Schumacher, 2014). Forty percent of the video recordings were reviewed by an independent rater and compared to the procedural checklist for each of the corresponding participants. The independent rater focused on the PMP administration and reported complete agreement with its administration. Inter-rater reliability is represented as a percentage calculated using the following formula (McMillan & Schumacher, 2014):

$$\frac{\text{Number of correctly scored items (agreements): } 176}{\text{Number of agreements} + \text{incorrectly scored items (disagreements): } 176} \times 100 = 100\%$$

#### *2.8.2.2 Data reliability*

Inter-rater reliability was determined to ensure data reliability (McMillan & Schumacher, 2014). The independent rater at the time of study held an honours degree in occupational therapy. The rater assessed a minimum of 40% of both the caregiver and child questionnaires, and compared whether the researcher had captured the data accurately on the SPSS software. Inter-rater reliability is represented as a percentage calculated using the following formula (McMillan & Schumacher, 2014):

$$\frac{\text{Number of agreement: } 686}{\text{Number of agreements} + \text{disagreements: } 686} \times 100 = 100\%$$

An overall score of 100% inter-rater reliability was calculated, indicating excellent inter-rater reliability.

## 2.9 Data analysis

Data were analysed with the assistance of a statistician. SPSS v.25 and Microsoft Excel 2016 were utilised for data analysis. Descriptive statistics (McMillan & Schumacher, 2014) were used to analyse and present the data collected. Descriptive statistics (i.e. frequency tables) were effective in allowing the researcher to summarise data which contained large amounts of numbers (McMillan & Schumacher, 2014).

Data from both child participants and primary caregiver participants were captured by the researcher using SPSS. The data consisted of 20 Likert-scale questions, of which responses were evaluated for (1) frequency of attendance and (2) level of involvement. Participant responses for each group were then captured according to the coding presented in the PMP and detailed below:

**Attendance Likert-scale options:**

- Always (1)
- Sometimes (2)
- Not really (3)
- Never (4)

**Involvement Likert-scale options:**

- Very (1)
- Somewhat (2)
- Minimally (3)

There were several missing values for the primary caregivers. The absence of multiple values in some questions made the already small sample even smaller. All the missing values were grouped into a group called “0”, and comparisons were run of the dependent groups to determine whether a difference exists between the overall results reported for Test 1 and Test 2. The captured data were then analysed for internal consistency and reliability. In addition, a prioritisation analysis was completed to determine whether a significant difference exists between the child participant and their primary caregivers. The results are presented visually in the next chapter through tables and figures.

# CHAPTER 3: Results and Discussion

## 3.1 Descriptions of Likert Variables

Tables 8-11 summarise the descriptive statistics for each of the questions which addressed frequency of attendance and level of involvement in the survey. Tables 8 and 9 represent the statistics for the primary caregiver participants and Tables 10 and 11 represent the statistics for the child participants. For each table, the two tests (T1 and T2) have been split. Those questions which had missing values have been highlighted in green.

### 3.1.1 Primary caregiver participants

**Table 8: Frequency of attendance: Primary caregivers – Test 1 and Test 2**

| | T1 | | | | | T2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Min | Max | Mean | Std. Deviation | N | Min | Max | Mean | Std. Deviation |
| Personal care | 15 | 4 | 4 | 4.00 | 0.000 | 16 | 3 | 4 | 3.87 | 0.342 |
| Family mealtime | 15 | 2 | 4 | 3.60 | 0.632 | 16 | 3 | 4 | 3.69 | 0.479 |
| My own health | 14 | 1 | 4 | 3.36 | 0.842 | 15 | 2 | 4 | 3.33 | 0.900 |
| Gathering supplies | 15 | 1 | 4 | 2.93 | 1.100 | 16 | 1 | 4 | 2.69 | 0.793 |
| Meal preparation | 15 | 1 | 4 | 2.87 | 0.990 | 16 | 1 | 4 | 2.81 | 0.981 |
| Cleaning at home | 15 | 1 | 4 | 3.13 | 0.990 | 16 | 1 | 4 | 2.88 | 1.088 |
| Caring for family | 15 | 1 | 4 | 3.07 | 1.163 | 16 | 1 | 4 | 2.94 | 1.124 |
| Caring for animals and pets | 14 | 1 | 4 | 2.14 | 1.406 | 16 | 1 | 4 | 2.19 | 1.328 |
| Family time | 15 | 1 | 4 | 3.47 | 0.915 | 16 | 1 | 4 | 3.25 | 0.931 |
| Celebrations | 15 | 2 | 4 | 3.40 | 0.737 | 15 | 3 | 4 | 3.60 | 0.507 |
| Playing with others | 15 | 2 | 4 | 3.73 | 0.594 | 16 | 2 | 4 | 3.69 | 0.602 |
| Organised leisure | 15 | 1 | 4 | 3.53 | 0.915 | 16 | 1 | 4 | 3.06 | 1.063 |
| Quiet leisure | 15 | 1 | 4 | 2.73 | 1.033 | 15 | 1 | 4 | 3.33 | 0.900 |
| Spiritual activities | 15 | 1 | 4 | 3.00 | 1.000 | 16 | 1 | 4 | 3.25 | 1.000 |
| Shopping | 15 | 1 | 4 | 3.13 | 1.060 | 16 | 1 | 4 | 3.06 | 0.854 |
| Social activities | 15 | 1 | 4 | 3.53 | 0.915 | 16 | 2 | 4 | 3.25 | 0.683 |
| Health centre | 15 | 1 | 4 | 2.73 | 1.163 | 16 | 1 | 4 | 2.81 | 0.981 |

| | T1 | | | | | T2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Min | Max | Mean | Std. Deviation | N | Min | Max | Mean | Std. Deviation |
| School | 15 | 2 | 4 | 3.47 | 0.743 | 15 | 3 | 4 | 3.80 | 0.414 |
| Trips and visits | 14 | 1 | 4 | 2.43 | 0.938 | 16 | 1 | 4 | 2.75 | 0.775 |
| Employment | 15 | 1 | 4 | 1.73 | 1.163 | 15 | 1 | 4 | 1.73 | 1.100 |
| Valid N (listwise) | 12 | | | | | 11 | | | | |

**Table 9: Level of involvement: Primary caregivers – Test 1 and Test 2**

| | T1 | | | | | T2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Min | Max | Mean | Std. Deviation | N | Min | Max | Mean | Std. Deviation |
| Personal care | 11 | 1 | 3 | 2.64 | 0.809 | 10 | 2 | 3 | 2.90 | 0.316 |
| Family mealtime | 11 | 1 | 3 | 2.45 | 0.820 | 10 | 2 | 3 | 2.80 | 0.422 |
| My own health | 10 | 1 | 3 | 2.50 | 0.707 | 10 | 1 | 3 | 2.60 | 0.699 |
| Gathering supplies | 11 | 1 | 3 | 2.00 | 0.775 | 10 | 1 | 3 | 2.00 | 0.667 |
| Meal preparation | 10 | 1 | 3 | 2.10 | 0.738 | 10 | 1 | 3 | 2.10 | 0.738 |
| Cleaning at home | 11 | 1 | 3 | 1.91 | 0.831 | 10 | 1 | 3 | 1.80 | 0.789 |
| Caring for family | 10 | 1 | 3 | 2.50 | 0.707 | 9 | 1 | 3 | 2.33 | 0.866 |
| Caring for animals and pets | 9 | 1 | 3 | 2.11 | 0.928 | 9 | 1 | 3 | 2.11 | 0.928 |
| Family time | 9 | 3 | 3 | 3.00 | 0.000 | 9 | 2 | 3 | 2.67 | 0.500 |
| Celebrations | 10 | 3 | 3 | 3.00 | 0.000 | 9 | 2 | 3 | 2.78 | 0.441 |
| Playing with others | 10 | 3 | 3 | 3.00 | 0.000 | 9 | 2 | 3 | 2.89 | 0.333 |
| Organised leisure | 10 | 2 | 3 | 2.90 | 0.316 | 9 | 1 | 3 | 2.56 | 0.726 |
| Quiet leisure | 10 | 1 | 3 | 2.20 | 0.632 | 8 | 1 | 3 | 2.25 | 0.886 |
| Spiritual activities | 10 | 1 | 3 | 2.30 | 0.823 | 9 | 1 | 3 | 2.44 | 0.726 |
| Shopping | 10 | 1 | 3 | 2.30 | 0.823 | 9 | 1 | 3 | 2.11 | 0.782 |
| Social activities | 10 | 1 | 3 | 2.60 | 0.699 | 9 | 2 | 3 | 2.56 | 0.527 |
| Health centre | 9 | 1 | 3 | 2.11 | 0.928 | 9 | 1 | 3 | 2.33 | 0.866 |
| School | 10 | 2 | 3 | 2.50 | 0.527 | 8 | 2 | 3 | 2.87 | 0.354 |
| Trips and visits | 9 | 1 | 3 | 2.00 | 0.707 | 9 | 1 | 3 | 2.00 | 0.866 |
| Employment | 6 | 1 | 3 | 1.83 | 0.753 | 8 | 1 | 3 | 1.38 | 0.744 |
| Valid N (listwise) | 5 | | | | | 6 | | | | |

### 3.1.2 Child participants

**Table 10: Frequency of attendance: Children – Test 1 and Test 2**

| | T1 | | | | | T2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Min | Max | Mean | Std. Deviation | N | Min | Max | Mean | Std. Deviation |
| Personal care | 16 | 3 | 4 | 3.81 | 0.403 | 16 | 2 | 4 | 3.44 | 0.727 |
| Family mealtime | 16 | 3 | 4 | 3.69 | 0.479 | 16 | 3 | 4 | 3.69 | 0.479 |
| My own health | 16 | 2 | 4 | 3.37 | 0.885 | 16 | 2 | 4 | 3.56 | 0.727 |
| Gathering supplies | 16 | 1 | 4 | 3.31 | 0.946 | 16 | 2 | 4 | 3.19 | 0.750 |
| Meal preparation | 16 | 1 | 4 | 2.88 | 0.957 | 16 | 2 | 4 | 3.13 | 0.619 |
| Cleaning at home | 16 | 3 | 4 | 3.56 | 0.512 | 16 | 2 | 4 | 3.50 | 0.632 |
| Caring for family | 16 | 2 | 4 | 3.87 | 0.500 | 16 | 2 | 4 | 3.81 | 0.544 |
| Caring for animals and pets | 16 | 1 | 4 | 2.75 | 1.125 | 16 | 1 | 4 | 2.63 | 1.204 |
| Family time | 16 | 2 | 4 | 3.25 | 0.577 | 16 | 3 | 4 | 3.50 | 0.516 |
| Celebrations | 16 | 2 | 4 | 3.31 | 0.704 | 16 | 1 | 4 | 3.25 | 0.856 |
| Playing with others | 16 | 2 | 4 | 3.56 | 0.629 | 16 | 2 | 4 | 3.44 | 0.629 |
| Organised leisure | 16 | 2 | 4 | 3.63 | 0.619 | 16 | 1 | 4 | 3.19 | 1.047 |
| Quiet leisure | 16 | 2 | 4 | 3.31 | 0.793 | 16 | 2 | 4 | 3.38 | 0.619 |
| Spiritual activities | 16 | 1 | 4 | 3.06 | 0.772 | 16 | 1 | 4 | 2.81 | 0.750 |
| Shopping | 16 | 2 | 4 | 2.94 | 0.574 | 16 | 2 | 4 | 3.31 | 0.602 |
| Social activities | 16 | 1 | 4 | 2.63 | 1.088 | 16 | 2 | 4 | 2.81 | 0.655 |
| Health centre | 16 | 1 | 4 | 3.06 | 0.854 | 16 | 2 | 4 | 3.19 | 0.655 |
| School | 16 | 2 | 4 | 3.87 | 0.500 | 16 | 4 | 4 | 4.00 | 0.000 |
| Trips and visits | 16 | 1 | 4 | 2.88 | 1.025 | 16 | 3 | 4 | 3.50 | 0.516 |
| Employment | 16 | 1 | 4 | 2.75 | 0.931 | 16 | 1 | 4 | 2.69 | 0.946 |
| Valid N (listwise) | 16 | | | | | 16 | | | | |

**Table 11: Level of involvement: Children – Test 1 and Test 2**

| | T1 | | | | | T2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Min | Max | Mean | Std. Deviation | N | Min | Max | Mean | Std. Deviation |
| Personal care | 16 | 1 | 3 | 2.56 | 0.727 | 16 | 2 | 3 | 2.75 | 0.447 |
| Family mealtime | 16 | 1 | 3 | 2.75 | 0.577 | 16 | 2 | 3 | 2.75 | 0.447 |
| My own health | 16 | 1 | 3 | 2.62 | 0.619 | 16 | 2 | 3 | 2.62 | 0.500 |
| Gathering supplies | 16 | 1 | 3 | 2.56 | 0.629 | 16 | 1 | 3 | 2.25 | 0.775 |
| Meal preparation | 16 | 1 | 3 | 2.25 | 0.683 | 16 | 2 | 3 | 2.38 | 0.500 |
| Cleaning at home | 16 | 2 | 3 | 2.56 | 0.512 | 16 | 2 | 3 | 2.56 | 0.512 |
| Caring for family | 16 | 3 | 3 | 3.00 | 0.000 | 16 | 2 | 3 | 2.75 | 0.447 |
| Caring for animals and pets | 16 | 1 | 3 | 2.06 | 0.854 | 16 | 1 | 3 | 1.94 | 0.998 |
| Family time | 16 | 2 | 3 | 2.75 | 0.447 | 16 | 1 | 3 | 2.62 | 0.619 |
| Celebrations | 16 | 2 | 3 | 2.63 | 0.500 | 16 | 1 | 3 | 2.56 | 0.629 |
| Playing with others | 16 | 2 | 3 | 2.63 | 0.500 | 16 | 1 | 3 | 2.44 | 0.727 |
| Organised leisure | 16 | 1 | 3 | 2.69 | 0.602 | 16 | 1 | 3 | 2.44 | 0.629 |
| Quiet leisure | 16 | 1 | 3 | 2.44 | 0.629 | 16 | 1 | 3 | 2.38 | 0.619 |
| Spiritual activities | 16 | 1 | 3 | 2.06 | 0.680 | 16 | 1 | 3 | 2.06 | 0.854 |
| Shopping | 16 | 2 | 3 | 2.56 | 0.512 | 16 | 2 | 3 | 2.38 | 0.500 |
| Social activities | 16 | 1 | 3 | 2.19 | 0.750 | 16 | 1 | 3 | 2.13 | 0.500 |
| Health centre | 16 | 1 | 3 | 2.62 | 0.619 | 16 | 2 | 3 | 2.63 | 0.500 |
| School | 16 | 2 | 3 | 2.94 | 0.250 | 16 | 2 | 3 | 2.94 | 0.250 |
| Trips and visits | 16 | 1 | 3 | 2.25 | 0.577 | 16 | 1 | 3 | 2.50 | 0.632 |
| Employment | 16 | 1 | 3 | 2.06 | 0.680 | 16 | 1 | 3 | 2.19 | 0.544 |
| Valid N (listwise) | 16 | | | | | 16 | | | | |

## 3.2 Internal consistency

Cronbach's alpha is the most common measure of internal consistency ("reliability"). It is most commonly used to determine whether a scale is reliable when you have multiple Likert-type questions. A value of 0.7 is considered sufficient (Hair, Black, Babin, & Anderson, 2010). Table 12 below provides the Cronbach alpha values for both primary caregivers and children, with respect to frequency of attendance and level of involvement.

**Table 12: Cronbach alpha values for the primary caregivers and the children**

| | Primary caregivers | Children |
|---|---|---|
| Frequency of attendance – T1 | 0.823 | 0.410 |
| Frequency of attendance – T2 | 0.905 | 0.739 |
| Level of involvement – T1 | 0.813 | 0.380 |
| Level of involvement – T2 | 0.926 | 0.699 |

The Cronbach alpha values for the caregiver participants are consistently high, which means there is good internal consistency. The fact that the values for the child participants are so inconsistent could suggest that the primary caregivers were more consistent and had a better understanding of the questions than the children, although it is important to note that the missing values for the questions answered by the primary caregivers were not considered in this calculation.

## 3.3 Test-retest reliability

Test-retest reliability assesses consistency between the responses provided by an individual across time (Hair et al., 2010). To test this, there is a pre-test administration of the questionnaire, followed by a post-test administration of the same questionnaire after a predetermined period of time. If scores from both administrations are highly correlated with stable scores and error variances across time, a high test-retest reliability is assumed. As the data were ordinal, Spearman's rank correlation coefficients were used to establish evidence of test-retest reliability (Hauke & Kossowski, 2011; Hair et al., 2010).

The results for T1 and T2 within each group are compared below (Tables 13-16). The significance of the correlation was also tested (note: if the p-value is less than 0.05, the correlation is significantly different from 0, which in turn means that a significant correlation exists) (Field, 2009). A correlation of approximately 0.7 or above would be considered a high test-retest reliability score. It is important to note that this measure can only be calculated for those participants who recorded values for both T1 and T2 (Hair et al., 2010). Where either one of those values were missing, that participant was not included in the calculation. For several of the questions, the reliability could thus not be determined because the affected variables only consisted of one value and consequently a relationship could not be statistically determined. In most of the

cases, the fact that the missing values decreased the sample size even more led to creating incomparable variables.

Once again, the results recorded for primary caregivers are more stable than for that of the children.

**Table 13: Comparing attendance results between T1 and T2: Primary caregivers**

| Variable | Spearman's rank correlation coefficient (r) | p-value | Conclusion |
|---|---|---|---|
| Personal care | Cannot be determined | Cannot be determined | |
| Family mealtime | 0.711 | 0.003 | Stable |
| My own health | 0.564 | 0.036 | Relatively stable |
| Gathering supplies | 0.398 | 0.141 | Not stable across time |
| Meal preparation | 0.776 | 0.001 | Stable |
| Cleaning at home | 0.639 | 0.010 | Stable |
| Caring for family | 0.876 | 0.000 | Stable |
| Caring for animals and pets | 0.860 | 0.000 | Stable |
| Family time | 0.407 | 0.132 | Not stable across time |
| Celebrations | 0.713 | 0.004 | Stable |
| Playing with others | 0.855 | 0.000 | Stable |
| Organised leisure | 0.753 | 0.001 | Stable |
| Quiet leisure | 0.591 | 0.026 | Relatively stable |
| Spiritual activities | 0.416 | 0.123 | Not stable across time |
| Shopping | 0.612 | 0.015 | Relatively stable |
| Social activities | 0.153 | 0.587 | Not stable across time |
| Health centre | 0.498 | 0.059 | Relatively stable |
| School | 0.786 | 0.001 | Stable |
| Trips and visits | 0.497 | 0.071 | Not stable across time |
| Employment | 0.462 | 0.083 | Not stable across time |

**Table 14: Comparing involvement results between T1 and T2: Primary caregivers**

| Variable | Spearman's rank correlation coefficient (r) | p-value | Conclusion |
|---|---|---|---|
| Personal care | -0.167 | 0.645 | Not stable across time |

| Variable | Spearman's rank correlation coefficient (r) | p-value | Conclusion |
|---|---|---|---|
| Family mealtime | 0.807 | 0.005 | Stable |
| My own health | 0.849 | 0.002 | Stable |
| Gathering supplies | 0.478 | 0.162 | Not stable across time |
| Meal preparation | 0.596 | 0.069 | Not stable across time |
| Cleaning at home | 0.866 | 0.001 | Stable |
| Caring for family | 0.969 | 0.000 | Stable |
| Caring for animals and pets | 0.544 | 0.163 | Not stable across time |
| Family time | Cannot be determined | Cannot be determined | |
| Celebrations | Cannot be determined | Cannot be determined | |
| Playing with others | Cannot be determined | Cannot be determined | |
| Organised leisure | 0.655 | 0.056 | Not stable across time |
| Quiet leisure | 0.507 | 0.200 | Not stable across time |
| Spiritual activities | 0.378 | 0.315 | Not stable across time |
| Shopping | 0.757 | 0.018 | Stable |
| Social activities | 0.207 | 0.593 | Not stable across time |
| Health centre | 0.892 | 0.001 | Stable |
| School | 0.378 | 0.356 | Not stable across time |
| Trips and visits | 0.771 | 0.025 | Stable |
| Employment | 0.219 | 0.677 | Not stable across time |

**Table 15: Comparing attendance results between T1 and T2: Children**

| Variable | Spearman's rank correlation coefficient (r) | p-value | Conclusion |
|---|---|---|---|
| Personal care | 0.273 | 0.306 | Not stable across time |
| Family mealtime | 0.418 | 0.107 | Not stable across time |
| My own health | 0.652 | 0.006 | Stable |
| Gathering supplies | 0.632 | 0.009 | Relatively stable |
| Meal preparation | 0.619 | 0.011 | Relatively stable |
| Cleaning at home | 0.513 | 0.042 | Relatively stable |
| Caring for family | 0.730 | 0.001 | Stable |
| Caring for animals and pets | 0.699 | 0.003 | Relatively stable |
| Family time | -0.207 | 0.443 | Not stable across time |
| Celebrations | 0.277 | 0.300 | Not stable across time |
| Playing with others | 0.160 | 0.555 | Not stable across time |

| Variable | Spearman's rank correlation coefficient (r) | p-value | Conclusion |
|---|---|---|---|
| Organised leisure | 0.747 | 0.001 | Stable |
| Quiet leisure | 0.232 | 0.387 | Not stable across time |
| Spiritual activities | -0.078 | 0.774 | Not stable across time |
| Shopping | 0.210 | 0.436 | Not stable across time |
| Social activities | 0.176 | 0.515 | Not stable across time |
| Health centre | 0.503 | 0.047 | Relatively stable |
| School | Cannot be determined | Cannot be determined | |
| Trips and visits | 0.106 | 0.696 | Not stable across time |
| Employment | 0.551 | 0.027 | Relatively stable |

**Table 16: Comparing involvement results between T1 and T2: Children**

| Variable | Spearman's rank correlation coefficient (r) | p-value | Conclusion |
|---|---|---|---|
| Personal care | 0.153 | 0.571 | Not stable across time |
| Family mealtime | 0.414 | 0.111 | Not stable across time |
| My own health | 0.344 | 0.192 | Not stable across time |
| Gathering supplies | 0.301 | 0.257 | Not stable across time |
| Meal preparation | 0.339 | 0.198 | Not stable across time |
| Cleaning at home | 0.746 | 0.001 | Stable |
| Caring for family | Cannot be determined | Cannot be determined | |
| Caring for animals and pets | 0.394 | 0.131 | Not stable across time |
| Family time | 0.289 | 0.278 | Not stable across time |
| Celebrations | 0.739 | 0.001 | Stable |
| Playing with others | 0.661 | 0.005 | Stable |
| Organised leisure | 0.654 | 0.006 | Stable |
| Quiet leisure | 0.308 | 0.245 | Not stable across time |
| Spiritual activities | 0.329 | 0.214 | Not stable across time |
| Shopping | 0.423 | 0.103 | Not stable across time |
| Social activities | 0.444 | 0.085 | Not stable across time |
| Health centre | 0.602 | 0.014 | Relatively stable |
| School | -0.067 | 0.806 | Not stable across time |
| Trips and visits | 0.278 | 0.298 | Not stable across time |
| Employment | 0.687 | 0.003 | Stable |

## 3.4 Comparing dependent groups

Comparisons were run to determine whether there is a difference between the overall results reported for Test 1 and Test 2. The results provided by the entire group in Test 1 were compared to the results provided by the same group for Test 2. Due to the fact that the sample size was small and the data were ordinal, a non-parametric test called the Wilcoxon Signed rank test (Rosner, Glynn, & Lee, 2006) was used to test the hypothesis:

**Ho:** No difference exists between the median scores in Test 1 and the median scores in Test 2.

**Ha:** A significant difference exists between the median scores in Test 1 and the median scores in Test 2.

The null hypothesis will be rejected, at a 5% level of significance, if the p-value is less than 0.05.

### 3.4.1 Primary caregiver comparison

Tables 17-20 compare the results for each of the questions which addressed frequency of attendance and level of involvement in the survey. Tables 17 and 18 provide a comparison for the primary caregiver participants and Tables 19 and 20 provide a comparison for the child participants.

**Table 17: Comparing attendance results between Test 1 and Test 2: Primary caregivers**

| Variable | p-value | Conclusion |
|---|---|---|
| Personal care | 0.157 | Cannot Reject Ho |
| Family mealtime | 0.564 | Cannot Reject Ho |
| My own health | 0.739 | Cannot Reject Ho |
| Gathering supplies | 0.477 | Cannot Reject Ho |
| Meal preparation | 0.414 | Cannot Reject Ho |
| Cleaning at home | 0.194 | Cannot Reject Ho |
| Caring for family | 0.317 | Cannot Reject Ho |
| Caring for animals and pets | 0.414 | Cannot Reject Ho |
| Family time | 0.380 | Cannot Reject Ho |

| | | |
|---|---|---|
| Celebrations | 0.564 | Cannot Reject Ho |
| Playing with others | 0.317 | Cannot Reject Ho |
| Organised leisure | 0.058 | Cannot Reject Ho |
| Quiet leisure | 0.011 | Reject Ho |
| Spiritual activities | 0.380 | Cannot Reject Ho |
| Shopping | 0.854 | Cannot Reject Ho |
| Social activities | 0.454 | Cannot Reject Ho |
| Health centre | 0.942 | Cannot Reject Ho |
| School | 0.046 | Reject Ho |
| Trips and visits | 0.160 | Cannot Reject Ho |
| Employment | 0.739 | Cannot Reject Ho |

Table 17 indicates that when comparing the attendance results of primary caregivers, there is a significant difference ($p<0.05$) between the scores in Test 1 and Test 2 for the variables 'quiet leisure' and 'school'. The null hypothesis for these variables is thus rejected.

**Table 18: Comparing involvement results between Test 1 and Test 2: Primary caregivers**

| Variable | p-value | Conclusion |
|---|---|---|
| Personal care | 0.276 | Cannot Reject Ho |
| Family mealtime | 0.157 | Cannot Reject Ho |
| My own health | 0.317 | Cannot Reject Ho |
| Gathering supplies | 0.655 | Cannot Reject Ho |
| Meal preparation | 1.000 | Cannot Reject Ho |
| Cleaning at home | 0.157 | Cannot Reject Ho |
| Caring for family | 0.317 | Cannot Reject Ho |
| Caring for animals and pets | 0.414 | Cannot Reject Ho |
| Family time | 0.083 | Cannot Reject Ho |
| Celebrations | 0.157 | Cannot Reject Ho |
| Playing with others | 0.317 | Cannot Reject Ho |
| Organised leisure | 0.083 | Cannot Reject Ho |
| Quiet leisure | 1.000 | Cannot Reject Ho |
| Spiritual activities | 0.414 | Cannot Reject Ho |
| Shopping | 0.564 | Cannot Reject Ho |
| Social activities | 1.000 | Cannot Reject Ho |
| Health centre | 0.157 | Cannot Reject Ho |

| | | |
|---|---|---|
| School | 0.083 | Cannot Reject Ho |
| Trips and visits | 1.000 | Cannot Reject Ho |
| Employment | 0.414 | Cannot Reject Ho |

Table 18 indicates that when comparing the involvement results of primary caregivers, no significant difference existed ($p>0.05$) between the scores in Test 1 and Test 2. Thus, the null hypothesis cannot be rejected.

### 3.4.2 Child comparison

**Table 19: Comparing attendance results between Test 1 and Test 2: Children**

| Variable | p-value | Conclusion |
|---|---|---|
| Personal care | 0.058 | Cannot Reject Ho |
| Family mealtime | 1.000 | Cannot Reject Ho |
| My own health | 0.257 | Cannot Reject Ho |
| Gathering supplies | 0.577 | Cannot Reject Ho |
| Meal preparation | 0.206 | Cannot Reject Ho |
| Cleaning at home | 0.655 | Cannot Reject Ho |
| Caring for family | 0.317 | Cannot Reject Ho |
| Caring for animals and pets | 0.589 | Cannot Reject Ho |
| Family time | 0.248 | Cannot Reject Ho |
| Celebrations | 0.914 | Cannot Reject Ho |
| Playing with others | 0.480 | Cannot Reject Ho |
| Organised leisure | 0.053 | Cannot Reject Ho |
| Quiet leisure | 0.792 | Cannot Reject Ho |
| Spiritual activities | 0.271 | Cannot Reject Ho |
| Shopping | 0.058 | Cannot Reject Ho |
| Social activities | 0.509 | Cannot Reject Ho |
| Health centre | 0.527 | Cannot Reject Ho |
| School | 0.317 | Cannot Reject Ho |
| Trips and visits | 0.047 | Reject Ho |
| Employment | 0.736 | Cannot Reject Ho |

Table 19 reports that when comparing the attendance results of the children, there is a significant difference ($p < 0.05$) between the scores in Test 1 and Test 2 for the variable 'trips and visits'. The null hypothesis for this variable is thus rejected.

**Table 20: Comparing involvement results between Test 1 and Test 2: Children**

| Variable | p-value | Conclusion |
|---|---|---|
| Personal care | 0.334 | Cannot Reject Ho |
| Family mealtime | 1.000 | Cannot Reject Ho |
| My own health | 1.000 | Cannot Reject Ho |
| Gathering supplies | 0.160 | Cannot Reject Ho |
| Meal preparation | 0.480 | Cannot Reject Ho |
| Cleaning at home | 1.000 | Cannot Reject Ho |
| Caring for family | 0.046 | Reject Ho |
| Caring for animals and pets | 0.603 | Cannot Reject Ho |
| Family time | 0.414 | Cannot Reject Ho |
| Celebrations | 0.564 | Cannot Reject Ho |
| Playing with others | 0.180 | Cannot Reject Ho |
| Organised leisure | 0.046 | Reject Ho |
| Quiet leisure | 0.739 | Cannot Reject Ho |
| Spiritual activities | 1.000 | Cannot Reject Ho |
| Shopping | 0.180 | Cannot Reject Ho |
| Social activities | 0.705 | Cannot Reject Ho |
| Health centre | 1.000 | Cannot Reject Ho |
| School | 1.000 | Cannot Reject Ho |
| Trips and visits | 0.206 | Cannot Reject Ho |
| Employment | 0.317 | Cannot Reject Ho |

Table 20 reports that when comparing the involvement results of Group C, there is a significant difference ($p < 0.05$) between the scores in Test 1 and Test 2 for the variables 'caring for family' and 'organised leisure'. The null hypothesis for these variables is thus rejected.

## 3.5 Prioritisation

Each participant was required to select three activities which they found to be most important (priority). The activities selected as most important by the two participating groups were

compared to determine if a significant difference exists between the two groups and between the activities listed. The three highest priorities were grouped together in order to evaluate the difference between the activities chosen by the children and those reported by the primary caregivers. Table 21 provides the activities prioritised by the caregiver participants and by the child participants. It depicts the frequency with which the children and the caregivers selected each activity.

**Table 21: Frequency of prioritisation for Children and Primary caregivers – Test 1**

| | | **Children** | | | | **Primary caregivers** | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Frequency | Percent | Valid Percent | Cumulative Percent | Frequency | Percent | Valid Percent | Cumulative Percent |
| Valid | Personal care | 3 | 6.3 | 6.3 | 6.3 | 4 | 8.3 | 8.7 | 8.7 |
| | Family mealtime | 7 | 14.6 | 14.6 | 20.8 | 2 | 4.2 | 4.3 | 13.0 |
| | My own health | 3 | 6.3 | 6.3 | 27.1 | | | | |
| | Cleaning at home | 2 | 4.2 | 4.2 | 31.3 | 2 | 4.2 | 4.3 | 17.4 |
| | Caring for family | 11 | 22.9 | 22.9 | 54.2 | 3 | 6.3 | 6.5 | 23.9 |
| | Caring for animals | 1 | 2.1 | 2.1 | 56.3 | 3 | 6.3 | 6.5 | 30.4 |
| | Family time | 2 | 4.2 | 4.2 | 60.4 | 3 | 6.3 | 6.5 | 37.0 |
| | Organised leisure | 6 | 12.5 | 12.5 | 72.9 | 7 | 14.6 | 15.2 | 73.9 |
| | Quiet leisure | 2 | 4.2 | 4.2 | 77.1 | 4 | 8.3 | 8.7 | 82.6 |
| | Shopping | 2 | 4.2 | 4.2 | 81.3 | 2 | 4.2 | 4.3 | 87.0 |
| | Health centre | 1 | 2.1 | 2.1 | 83.3 | | | | |
| | School | 7 | 14.6 | 14.6 | 97.9 | 3 | 6.3 | 6.5 | 93.5 |
| | Employment | 1 | 2.1 | 2.1 | 100.0 | 1 | 2.1 | 2.2 | 95.7 |
| | Celebrations | 0 | | | | 3 | 6.3 | 6.5 | 43.5 |
| | Playing with others | 0 | | | | 7 | 14.6 | 15.2 | 58.7 |
| | Other | 0 | | | | 2 | 4.2 | 4.3 | 100.0 |
| | Total | 48 | 100.0 | 100.0 | | 46 | 95.8 | 100.0 | |
| Missing | System | | | | | 2 | 4.2 | | |
| Total | | 48 | 100.0 | | | 48 | 100 | | |

The priority activities referred to in Table 21 were categorised into four groups: Group 1 – Organized Activities; Group 2 – Social Interactions; Group 3 – Family Activities; and Group 4 – Personal Activities. Question 20 (paid and unpaid employment) was not included in either of the

four groups. One of the children and one of the primary caregivers chose this as an option and were removed from this study. In addition, two caregivers did not supply values for all three activities and another two selected the "other" option – these were also removed. The children group contained 47 results and the caregivers 43.

The proportion of responses showed similarities between the children and the primary caregivers, as illustrated in Figure 2.

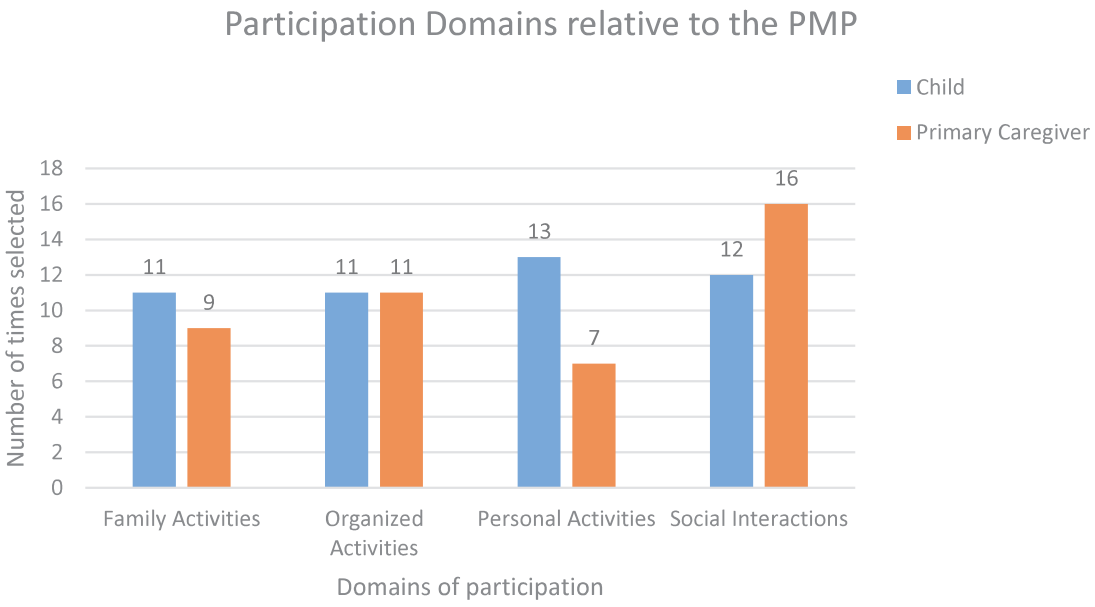



**Figure 2: Compared prioritisation between children and primary caregivers**

The children prioritised Family activities 11 times (55%), whereas the caregivers prioritised the same nine times (45%). Organised activities were prioritised 11 times by the children (50%) and 11 times by the caregivers (50%). Personal activities were selected 13 times by the children (65%), while selected seven times by the caregivers (35%). Lastly, social interactions were prioritised 12 times (42.9%) by the children and 16 times (57.1%) by the caregivers.

The different outcomes (the decision between the four activity groups) were tested to determine whether a relationship exists between the outcomes and the different participant groups (Children and Primary Caregivers). A chi-squared test of independence is appropriate when working with two categorical variables (McMillan & Schumacher, 2014). The hypothesis below

was tested at a 5% level of significance, which means that the null hypothesis would be rejected if the p-value was less than 0.05.

**Ho:** The distribution of the outcomes is independent of the comparison groups.

**Ha:** The distribution of the outcomes is dependent on the comparison groups (There is a difference of responses to the outcome variable among the comparison groups).

Table 22 below provides the result obtained for the chi-squared test of independence.

**Table 22: Chi-squared test results**

| | Value | df | Asymptotic significance (2-sided) |
|---|---|---|---|
| Pearson chi-square | 2.398[a] | 3 | 0.494 |
| Likelihood ratio | 2.424 | 3 | 0.489 |
| N of valid cases | 90 | | |
| a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 9.56. | | | |

The null hypothesis cannot be rejected at a 5% level of significance as the p-value of 0.494 is greater than 0.05 (p-value=0.494>0.05). This confirms the initial thought that the proportions for the two groups (children and primary caregivers) did not differ significantly for the four activity groups. The participant groups thus do not influence which of the four activity groups will be chosen.

# CHAPTER 4: CONCLUSION

The Cronbach's alpha values for the primary caregivers were consistently high and indicated good internal consistency to the PMP questionnaire. The inconsistent values obtained from the children suggest that the primary caregivers were more consistent and possibly had a better understanding of the questions than the children. Alternatively, frequency of young children's participation might be more likely to fluctuate in the same setting. Taking into consideration that the missing values for the questions answered by the primary caregivers were not included in this calculation, it is important to bear in mind that while there is no way of predicting how the numerous missing values would have affected alpha scores. The likelihood exists that the missing values could have affected the result.

A further consequence of reducing the already very small sample due to missing values was that for several of the questions the test-retest reliability could not be determined because the affected variables only consisted of one value and consequently a relationship could not be statistically determined. In most of the cases, the fact that the missing values decreased the sample size even more led to creating incomparable variables.

As a point of interest, the proportion of responses between the primary caregiver and child participants were compared. The proportion of responses showed similarities between the children and the primary caregivers in prioritisation of activities. This means that participant group does not influence which of the four activity groups will be chosen and confirms the initial thought that the proportions for children and primary caregivers did not differ significantly for the activity groups.

## 4.1 Strengths and Weaknesses

This study was largely limited by the sample size on two compounding levels. While the initial sample was already small, the insufficient completion of the caregiver questionnaire made the sample even smaller and impacted the conclusions that could be made. Because of this, parametric tests could not be selected and analysis was reliant on non-parametric testing.

As this study forms part of another study, the data collected will contribute to a larger data sample and may yield more diverse and comparable results. As a strength to aid in this, the study was reliable in terms of the data collection procedures applied. This ensured that the results obtained were comprehensive and can be replicated in future.

## 4.2 Recommendations for Further Studies

Further research is needed to further evaluate the psychometric properties of the PMP instrument with a larger and more diverse sample. With a larger data sample, the limitations are remedied and a wider variety of analyses becomes more accessible to include parametric testing.

In addition, further exploration of the prioritised activities as well as perceived barriers and facilitators to the various activities is required. When taking into consideration that in sending the questionnaires home for completion by primary caregivers, does not provide surety of the participants' state of mind at the time (Leedy & Ormrod, 2005). The analysis of the test retest reliability of prioritisation could provide valuable information of the stability of the responses provided in prioritisation of activities as well. Taking into further consideration that prioritisation of activities with regards to the activity groups was found to be similar for the children and their primary caregivers, there is merit in exploring whether similarities exist also, in the perceived barriers and facilitators of the same activities.

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# Appendix A: Approval Letter Provided by the Research Ethics Committee, University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

**Faculty of Humanities**

14 September 2018

Dear Ms Buthelezi

| | |
|---|---|
| **Project:** | **Test-retest reliability of the Picture My Participation (PMP) instrument** |
| **Researcher:** | **CL Buthelezi** |
| **Supervisor:** | **Prof S Dada** |
| **Department:** | **Centre for Augmentative and Alternative Communication** |
| **Reference Number:** | **27485693 (GW20100605HS)** |

Thank you for your response to the Committee's letter of 15 August 2018.

I have pleasure in informing you that the amendment was **approved** the Research Ethics Committee at an *ad hoc* meeting held on 14 September 2018. Further data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

cc: Prof S Dada (Supervisor) Prof J Bornman (HoD)

# Appendix B: Permission Letter from Gauteng Department of Education

**GAUTENG PROVINCE**
Department: Education
REPUBLIC OF SOUTH AFRICA

8/4/4/1/2

# GDE AMENDED RESEARCH APPROVAL LETTER

| | |
|---|---|
| **Date:** | **10 September 2018** |
| **Validity of Research Approval:** | **05 February 2018 – 28 September 2018**<br>**2018/264A** |
| **Name of Researcher:** | **Buthelezi C.L** |
| **Address of Researcher:** | |
| | |
| | |
| **Telephone Number:** | |
| **Email address:** | |
| **Research Topic:** | **Test-retest reliability of the Picture My Participation instrument.** |
| **Type of qualification** | **M.AAC** |
| **Number and type of schools:** | **Two LSEN Schools** |
| **District/s/HO** | **Tshwane North, Tshwane West, Tshwane South.** |

## *Re: Approval in Respect of Request to Conduct Research*

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

10/09/2018

**The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:**

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this*





**Office of the Director: Education Research and Knowledge Management**
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outline the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

.....

Mrs Faith Tshabalala
Acting Director: Education Research and Knowledge Management

DATE: 10/09/2018

# Appendix C: Principal Permission Letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

The Principal

Dear

**REQUEST TO CONDUCT RESEARCH AT YOUR INSTITUTION**

I am conducting a research project to investigate the perceptions of children with disabilities and those of their primary caregivers regarding the children's participation in home and community activities. Please be advised that the data collected will be used as part of a bigger international study focusing on participation in developing and developed countries with Prof Shakila Dada as the project leader. The title of the larger project is "Picture my Participation: Validation of the instrument".

**Rationale for the study**

Children with intellectual disabilities often don't participate to the extent that typically developing children do. It is important to find out what these children are involved in, in both home and community activities, so that appropriate intervention can be planned for their future. In addition, we aim to validate the survey questions for South Africa by obtaining test re-test data on the survey.

**What are the aims for the study?**

This study forms part of a larger international study that will focus on participation in the developing and the developed world. The aim of the study is to describe and compare the perceptions of children, with mild to moderate intellectual disabilities and the perceptions of their primary caregivers regarding the children's participation in home and community activities.

**What will be expected of you the principal and of your institution?**

Upon approval of this request, you grant the researcher, Lesego Buthelezi, permission to conduct the study at your institution. For this research, approximately 20 children with intellectual disabilities between the ages of 7.00 and 17.11 years will be required. A quiet, suitable venue in which the study can be conducted would need to be provided. A table and two chairs in the venue should also be available for the duration of the study. You would grant the researcher permission to withdraw the learners from class to complete this study. Furthermore, you would be granting the researcher permission to video record and take photographs of the completed materials for the duration of the study. You will also be required to introduce the researcher to teachers of the children, aged 7.00 to 17.11 years, with mild to moderate intellectual disabilities.

Fakulteit Geesteswetenskappe
Lefapha la semelo

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Fax +27 (0) 86 5100841
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www.caac.up.ac.za

**What will be expected of the teachers?**

Informed consent from the teachers will be obtained.

The teachers will be required to:

a. Fill out a learner screening tool to identify possible participants,
b. Distribute and collect informed consent forms and survey booklets to and from the primary caregivers of possible participants that match the selection criteria, and repeat this two weeks later,
c. Make the class list available for the researcher,
d. and assist the researcher in locating the child participants.

**What will be expected of the children?**

The children will be taken, one at a time, to a quiet venue for 60 minutes each. During those 60 minutes, assent will be obtained from the child. The screening portion of the KBIT-2, along with another screening tool will be used for screening purposes. The child will answer questions about their participation with visual supports using the Talking Mat Framework™.

**What will happen to the data?**

The research results will be sent to you following the completion of the research. The video recordings and photographs form part of the data collection process and will be treated as strictly confidential. The letter and the questionnaires will be stored using participant numbers to ensure confidentiality of the data. The research data will be stored both as hard copy and in electronic format at the University of Pretoria for 15 years. Results may also be shared with other researchers in article format and as an academic conference presentation. The data may be re-analyzed in the future for further studies.

**Who can be contacted if you have further questions?**

Should you require any further information, you are welcome to contact the researcher on the details provided below.
I trust that this letter has provided you with sufficient information. Please complete the attached reply slip as proof of permission.

Thanking you in advance,

Mrs Lesego Buthelezi
Masters Student - University of Pretoria
Tel:
Email:

Prof. Shakila Dada
Research Supervisor - University of Pretoria
Tel:
Email:

Appendix C

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

**REPLY SLIP**

**PERMISSION TO CONDUCT THE STUDY OF THE PROPOSED RESEARCH AT THIS INSTITUTION**

I, _____, principal of _____, grant permission to Lesego Buthelezi and Shakila Dada to conduct the study as outlined in the informed consent letter.

Signed at _____ on the _____ day of _____ 2018.

_____ Principal Signature

_____ Researcher Signature

School stamp

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Lefapha la Bomotho

# Appendix D: Teacher Consent Letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

Dear Teacher,

**REQUEST FOR ASSISTANCE IN CONDUCTING RESEARCH AT YOUR INSTITUTION**

I hereby wish to inform you that I have requested permission to conduct a research project to investigate the perceptions of children with disabilities and those of their primary caregivers regarding the children's participation in home and community activities. Please be advised that the data collected will be used as part of a bigger international study focusing on participation in developing and developed countries with Prof Shakila Dada as the project leader. The title of the larger project is "Picture my Participation: Validation of the instrument".

**Rationale for the study**

Children with intellectual disabilities often don't participate to the extent that typically developing children do. It is important to find out what these children are involved in, in both home and community activities, so that appropriate intervention can be planned for their future. In addition, we aim to validate the survey questions for South Africa by obtaining test re-test data on the survey.

**What are the aims for the study?**

This study forms part of a larger international study that will focus on participation in the developing and the developed world. The aim of the study is to describe and compare the perceptions of children, with mild to moderate intellectual disabilities and the perceptions of their primary caregivers regarding the children's participation in home and community activities.

**What will be required of you as a teacher?**

You will be asked to assist in the following ways:

a. Completion of a checklist (Learner Screening Tool by Educators) to help the researcher to determine which children in your class meet the selection criteria. Approximately 20 participants aged 7.0 years to 17.11 years and have mild to moderate intellectual disability are required.
b. Distribution and collection of consent forms and survey booklets to and from the selected participants.

Centre for Augmentative and Alternative Communication, Room 2-36, Com path Building, Lynnwood Road
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www.caac.up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

c. Assisting the researcher in locating the children on the day(s) that the research will be conducted. Each child will spend approximately 60 minutes on one-on-one time with the researcher.

**Will you have access to the results of the study?**

After completing the project, the research results will be sent to the principal of your school.

**Who should you contact if you have further questions?**

If you need any further information, please contact the researcher on the details provided below.

Thanking you in advance,

Mrs Lesego Buthelezi
Tel:
Email:

Prof. Shakila Dada
Tel:
Email:

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

**REPLY FORM**

**Consent to assist in the research process**

**Project title:** Test-retest reliability of the picture my participation instrument.

I, _____, a _____ at _____, hereby confirm that:

1. I have received and read the request form from Lesego Buthelezi (researcher) to conduct research at this institution.

2. I understand the requirements for the completion of the study.

3. I agree to assist _____ with the identification of potential participants for this study at _____ in accordance with the requirements that were stipulated in the letter of request.

Signed at _____ on the _____ day of _____ 2018.

_____ _____

Teacher Name Teacher Signature

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# Appendix E: Primary Caregiver Informed Consent Letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

Dear primary caregiver,

**REQUEST FOR PARTICIPATION IN A RESEARCH PROJECT**

I am conducting a research project to investigate the perceptions of children with disabilities and those of their primary caregivers regarding the children's participation in home and community activities. Please be advised that the data collected will be used as part of a bigger international study focusing on participation in developing and developed countries with Prof Shakila Dada as the project leader. The title of the larger project is "Picture my Participation: Validation of the instrument".

**Aim and Rationale**

The aim of the study is to investigate the perceived participation of children with disabilities in South Africa. This study will also look at perceived participation of the primary caregiver's regarding their child's participation in home and community activities. In addition, we aim to validate the survey questions for South Africa by obtaining test-retest data on the survey.

**What will be required of you as a participant?**

Participation in the study is voluntary and you may withdraw at anytime, with no consequences to you. It is not a knowledge based questionnaire, therefore there is no wrong or right answer. If you choose to participate in the study, please fill in the attached forms and return them to your child's class teacher as soon as possible.

a. Consent
b. Primary caregiver survey booklet
c. After two weeks, you will be requested to complete the same survey booklet again, in order for us to obtain test-retest data on the survey.

**What will be required of your child?**

Your child will be asked similar questions to those in the survey booklet, using the tool Picture my Participation. It is anticipated that 30 minutes one-on-one time will be required with each child. To facilitate understanding and aid responses, the Talking Mats Framework™ will be used. This means

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Lefapha la Bomotho

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Hatfield 0020, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
www.caac.up.ac.za

that your child will be shown images of the questions asked, and respond by placing pictures on a mat.

Participation of your child is voluntary, and they may withdraw at any time without consequences to them. Assent to participate in the study will be acquired from your child.

**Procedural integrity**

Video recording of your child will take place to ensure that the researcher maintains procedural integrity. The collected data will be kept for data analysis. Information recorded will be kept confidential and only shared amongst colleagues involved in the study.

**Risks and benefits**

There is no risk to you or your child in this study. Please be aware that no direct benefit will be received from participating in this study, but information will be used to facilitate better understanding and intervention planning for this population of children.

**Data storage**

This data will be kept at the University of Pretoria for period of 15 years for archive purposes and for possible re-analysis in the future. Data collected may be used for scientific papers and possible academic conferences.

If you have further questions, please feel free to contact me on the details below.

Thanking you in advance.

Yours sincerely,

Mrs Lesego Buthelezi
Tel:
Email:

Prof. Shakila Dada
Tel:
Email:

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

**REPLY FORM**

**Consent to participate in the study**

Name of caregiver: _____

Name of child: _____

**Project title:** Test-retest reliability of the picture my participation instrument.

Please tick √ the appropriate box

☐ I hereby consent for myself and my child to participate in the research study outlined in the information letter. Kindly email me articles based on the results of the study at _____.

Or

☐ I hereby do not consent for myself and my child to participate in the research study outlined in the information letter.

Signed at _____ on the _____ day of _____ 2018

_____
Caregiver Signature

Centre for Augmentative and Alternative Communication, Room 2-36, Com path Building, Lynnwood Road
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
www.caac.up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

# Appendix F: Survey Booklet

| For office use only |
| --- |
| Participant number: |

**Participation: Survey Booklet**

**Thank you for taking part in this study.**

**Section A: Demographic Information.**

Please fill out all the questions below by marking an **X** in the appropriate box or writing the answer on the dotted line.

1. Since when has your child been attending the current School? ……
2. Date of birth of the child: **year / month / date**
3. Date of birth of the primary caregiver: **year / month / date**
4. What is the gender of your child?

   ☐ Male ☐ Female

5. What is your relationship with the child?

   ☐ Father ☐ Mother ☐ Grandmother

   ☐ Other (please specify): ……

6. What is your current work status?

   ☐ Employed full-time ☐ Part-time ☐ Unemployed

7. Are you receiving a social grant or government funding for your child?

   ☐ Yes ☐ No

8. What is the highest educational qualification that you completed?

   ☐ Grade 10 or less ☐ Grade 12 ☐ Diploma

☐ Postgrad. degree ☐ Other(s): ……

9. How many people are living in your house (including you)?

☐ Adults ☐ Children

10. Does your child understand English?

☐ Yes ☐ No

11. In your opinion what is the severity of your child's learning difficulty?

☐ Mild ☐ Moderate ☐ Severe

12. Please mark the 'Yes' or 'No' column with an **X** in relation to your child

| | **Yes** | **No** |
|---|---|---|
| Compared with other children, does or did your child have any serious delay in sitting, standing, or walking? | | |
| Compared with other children, does your child have difficulty seeing, either in the daytime or at night? | | |
| Does your child appear to have difficulty hearing? (Uses a hearing aid/s, hears with difficulty, completely deaf?) | | |
| When you tell your child to do something, does he/she seem to understand what you are saying? | | |
| Does your child have difficulty in walking or moving his/her arms or does he/she have weakness and or stiffness in the arms or legs? | | |
| Does your child sometimes have fits, become rigid, or lose consciousness? | | |
| Does your child learn to do things like other children his/her age? | | |
| Does your child speak at all? (can he or she make him or herself understood in words; can he or she say recognizable words?) | | |
| Is your child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)? | | |
| Compared with other children of the same age does your child appear in any way mentally slow? | | |

**Section B: PARTICIPATION IN HOME AND COMMUNITY ACTIVITIES**

Please complete the following questions that look at your child's participation and involvement in home and community activities. You are provided with different home and community activities below:

Please indicate under the Frequency of Attendance Column if your child does these activities by marking the appropriate column with an **X.**

| Level | Definition of attendance |
|---|---|
| Always | The child attends all of the time |
| Sometimes | The child attends some of the time |
| Not really | The child occasionally/rarely attends |
| Never | The child does not attend |

Please indicate under the Involvement Column if your child is involved in does these activities by marking the appropriate column with an **X**.

| Level | Definition of Involvement |
|---|---|
| Very involved | Generally, the child is involved throughout the activity. He/she shows a lot of initiative and/or interest in and attention to what he/ she and others are doing during the activity. |
| Somewhat involved | The child is involved in the activity some of the time. He/she shows some initiative and/or interest in and attention to what he/she and others are doing during the activity. |
| Minimally involved | Child is involved in a small part of the activity. He/she only shows a little initiative and/or interest in and attention to what he/she and others are doing during the activity. |

| | Attendance | | | | Involvement | | |
|---|---|---|---|---|---|---|---|
| **Home and Community Activities** | Always | Some-times | Not really | Never | Very | Somewhat | Minimally |
| 1. Daily routines at home for **personal care** (dressing, choosing clothing, hair care, brushing teeth) | | | | | | | |
| 2. **Family mealtime** (with usual family members) | | | | | | | |
| 3. Looking after his/her **own health** (medication) | | | | | | | |
| 4. Gathering **daily necessities** for the family (water, food, picking vegetables, fuel) | | | | | | | |

| | Attendance | | | | Involvement | | |
|---|---|---|---|---|---|---|---|
| **Home and Community Activities** | Always | Some-times | Not really | Never | Very | Somewhat | Minimally |
| 5. **Meal preparation** with or for the family | | | | | | | |
| 6. **Cleaning up at home** (clothing, house-hold objects, laundry, rubbish, yard work) | | | | | | | |
| 7. Taking **care** of other **family** members | | | | | | | |
| 8. Taking **care** of **animals** (pet, or domestic livestock) | | | | | | | |
| 9. Interact with the **family** (family time) | | | | | | | |
| 10. Family/community **celebrations** (birthdays, weddings, holiday gatherings) | | | | | | | |
| 11. Getting together with other children in the community (playing with others) | | | | | | | |
| 12. **Organised leisure** activities (sports, clubs, music, art, dance) | | | | | | | |
| 13. **Quiet leisure** (listening to music, reading) | | | | | | | |
| 14. Religious and spiritual gatherings and activities | | | | | | | |
| 15. Shopping and errands (market) | | | | | | | |
| 16. Taking part in **social activities** in the community (parties, play group, parades) | | | | | | | |
| 17. Visit to **health centre** (e.g. Doctor, dentist, other health care service) | | | | | | | |
| 18. **Formal learning** at school | | | | | | | |
| 19. Overnight visits and trips | | | | | | | |
| 20. Paid and unpaid **employment** | | | | | | | |
| 21. Does your child participate in any other activities? Please list: | | | | | | | |
| | | | | | | | |
| **TOTAL** *(for office use only)* | | | | | | | |

**Section C: PRIORITISATION**

Of all of the activities listed above, what are the 3 activities that you think are the most important to your child? Please fill these 3 chosen activities starting with the most important one.

| Most important activities |
|---|
| 1. |
| 2. |
| 3. |

**Section D: BARRIERS AND FACILITATORS**

We are now interested in what things help your child and what things make it harder for your child to participate in these activities. Please fill in the same 3 most important activities identified above into the table below. You will then need to think about what makes it easier or harder for your child to participate in the activity. Please write the reasons in your own words.

| Childs most important activities *(list here)* | Easier/Harder | Please write in your own words what makes it easier or harder for your child to do the activity. |
|---|---|---|
| 1. | What makes it easier to do? | |
| | What makes it harder to do? | |
| 2. | What makes it easier to do? | |
| | What makes it harder to do? | |
| 3. | What makes it easier to do? | |
| | What makes it harder to do? | |

**Thank you for taking the time to complete all the questions.**

# Appendix G: Learner Screening Tool by Educators

# LEARNER SCREENING TOOL BY EDUCATORS (LeSTE)

| Participant Nr. | |
|---|---|

**Learner Name: _____**

**Date of Birth: _____**

**Age: ____ years ___ month/s**

**Gender: ___**

**Primary Diagnosis: _____**

For each of the following questions, please indicate (√) this learner's ability in each of the areas listed.

| AREAS | | YES | NO | *Admin Use* | |
|---|---|---|---|---|---|
| Vision | 1. Are you aware of any visual problems that affect this learner's ability to learn? | | | | |
| | 2. Does the learner wear glasses or contact lenses? | | | | |
| Hearing | 3. Are you aware of any hearing problems that affect this learner's ability to learn? | | | | |
| | 4. Does the learner wear a hearing aid? | | | | |
| | 5. Does the learner respond when called by a person not facing him/her? | | | | |
| Motor Skills | 6. Does the learner have any physical disabilities that affect his/her ability to use his/her hands? | | | | |
| | 7. Can the learner hold a piece of paper or cardboard in his/her hands? | | | | |
| | 8. Can the learner pick up small objects the size of a 5c coin with one or both hands? | | | | |
| | 9. Can the learner control a pencil / crayon to write? | | | | |
| Cognitive | 10. Can the learner identify visual objects (e.g. pictures) in the front of the classroom from his/her desk? | | | | |
| | 11. Can the learner identify pictures, symbols or words in a book s/he is holding? | | | | |
| | 12. Can the learner follow instructions? | | | | |
| | 13. Can the learner listen to an explanation without interrupting? | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | 14. Can the learner concentrate on a task for 20 minutes? | | | | | |
| | | | | | | |
| LoLT | 15. Does the learner understand English as the Language of Learning and Teaching? | | | | | |
| | 16. Can the learner use English as the Language of Learning and Teaching to communicate? | | | | | |
| | | | | | | |
| PCS | 17. Has the learner been exposed to Picture Communication Symbols (Boardmaker) at school? | | | | | |
| | 18. Can the learner recognize any Picture Communication Symbols used in lessons? | | | | | |
| | | | | | | |
| | | | | | | |

**Learner Screening Tool by Educators completed by: _____**

# Appendix H: Child Assent Letter

| Participant number: | For office use only |
|---|---|
| | |

## Child participant assent letter

Hello (name), my name is Lesego.

I would like to work with you today.

I will show you some pictures and ask you questions about different things in the pictures.

I want you to tell me how you feel about some things.

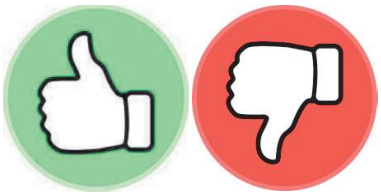
There is no right or wrong answer and I am not going to tell anybody what you have answered.

As soon as we have finished then you can go.

In two weeks, I will come back and ask you the same questions again.

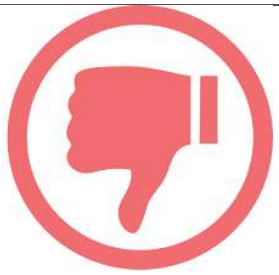
You can stop at any time, if you don't want to answer any more questions. You just let me know or point to the stop sign.

### Assent questions

| | | |
|---|---|---|
| 1. |  | Did you understand the letter I just read to you?<br>yes / no |
| 2. |  | Do you know that you can choose if you want to help me or not?<br>yes / no |

| | | |
|---|---|---|
| 3. |  | Do you understand that you can stop at any time you want?<br>yes / no |
| 4. |  | Is it okay if I video tape while we are working?<br>yes / no |
| 5. |  | Do you want to ask me anything?<br>yes / no |
| 6. |  | Would you like to work with me today?<br>yes / no |

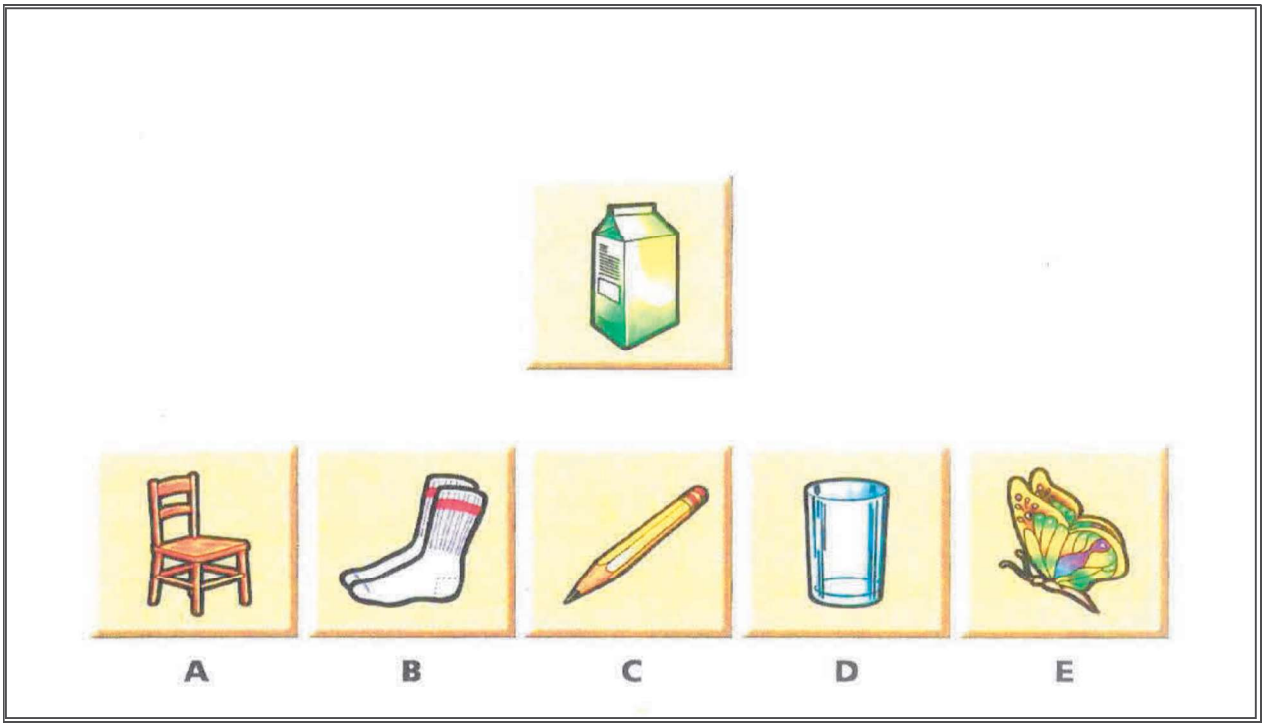
**Assent symbols:**

| | |
|---|---|
|  |  |
| yes | no |

# Appendix I: Kaufman Brief Intelligence Test - Second Edition

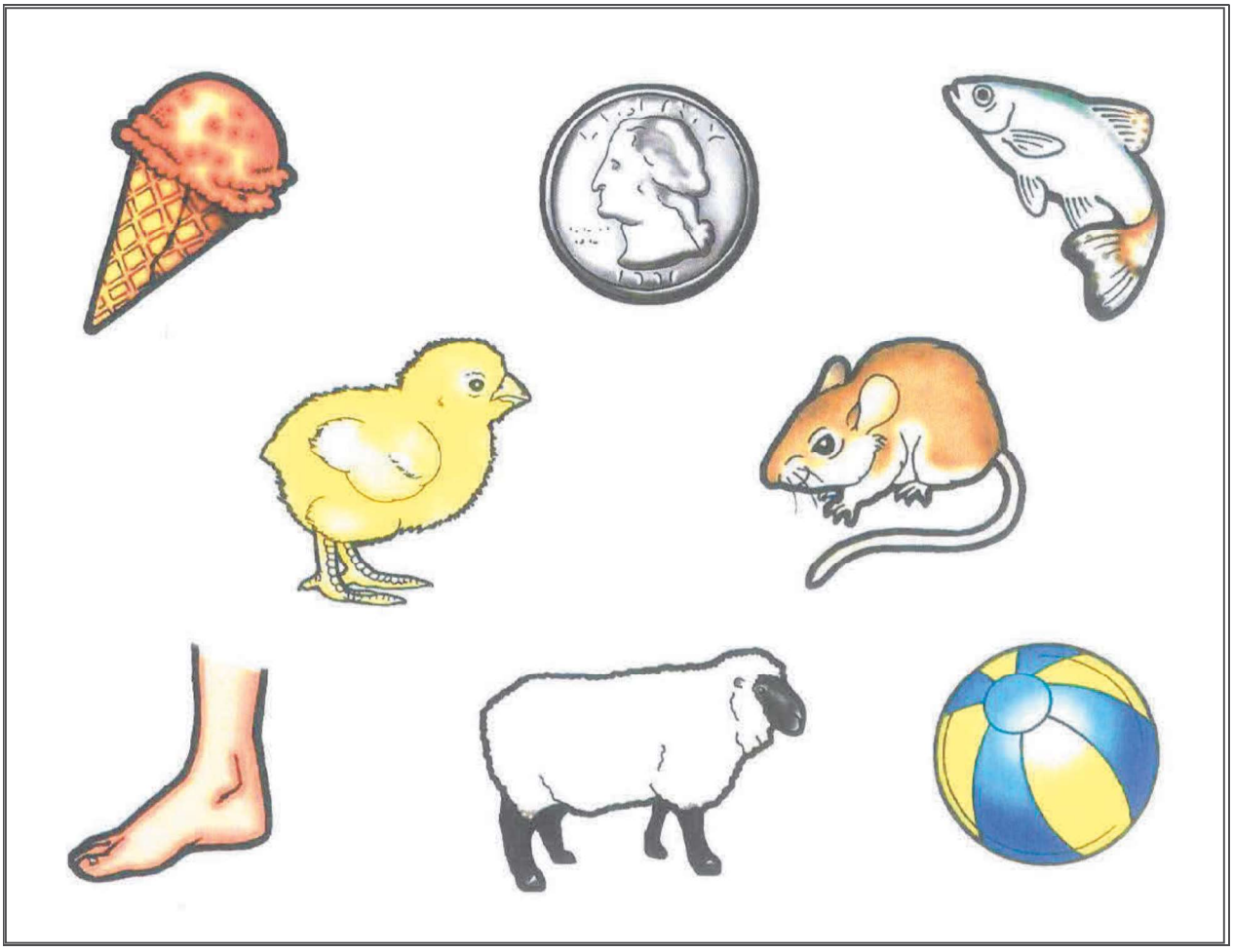

**Subtest 1** (Sample)**:** Verbal Knowledge

The examiner says a word or phrase and the examinee then chooses a picture from a selection of six, which best describes the word or phrase.




**Subtest 2** (Sample)**:** Matrices

The examiner reads a verbal instruction and the examinee chooses which picture in a set of pictures best matches the concept portrayed in the single stimulus picture.



**Subtest 3** (sample)**:** Riddles

The examiner presents a verbal problem in riddle format (e.g. "What is . . ."). The examinee must point to the correct picture for Items 1-8 and/or provide a one-word answer on Items 9-48.

# Appendix J: Picture My Participation Instrument

**Picture My Participation**

**Administration of the assessment**

*Test population*

Picture My Participation has been developed for children aged 5 to 21 years who have a disability. Disability is an umbrella term, referring to impairments (a problem in body function or structure), activity limitations (a difficulty encountered by individual in executing a task or action), and participation restrictions (a problem experienced by an individual in involvement in life situations). It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (WHO, 2015).

*Test environment*

Picture My Participation should be administered in an environment where the child and family are comfortable and is culturally appropriate

*Equipment required*

- Primary caregivers:
  - Consent letter
  - Picture my Participation Response Sheet: Caregiver (Appendix 1)

- Children:
  - Assent letter for children
  - Talking Mat (piece of carpet or cardboard to display the picture cards)
  - Picture my Participation Response score sheet: Child (Appendix 2)
  - Pen or pencil for recording

*Administration time*

The interview takes approximately 30 minutes to administer depending upon the child's ability to follow the ideas and respond. Prior to administration of the interview, the setting up of the test equipment takes approximately 2 minutes and packing up requires about 2 minutes. The scoring takes approximately 10 minutes.

*Test administrators*

The interviewers can be from any background. The instrument has been designed so that 'expert training' is not required for its use. Rather, interviewers who are new to Picture my Participation should complete a self directed eLearning tutorial. This tutorial provides an understanding of the ICF, the rights of children, and the construct of participation, concepts central to the Picture My Participation.

It is essential that the test uses complete the tutorial, read the manual completely and are familiar with the requirements of each subsection of the assessment prior to administration.

*Test items and instructions*

Step 1: Introduction of *Picture my Participation* to child and family

"We want to hear your story about who you are and what you do. Your story is important to us because we want to understand your involvement with your home, school and community. We are interested in how often you do certain activities, how involved you are in these activities and what makes it easier or more difficult to participate. There are no right or wrong answers, just a sharing of ideas. We understand that this is your business and we will make sure your story does not become part of the 'grapevine'".

- The following components are for the primary caregiver to complete (Appendix 1):
  - Consent letter
  - Picture my Participation Response Sheet: Caregiver (Appendix 1)

- The following components are for the interview with the child (see Appendix 2):
  - Assent letter for children
  - Picture my Participation Response score sheet: Child (Appendix 2)

Step 2: Caregivers complete the consent letters and if applicable the Picture My Participation Response Score Sheet: Caregiver (Appendix 1)

Step 3: Interviewer administering the Picture my Participation Response Score Sheet: Child (Appendix 2)

- Assent from the child
- Complete Demographic Information (Appendix 2: Section A)

- Frequency of attendance and involvement dimensions

a. Place the frequency template in front of the child and explain the levels of frequency using clear plain and appropriate language.

For example: *"These pictures show different amounts of apples in a basket. The basket full of apples (point to the picture) means always, this basket with fewer apples means sometimes (point to the picture), the basket with one apple means (point to the picture) not really and the empty basket (point to the picture) means never".*

*Attendance template*

| Always | Sometimes | Not really | Never |
|---|---|---|---|
|  |  |  |  |

b. Explain to the child that you are going to show them some pictures (picture cards are the pictures in (Appendix 2: Section C) of children attends in various activities and that you would like to know if they also attendance in these activities.

c. Then ask the child the trial items. (Appendix 2: Section B)

*Example "Do you eat ice cream?". Give the picture to the child. "Could you put the ice cream picture under the basket that matches for you?"*

d. Explain to the child that you are going to show them some pictures (picture cards (Appendix 2: Section C) of children in various activities and that you would like to know if they also participate in these activities.

e. Through a process of talking with the child about their usual daily lives and sharing ideas and conversation, ask the child to sort each of the picture cards on the attendance template (if the child uses a Talking Mat™, place the template close to the Mat).

f. Record the child's participation profile on the Picture my Participation Response Score Sheet (Appendix 2: Section C).

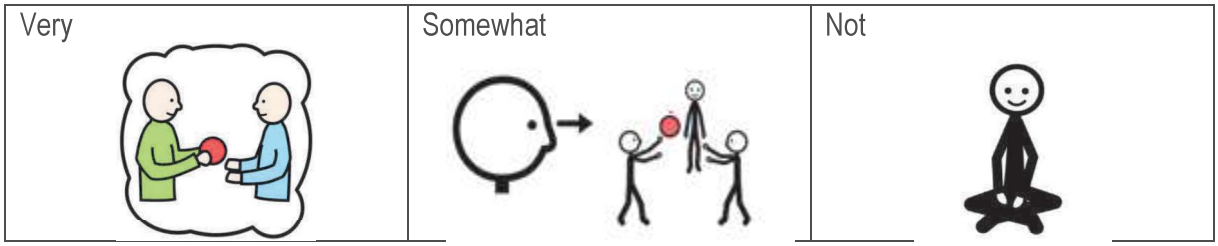
*Attendance scoring table*

| Score | Level | Definition |
|---|---|---|
| 4 | Always | The child attends all of the time |
| 3 | Sometimes | The child attends some of the time |
| 2 | Not really | The child occasionally/rarely attends |
| 1 | Never | The child does not attend |

g. Place the involvement template in front of the child and explain the levels of involvement using clear plain and appropriate language.

For example: *"These pictures show different levels of involvement. In this picture (point to picture) these children are very involved – they are really trying hard, and doing a lot of in the activity of playing ball. In this picture (point to picture) this child is only somewhat involved – he/she is watching what others are doing more than doing the activity her/himself. In this picture (point to picture) this child is not involved. He is waiting for something else to happen or do."*

*Involvement Template*




Example: *"Alex, you say that you always attend meal preparation with or for the family. When this happens, how involved are you? Are you doing a lot of things, are you very involved (point to picture) or are you a little involved (point to picture) or are you not involved (point to picture)."*

h. Through a process of talking with the child about their usual daily lives and sharing ideas and conversation, ask the child to sort each of the picture cards on the level of involvement template (if the child uses a Talking Mat, place the template close to it).

i. Record the child's participation profile on the Picture my Participation Response Score Sheet (Appendix 2 Section C).

Involvement Scoring Table

| Score | Level | Definition |
|---|---|---|
| 3 | Very | These children are very involved – they are really trying hard, and doing a lot of the game |
| 2 | Somewhat | This child is only somewhat involved – he/she is watching what others are doing more than doing the activity herself |
| 1 | Not | This child is not involved. He is just waiting for something else to happen or do. |

- Prioritisation

a. Ask the child "Of all of the activities that we have talked about, what are the 3 activities that are the most important to you?"

Example: *They might be important because you must do them really often, or they might be important because you really love to do them, or they might be important because you really want to be able to do them. There are lots of reasons why an activity might be important to you.*

b. Talk with the child about the 3 most important activities and select the picture cards for those activities (place them on the Talking Mat if the child uses one).

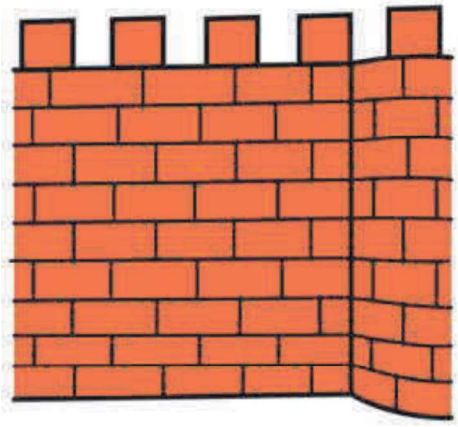
c. Record the child's participation profile on the Picture my Participation Response Score Sheet (Appendix 2 Section D)

- Barriers and Facilitators

a. Place the Barriers and Facilitators Template in front of the child and explain the barriers and facilitators using clear plain and appropriate language.

For example: *"This is a wall. It stops you from going further, even if you wanted to go further. It is a barrier. This picture (point to picture) is for the things that make it difficult for you to do the activity. This is a ladder. It helps you to get higher than you can reach. This picture (point to picture) is for the things that make it easier to do the activity."* Ask the child about the first activity identified in the above step (Prioritization). Explain to the child that you are interested in knowing what makes it easier (point to the facilitator picture) or makes it harder to do (point to the barrier picture).

*Barriers and Facilitators Template*

| Barrier | Facilitator |
| --- | --- |
|  |  |

*b.* Example: *"Thinking about [activity 1], are there things that make this hard to do? Can you tell me about them? Are there things that make it easier/help you to do this activity? Can you tell me about them?*

c. Repeat process for activity 2 & 3.

d. Transcribe what the child says on to the Picture my Participation Response Sheet: Child (Appendix 2 Section D).

e. Score and Code the Childs response on to the Picture my Participation Response Sheet: Child (Appendix 2 Section D).

Barriers and Facilitators Scoring table

| Score | Level | Definition |
| --- | --- | --- |
| 2 | Facilitator (easier) | Anything that helps the child to participate |
| 1 | Barrier (harder) | Anything that makes it harder for the child to participate |

Barriers and Facilitators Coding Table

| Code | Definition of code | Example |
|---|---|---|
| Products and technology | This relates to products, instruments, equipment or technology adapted or specially designed for improving the functioning of persons with disability. | I use my mobile phone to set a reminder to take my medication |
| Natural environment and human-made changes to the environment | This relates to animate and inanimate elements of the physical or natural environment and components of that environment that have been modified by people. | I cannot use my wheelchair when we go hiking |
| Support and relationships | This relates to people or animals that provide practical, physical or emotional support, nurturing, protecting and assisting as well as relationships to other persons in all aspects of daily living, but excludes the attitudes of the person(s) who are providing the support. | I enjoy shopping on my own but and I can go by myself with my guide dog. |
| Attitudes | This relates to the attitudes that are observable through consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs, and relates to those attitudes of the person(s) external to the person with disability, not of the persons with disability themselves. | I love pets but my mom won't allow me to keep a dog. |
| Services, systems and policies | Services relate to structured programmes, public, private or voluntary services established at local, community, regional, national or international level in order to meet the needs of persons with disabilities. Systems and policies respectively relate to administrative control and monitoring mechanism and rules, regulations and standards established at the different levels mentioned above, in various sectors of society. | I would like to go to the neighborhood school but the school do not allow me to attend there. |

# Appendix 1

## Picture my Participation Response Score Sheet: Caregiver

**Section A: Demographic Information.**

Please fill out all the questions below by marking an **X** in the appropriate box or writing the answer on the dotted line.

1. Since when has your child been attending the current School? ……
2. Date of birth of the child: year / month / date
3. Date of birth of the primary caregiver: year / month / date
4. What is the gender of your child?

   ☐ Male ☐ Female

5. What is your relationship with the child?

   ☐ Father ☐ Mother ☐ Grandmother

   ☐ Other (please specify): ……

6. What is your current work status?

   ☐ Employed full-time ☐ Part-time ☐ Unemployed

7. Are you receiving a social grant or government funding for your child?

   ☐ Yes ☐ No

8. What is the highest educational qualification that you completed?

   ☐ Grade 10 or less ☐ Grade 12 ☐ Diploma

   ☐ Postgrad. degree ☐ Other(s): ……

9. How many people are living in your house (including you)?

   ☐ Adults ☐ Children

10. Does your child understand English?

☐ Yes ☐ No

11. In your opinion what is the severity of your child's learning difficulty?

☐ Mild ☐ Moderate ☐ Severe

12. Please mark the 'Yes' or 'No' column with an **X** in relation to your child

| | Yes | No |
|---|---|---|
| Compared with other children, does or did your child have any serious delay in sitting, standing, or walking? | | |
| Compared with other children, does your child have difficulty seeing, either in the daytime or at night? | | |
| Does your child appear to have difficulty hearing? (Uses a hearing aid/s, hears with difficulty, completely deaf?) | | |
| When you tell your child to do something, does he/she seem to understand what you are saying? | | |
| Does your child have difficulty in walking or moving his/her arms or does he/she have weakness and or stiffness in the arms or legs? | | |
| Does your child sometimes have fits, become rigid, or lose consciousness? | | |
| Does your child learn to do things like other children his/her age? | | |
| Does your child speak at all? (can he or she make him or herself understood in words; can he or she say recognizable words?) | | |
| Is your child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)? | | |
| Compared with other children of the same age does your child appear in any way mentally slow? | | |

**Section B: PARTICIPATION IN HOME AND COMMUNITY ACTIVITIES**

Please complete the following questions that look at your child's participation and involvement in home and community activities. You are provided with different home and community activities below:

Please indicate under the Frequency of Attendance Column if your child does these activities by marking the appropriate column with an **X.**

| Level | Definition of attendance |
|---|---|
| Always | The child attends all of the time |
| Sometimes | The child attends some of the time |
| Not really | The child occasionally/rarely attends |
| Never | The child does not attend |

Please indicate under the Involvement Column if your child is involved in does these activities by marking the appropriate column with an **X**.

| Level | Definition of Involvement |
|---|---|
| Very involved | Generally, the child is involved throughout the activity. He/she shows a lot of initiative and/or interest in and attention to what he/ she and others are doing during the activity. |
| Somewhat involved | The child is involved in the activity some of the time. He/she shows some initiative and/or interest in and attention to what he/she and others are doing during the activity. |
| Minimally involved | Child is involved in a small part of the activity. He/she only shows a little initiative and/or interest in and attention to what he/she and others are doing during the activity. |

| | Attendance | | | | Involvement | | |
|---|---|---|---|---|---|---|---|
| **Home and Community Activities** | Always | Some-times | Not really | Never | Very | Somewhat | Minimally |
| 22. Daily routines at home for **personal care** (dressing, choosing clothing, hair care, brushing teeth) | | | | | | | |
| 23. **Family mealtime** (with usual family members) | | | | | | | |
| 24. Looking after his/her **own health** (medication) | | | | | | | |
| 25. Gathering **daily necessities** for the family (water, food, picking vegetables, fuel) | | | | | | | |

| | Attendance | | | | Involvement | | |
|---|---|---|---|---|---|---|---|
| **Home and Community Activities** | Always | Some-times | Not really | Never | Very | Somewhat | Minimally |
| 26. **Meal preparation** with or for the family | | | | | | | |
| 27. **Cleaning up at home** (clothing, house-hold objects, laundry, rubbish, yard work) | | | | | | | |
| 28. Taking **care** of other **family** members | | | | | | | |
| 29. Taking **care** of **animals** (pet, or domestic livestock) | | | | | | | |
| 30. Interact with the **family** (family time) | | | | | | | |
| 31. Family/community **celebrations** (birthdays, weddings, holiday gatherings) | | | | | | | |
| 32. Getting together with other children in the community (playing with others) | | | | | | | |
| 33. **Organised leisure** activities (sports, clubs, music, art, dance) | | | | | | | |
| 34. **Quiet leisure** (listening to music, reading) | | | | | | | |
| 35. Religious and spiritual gatherings and activities | | | | | | | |
| 36. Shopping and errands (market) | | | | | | | |
| 37. Taking part in **social activities** in the community (parties, play group, parades) | | | | | | | |
| 38. Visit to **health centre** (e.g. Doctor, dentist, other health care service) | | | | | | | |
| 39. **Formal learning** at school | | | | | | | |
| 40. Overnight visits and trips | | | | | | | |
| 41. Paid and unpaid **employment** | | | | | | | |
| 42. Does your child participate in any other activities? Please list: | | | | | | | |
| | | | | | | | |
| **TOTAL** *(for office use only)* | | | | | | | |

**Section C: PRIORITISATION**

Of all of the activities listed above, what are the 3 activities that you think are the most important to your child? Please fill these 3 chosen activities starting with the most important one.

| **Most important activities** |
|---|
| 1. |
| 2. |
| 3. |

**Section D: BARRIERS AND FACILITATORS**

We are now interested in what things help your child and what things make it harder for your child to participate in these activities. Please fill in the same 3 most important activities identified above into the table below. You will then need to think about what makes it easier or harder for your child to participate in the activity. Please write the reasons in your own words.

| Childs most important activities *(list here)* | Easier/Harder | Please write in your own words what makes it easier or harder for your child to do the activity. |
|---|---|---|
| 1. | What makes it easier to do? | |
| | What makes it harder to do? | |
| 2. | What makes it easier to do? | |
| | What makes it harder to do? | |
| 3. | What makes it easier to do? | |
| | What makes it harder to do? | |

**Thank you for taking the time to complete all the questions**

# Appendix 2

## Picture my Participation Response Score Sheet: Child

**Section A:** Demographics (Interviewer to complete)

Date completed:_____

Administrator: _____ Profession: _____

Where the interview was conducted:

_____

(e.g., School playground, at home, at a library, at the soccer field)

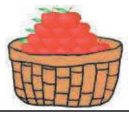
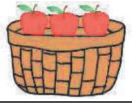
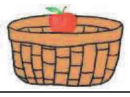
Participant number: _____

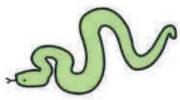
Country/City:_____

Gender:
Male ☐ Female ☐

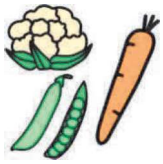
Date of birth: year / month / day

**Section B:** Trial Items

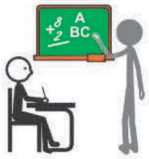
| Always =  | Sometimes =  | Not really =  | Never =  |
|---|---|---|---|

| PCS symbol | Questions | Always  | Sometimes  | Not really  | Never  |
|---|---|---|---|---|---|
|  | Do you eat ice cream? | | | | |
|  | Do you watch TV? | | | | |
|  | Do you play with real snakes at home? | | | | |

**Section C:** Record Attendance and Involvement

| | | Attendance | | | | Involvement | | |
|---|---|---|---|---|---|---|---|---|
| **Home and Community Activities** | | 4 Always | 3 Sometimes | 2 Not really | 1 Never | 3 Very involved | 2 Somewhat involved | 1 Minimally involved |
| 1. Personal care<br>Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth) |  | | | | | | | |
| 2. Family mealtime (with usual family members) |  | | | | | | | |
| 3. My own health<br>Looking after his/her own health (medication) |  | | | | | | | |
| 4. Gathering supplies<br>Gathering daily necessities for the family (water, food, picking vegetables, fuel) |  | | | | | | | |
| 5.Meal preparation<br>Meal preparation with or for the family |  | | | | | | | |
| 6. Cleaning at home<br>Cleaning up at home (clothing, house-hold objects, laundry, rubbish, yard work |  | | | | | | | |
| 7. Caring for family<br>Taking care of other family members |  | | | | | | | |

| | | Attendance | | | | Involvement | | |
|---|---|---|---|---|---|---|---|---|
| **Home and Community Activities** | | 4 Always | 3 Sometimes | 2 Not really | 1 Never | 3 Very involved | 2 Somewhat involved | 1 Minimally involved |
| 8. Caring for animals/pets<br>Taking care of animals (pet, or domestic livestock) |  | | | | | | | |
| 9. Family time<br>Interact with the family |  | | | | | | | |
| 10. Celebrations<br>Family/community celebrations (birthdays, weddings, holiday gatherings) |  | | | | | | | |
| 11. Playing with others<br>Getting together with other children in the community |  | | | | | | | |
| 12. Organised leisure<br>Organised leisure activities (sports, clubs, music, art, dance) |  | | | | | | | |
| 13. Quiet leisure<br>Quiet leisure (listening to music, reading) |  | | | | | | | |
| 14. Spiritual activities<br>Religious and spiritual gatherings and activities |  | | | | | | | |
| 15. Shopping<br>Shopping and errands (market)<br>Shopping |  | | | | | | | |

| | | Attendance | | | | Involvement | | |
|---|---|---|---|---|---|---|---|---|
| **Home and Community Activities** | | 4 Always | 3 Sometimes | 2 Not really | 1 Never | 3 Very involved | 2 Somewhat involved | 1 Minimally involved |
| 16. Social activities<br>Taking part in social activities in the community (parties, play group, parades) |  | | | | | | | |
| 17. Health centre<br>Visit to health center (e.g. Doctor, dentist, other health care service) |  | | | | | | | |
| 18. School<br>Formal learning at school |  | | | | | | | |
| 19. Trips and Visits<br>Overnight visits and trips |  | | | | | | | |
| 20. Employment<br>Paid and unpaid employment |  | | | | | | | |
| Other (a) | | | | | | | | |
| Other (b) | | | | | | | | |

**Section D:** Choose the three most important activities

| Childs most important activities *(list here)* | Easier/Harder | Please write in your own words what makes it easier or harder for your child to do the activity. |
|---|---|---|
| 1. | What makes it easier to do? | |
| | What makes it harder to do? | |
| 2. | What makes it easier to do? | |
| | What makes it harder to do? | |
| 3. | What makes it easier to do? | |
| | What makes it harder to do? | |

# Appendix K: Talking Mats

Frequency of attendance

Participant responses arranged according to frequency of attendance
(1) = Never
(2) = Not really
(3) = Sometimes
(4) = Always

Talking Mat completed: Frequency Template

Levels of involvement

Participant responses arranged according to levels of involvement
(1) = Not
(2) = Somewhat
(3) = Very

Talking Mat completed: Involvement Template

20 activities arranged in alphabetical order for prioritization.

The 3 most important activities selected are arranged on the mat by the child. Barrier and facilitator cards are used to discuss barriers and facilitators for each.

Talking Mat completed: Barriers and Facilitators Template

# Appendix L: Procedural Script

**Procedural script:** Child data collection

1. Check the completed LeSTE
2. Fetch the child from class and introduce self to child
3. Proceed with child to a quiet room
4. Complete the assent procedure:
    4.1. Explain the purpose of the study using the wording detailed in the PMP
    4.2. Ask if child has any questions
    4.3. Ask assent from child participant
    4.4. If child assents continue with procedures below
    4.5. If child does not assent, walk child back to their classroom
5. Administer the KBIT-2 screener
6. PMP instrument procedure:
    6.1. Administer PMP child demographics
    6.2. Administer Trial items
7. PMP instrument procedure:
    7.1. Frequency: Administer the frequency procedure
        7.1.1. Place the frequency template (Appendix 1) in front of the child and explain the levels of frequency using clear, plain and appropriate language.
        7.1.2. Explain to the child that you are going to show them some drawings (participation cards, Appendix 2) of children participating in various activities and that you would like to know if they also participate in the activities.
        7.1.3. Get the child to sort the participation cards on the frequency template (Appendix 1).
        7.1.4. Document the child's participation profile on the scoring sheet (Appendix 3 Part A). An explanation of the scoring is found in Appendix
    7.2. Prioritization: Administer the prioritization procedure
        7.2.1. Ask the child, “Of all of the activities that you've seen, what are the 3 activities that are the most important to you?”

7.2.2. Get the child to sort the cards for the 3 most important activities and put in a pile.

7.2.3. List the activities on the scoring sheet (Appendix 3 part B).

7.3. Level of Involvement: Administer the level of involvement procedure

7.3.1. Explain to the child that for each of these 3 most important activities we would like to understand how involved you are with the activity.

7.3.2. "We are going to do this by you placing these cards where you think they fit best on this table" (Level of involvement template, Appendix 5).

7.3.3. Explain each level of involvement.

7.3.4. Score level of involvement for the 3 most important activities using the score sheet (Appendix 3, part B).

8. PMP instrument procedure:

8.1. Barriers and Facilitators

8.1.1. *Environmental factors*

i. Explain to the child that you are going to show them some drawings (participation cards, Appendix 2) of children participating in various activities and that you would like to know if they also participate in the activities.

ii. Get the child to sort the participation cards on the frequency template (Appendix 1).

iii. Document the child's participation profile on the scoring sheet (Appendix 3 Part A). An explanation of the scoring is found in Appendix 4

8.1.2. *Personal factors*

i. Ask the child, "Of all of the activities that you've seen, what are the 3 activities that are the most important to you?"

ii. Get the child to sort the cards for the 3 most important activities and put in a pile.

iii. List the activities on the scoring sheet (Appendix 3 part B).

9. Thank the child for participating, provide token and walk him/her to class

# Appendix M: Procedural Checklist

| Participant Nr. | |
|---|---|

**Procedural checklist:** Child data collection

| Step | Description | Yes | No |
|---|---|---|---|
| 1 | Check the completed LeSTE | | |
| 2 | Fetch the child from class and introduce self to child | | |
| 3 | Proceed with child to a quiet room | | |
| 4 | Assent procedure: | | |
| | i. Explain the purpose of the study using the wording detailed in the PMP | | |
| | ii. Ask if child has any questions | | |
| | iii. Ask assent from child participant | | |
| | iv. If child assents continue with procedures below | | |
| | v. If child does not assent, walk child back to their classroom | | |
| 5 | Administer the KBIT-2 screener | | |
| 6 | PMP instrument procedure: | | |
| | i. Administer PMP child demographics | | |
| | ii. Administer Trial items | | |
| 7 | PMP instrument procedure: | | |
| | Frequency: Administer the frequency procedure | | |
| | i. Place the frequency template (Appendix 1) in front of the child and explain the levels of frequency using clear, plain and appropriate language. | | |
| | ii. Explain to the child that you are going to show them some drawings (participation cards, Appendix 2) of children participating in various activities and that you would like to know if they also participate in the activities. | | |
| | iii. Get the child to sort the participation cards on the frequency template (Appendix 1). | | |
| | iv. Document the child's participation profile on the scoring sheet (Appendix 3 Part A). An explanation of the scoring is found in Appendix 4. | | |
| | Level of Involvement: Administer the level of involvement procedure | | |

| | | | |
|---|---|---|---|
| | i. Explain to the child that for each of these activities we would like to understand how involved you are with the activity. | | |
| | ii. "We are going to do this by you placing these cards where you think they fit best on this table" (Level of involvement template, Appendix 5). | | |
| | iii. Explain each level of involvement. | | |
| | <u>Prioritisation</u>: Administer the prioritisation procedure | | |
| | i. Ask the child, "Of all of the activities that you've seen, what are the 3 activities that are the most important to you?" | | |
| | ii. Get the child to sort the cards for the 3 most important activities. | | |
| | iii. List the activities on the scoring sheet (Appendix 3 part B). | | |
| | <u>Barriers and Facilitators</u> | | |
| | i. Explain to the child that for these 3 activities we would like to understand how what makes it easier or harder to participate in the activity. | | |
| | ii. "We are now interested in what things help or make it harder for you to participate in these activities." | | |
| | iii. "We are now interested in what things help or make it harder for you to participate in these activities." | | |
| | iv. Record responses on the scoring sheet. | | |
| 8 | Thank the child for participating, provide token and walk him/her to class. | | |

# Appendix N: Feedback Form

Appendix N

# Test-retest reliability of the Picture My Participation instrument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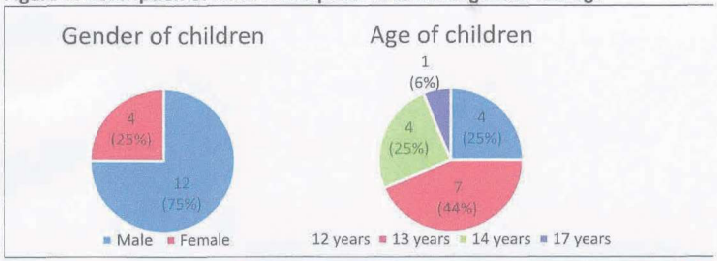
## Introduction

The Picture my Participation (PMP) instrument was developed for use in low- to middle-income countries and ensures children with intellectual disabilities can provide their own views on their participation. The current study aimed to assess the test-retest reliability of the PMP instrument, that is, the consistency of the responses provided by an individual across time. Parents and their children with intellectual disabilities' responses were obtained on Test 1 (T1) and again two weeks later on Test 2 (T2).

## Participants

16 children with intellectual disabilities and their primary caregivers took part in the study. 75% of the children who participated in the study were male and the average age of child participants was 13;3 years.

**Figure 1. Description of Child Participants in terms of gender and age**





National Research Foundation

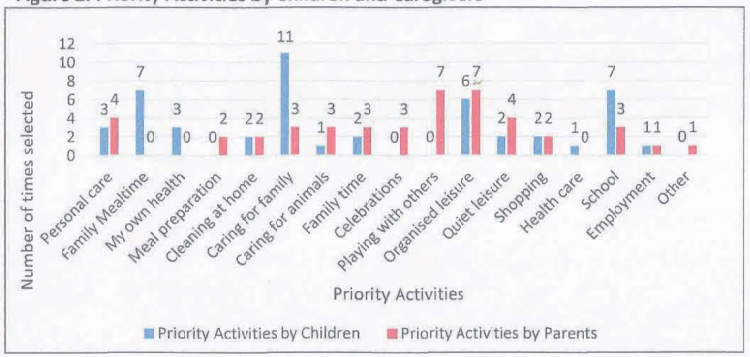
STINT
The Swedish Foundation for International Cooperation in Research and Higher Education

This study form part of a larger international study funded by the National Research Foundation (NRF)/ STINT. Opinions expressed and conclusions arrived at, are those of the authors and are not necessarily to be attributed to the NRF/ STINT.


## Results

The Figure below shows a comparison of activities which were prioritised by the children and the caregivers. It is evident that similarities exist in many of the priorities selected between caregivers and children.

**Figure 2. Priority Activities by Children and Caregivers**




The questionnaire yielded high internal consistency (α=>0.7) indicating that the scale is reliable (Hair, Black, Babin, & Anderson, 2010)*. The values for test-retest however were not as consistent due to a small sample size and limited data.

## What next?

The data collected from this study will form part of a larger study. Additional data has been collected at other schools and will be combined to ensure test retest reliability of the instrument.

Future research will focus on the PMP use as clinical tool for goal setting with children with disabilities and their family.


* Hair, J. F., Black, W. C., Babin, B. J., & Anderson, R. E. (2010). *Multivariate data analysis* (7th edition). NJ: Pearson Prentice Hall.

# Appendix O: Declaration of Originality

**UNIVERSITY OF PRETORIA**

**DECLARATION OF ORIGINALITY**

This document must be signed and submitted with every

essay, report, project, assignment, dissertation and/or thesis.

Full names of student: Mrs Colette Lesego Buthelezi

Student number: 27485693

**Declaration**

1. I understand what plagiarism is and am aware of the University's policy in this regard.

2. I declare that this mini-dissertation is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

3. I have not used work previously produced by another student or any other person to hand in as my own.

4. I have not allowed, and will not allow, any one to copy my work with the intention of passing it off as his or her own work.

SIGNATURE OF STUDENT: .....  .....

SIGNATURE OF SUPERVISOR: .....

# Appendix P: Declaration by Language Editor

Rephrase it!
Academic Text Editing

17 Fallopius Street, Bloemfontein
+(27) 076 081 0730
info@rephraseit.co.za

**26 November 2018**

**Student:** **C.L. Buthelezi**
**Student no.:** **27485693**

I declare that I edited the master's mini-dissertation titled, *Test-Retest Reliability of the Picture My Participation Instrument*

During the editing process, I looked for and corrected spelling, grammar, punctuation, sentence and paragraph errors. Where I noticed inconsistencies or unclarities in the text, I made comments to draw the author's attention to the inconsistency or unclarity. I also made suggestions where changes could be made. I double-checked the references in-text and in the reference list to make sure that they are consistent throughout. Where sources or source information were missing, I indicated such to the author so that she could locate and add the missing information. Finally, I formatted the document to present neatly.

Yours sincerely

Johannes Pieter Odendaal